

What about us? Aging with Disability and Dignity

A Nova Scotia Research Project

FULL REPORT

March, 2008



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Pour obtenir un exemplaire français du rapport, veuillez communiquer avec le Centre de ressources pour la vie autonome.

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*Note: The Independent Living Resource Centre and the Government of Canada's Social Development Partnerships Program sponsored this project as part of their research and innovative approach to improving the lives of people who live with disability. The facts presented and views expressed in this report, however, are those of the authors and not necessarily those of the sponsors.

Introduction

We currently have very little knowledge about the critical pathway followed by Nova Scotians who are aging with a disability. According to the Participation and Activity Limitation Survey 2006, there were 197, 840 people over the age of 45 who are aging with a disability in Nova Scotia. This population represents 35.5% of people over the age of 45 in this province. This statistic has important implications in terms of health care, community planning, transportation, housing, community supports, and recreation.

This report details the findings from the first major study on aging with a disability in Nova Scotia. To be clear, this study does not refer to people who experience disability as part of the aging process, but to those who are disabled in child or adulthood and who are now aging.

Objectives

- To increase the understanding of the appropriateness of and access to needed services for continued participation and living for Nova Scotians who are aging with a disability
- To develop recommendations for building age-friendly communities
- To inform key decision makers

Based on responses from 74 older disabled people, the report reviews the relevant literature with a view to best practice standards. It examines people's personal experiences of aging and the impact it has on their lives. The report focuses on the practical implications of aging with a disability and considers how well existing supports are providing for the range of needs associated with aging.

There are many obstacles to older disabled people being able to articulate their needs and most important of all – to have their voices heard. This report provides a snapshot of how people aging with disability in Nova Scotia understand and experience their lives. We believe it makes an important contribution to raising awareness about aging with a disability, and provides a roadmap for future considerations. It is our hope that the content will be of interest to those in a position to develop policies and services for older people and persons with disabilities in general.

The Report

The full report was designed for a variety of audiences, and is not intended to be read as a single document. The Executive Summary outlines project objectives, key findings and recommendations; describes the Round Table; and notes implications for future research. These topics also appear in other sections of the full report. The Summary in Plain Language describes the project, and outlines findings and recommendations. The French version of the report includes the executive summary, literature review and references. Please contact the Independent Living Resource Centre for the report in French, and for further information about *Aging with Disability and Dignity*.

Executive Summary

This report provides a brief overview of the *Aging with Disability and Dignity* research project conducted from October, 2007 through March, 2008. The project was sponsored by the Independent Living Resource Centre, Halifax, NS. Funding for the project was provided by the Government of Canada's Social Development Partnerships Program. For a more in-depth examination of the data and methods used, please contact the Independent Living Resource Centre for a copy of the full project report.

Introduction

We currently have very little knowledge about the critical pathway that Nova Scotians who are aging with a disability follow. Like all Canadians, persons with disabilities are living longer and have greater relative power as consumers. What is generally not recognized is that the ordinary disabilities that occur as a result of normal aging occur 20-25 years earlier in people who are aging with a disability.

According to the Participation and Activity Limitation Survey 2006, there were 197, 840 people over the age of 45 who are aging with a disability in Nova Scotia. This population represents 35.5% of people over the age of 45 in this province. This statistic has important implications in terms of health care, community planning, transportation, housing, community supports, and recreation.

Objectives

This project utilized a community-based participatory action research approach. In addition to providing a snapshot of the experiences and needs of people aging with disability in Nova Scotia,

project activities included: strengthening the partnerships among agencies and individuals who serve this population, conducting a relevant literature review with an eye to best practice standards, developing an educational package that could be used by each of the 28 Independent Living Resource Centres across Canada, and hosting a provincial Round Table where key findings and recommendations could be made available to decision makers.

Key Findings

- Aging with a disability is expensive and there is a lack of support to assist with these costs.
- Many service providers do not have adequate funding to meet the needs of their clients.
- Transportation, housing and recreational needs for people aging with disabilities are not being met.
- Employment supports are inadequate to meet the needs.
- There is no central navigation system for people needing to access services.
- People who are aging with disabilities must be seen as an “inclusive” part of our communities.
- There is no system of evaluation for programs and services, nor any system for evaluating the needs of this population.
- There is a need for education to deal with the social stigma of disability; e.g., a wheelchair is a source of pride and independence and full participation for a disabled person, but is perceived to be a limitation or loss of capacity by the general public.

Recommendations

- **Accessible and Affordable Housing**

- Periodic assessment regarding housing needs
- Home maintenance assistance

- **Accessible Transportation Options**

- Transportation strategy in regard to employment, medical appointments, shopping, recreation and isolation reduction

- **Person-Centered Disability Supports**

- Resources that allow someone to age in place
- System navigation services to help guide people through the variety of services
- Employment supports to meet needs not currently being addressed

- **Central Access to Service**

- Such as a 1-800 service, or online website

- **Disability Act for Nova Scotia**

- With funding to support the promotion of and compliance with the act
- A Provincial Evaluation Council to evaluate programs/services for the disabled

- **Investment in Agencies that serve Persons with Disabilities**

- Interpretation costs, educational needs

- Tax-based relief for costs related to living with a disability

- **An expanded Disabled Persons Commission**

- An office in each region of the province

- An expanded mandate

- **A Double-Lens Approach to Service Delivery**

- Policy implementation and improvement need to be applied using a “double-lens” approach to seniors and persons aging with disabilities. The points of entry may be different but these groups share a large portion of service needs.

- **Greater Commitment to Full Citizenship and Inclusion**

- Lost in the shuffle of retirement planning and a wealth of expert advice, this subgroup of the seniors’ community continues to ask, “What about us?” Largely dependent on charitable organizations, they are not treated with inclusion within most social institutions within our society. They need a political identity.

- **Greater Awareness of Policy Implications**

- There is a need for further research and knowledge about the impending social implications of this research.

- **Development of Best Practice Standards**

Round Table Event

About 80 people met at the Round Table on March 18 in Halifax. The participants—including seniors, persons with disabilities and representatives of government and agencies—met to review the project’s key findings and recommendations. Evaluations of the Round Table event were overwhelmingly positive. Two areas of significance worth noting are: the entire audience scored 3.9 out of 5 in feeling that the event improved their skill, knowledge and understanding of people who are aging with a disability, and 4.2 out of 5 in their motivation to take the information and use it to effect change in their personal and public spheres of influence. This is significant because it is an indication that this workshop has made a positive contribution towards improving the lives of people who are aging with disability in Nova Scotia.

Implications for Future Research

The constraints and findings inherent in this project have implications for future research and follow-up work.

1. More funding over a longer period of time is needed to get a representative sample of persons with disabilities across Nova Scotia.
2. The research tool was too long for most participants and future researchers would be advised to use a shorter version of the tool used here.
3. Budgeting for future research of this nature must take into consideration the vast geography, the isolation of many communities, and the need to utilize regular mail in addition to the electronic media.

4. There is need for extensive follow-up as in giving briefings to political parties, government bureaucrats, community leaders, agency representatives and consumer groups, and lining up regular media spots. If we are to move the voice a step forward we need to communicate, coordinate, collaborate and build community.
5. The research team recommends that the ILRC based in Halifax take the lead in moving forward the issue of aging with disability, and seek national recognition as a “centre of excellence” in this field. We recommend, as a first step, that the ILRC pursue a “phase II” project to create a detailed, comprehensive program plan for a new array of services that will support Nova Scotians with disabilities to “age in place”.
6. The research team also recommends a greater media awareness campaign highlighting the issues of aging with a disability in Nova Scotia as part of an expanded research project.

Plain Language Summary

Aging with Disability and Dignity is a research project of the Independent Living Resource Centre (ILRC) in Halifax, Nova Scotia. We finished the project in March, 2008.

This is a summary of the final report.

Introduction

We looked at the needs of persons with disabilities who are getting older or “aging” in Nova Scotia. These are people who have had disabilities since they were children or young adults. We did not look at the needs of seniors who become disabled as they get older; for example, seniors who just started using a walker or hearing aids.

We don't know much about what happens to persons with disabilities as they age. We do know persons with disabilities are living longer than they used to.

We also know that persons with disabilities face the same health problems other Canadians face as they get older. These health problems may include loss of hearing and eyesight, heart disease, and Alzheimer's Disease. But some health problems hit persons with disabilities 20 to 25 years earlier than other Canadians.

There are almost 200,000 thousand Nova Scotians with disabilities over the age of 45. This is 35 % of all the people over 45 in Nova Scotia.

What we did

We used participatory action research methods. Persons with disabilities were involved throughout the research, and the information from the research goes back to them.

We read many books and articles to find out what other research has been done. Our reading is summarized in the literature review. You can read it in the full report.

We asked persons with disabilities who are aging to fill out a survey. We got back 74 surveys. Most of the people who filled out the surveys were between 45 and 59 years old. There were more men than women. They had a wide range of disabilities. The largest number lived in the Halifax region of Nova Scotia.

We also held a Round Table in Halifax on March 18, 2008. About 80 people came. Some were persons with disabilities and seniors. Others came from government and agencies. Most people at the Round Table said they learned a lot about aging with a disability. Most said they will use this new knowledge to make changes in their workplaces and among their family and friends.

What people said in their surveys

- Most are worried about where they will live as they age.
- Most are not worried about losing social connections—friends and family. But they do face barriers to social activity. Transportation is the biggest barrier.
- Most have enough money now for their basic needs, but they are worried about having enough money in the future.
- They are working less than they used to, but they get the help they need at work to do their jobs well.
- They feel ignored by people who make decisions in society, but not ignored by the people who help them make decisions in their own lives.
- They have more anxiety as they get older.

What we learned from the research

- It costs a lot to age with a disability. There are few places to help you with these costs.
- Agencies do not have enough funds to help their clients.
- Transportation, housing and recreation are the three main needs for people with disabilities who are aging.
- There is not enough help for older persons with disabilities to get jobs.
- Persons with disabilities who are aging should be fully included in our communities.

- There is no way to know if programs and services are really working for persons with disabilities who are aging. There is also no way to find out exactly what these people's needs are.
- We need to tell the public more about disability. For example, a woman who uses a wheelchair will see her chair in a positive way. It's an important means for her to get around independently. But other people may see the wheelchair in a negative way as a sign of loss and dependence.

What we recommend

- Build more accessible and affordable housing, and offer help with home maintenance.
- Provide better accessible transportation.
- Provide disability supports that fit the person. Let people age in place; that is, stay in their own homes as they get older.
- Set up a central information line and website. A 1-800 line is a good start.
- Bring in a Disability Act for Nova Scotia.
- Give enough funds to agencies that serve persons with disabilities.
- Expand the Disabled Persons Commission. There should be an office in each region of the province.
- Use a "double lens" approach. When you look at new programs and policies, look at both seniors (one lens) and persons with disabilities (the second lens).
- Include persons with disabilities in society. Listen to their voices.
- Find out what really works and set standards for services. These standards are sometimes called "best practices".
- Do more research into this important issue.

For more information

If you want a copy of the full report, call the Independent Living Resource Centre at 902-453-0004, or send us an email: info@ilrc-halifax.ns.ca. Ask for the *Aging with Disability and Dignity* full report.

Literature Review

The aging of the population in Canada is beginning to have a profound impact on social policy, professional practice and academic research. It is said that the road to inclusion and access for persons with disabilities has been marked with long, barren stretches. It has been a long struggle, especially for those who were born in the middle of the 20th century. In many respects this age group has enjoyed the relative success of arduous political and social battles, as well as the advancement of medical treatment and rehabilitation. Changing patterns of life expectancy brought about by advances in medical technology, treatment and rehabilitation mean the number of older disabled persons is increasing. Like all Canadians, persons with disabilities are living longer and have greater relative power as consumers. What is generally not recognized is that the ordinary disabilities that occur as a result of normal aging occur 20-25 years earlier in people who are aging with a disability. This is referred to as accelerated aging throughout the literature. Changing needs and, indeed, the fluidity of disability as it intersects with the natural aging process demand a continued sense of journey.

At first glance, issues of “disability” and “aging” may be seen as interlinked. After all, the more popular versions of the healthy, athletic senior are often regarded as the attainable norm which overshadows reality. The very real issues of economic uncertainty, abuse, neglect and isolation are sadly the growing struggles that many seniors in Canada face. The simple fact is that Canada’s population is dominated by a growing number of older citizens. The reality is an increasing demand on social

programming and services, coupled with a shrinking economic base. This has serious implications for every Canadian. From the perspective of persons with disabilities who are aging, these concerns are perhaps more acute. Lost in the shuffle of retirement planning and a wealth of expert advice, this subgroup of the seniors' community continues to ask, "What about us?"

Much of the research on aging with disability leads to two interconnected issues. First, the research points to a sense of fear within the aging disability community that their concerns are being neither heard nor regarded. Second, from a medical and policy perspective, there appears to be a need for research and knowledge about the impending social implications. Under close scrutiny there is a fundamental disconnect between these two themes. The demographic and social realities outlined in this literature review endeavor to bridge this gap between life experience and social action.

Much discussion of disability within academic and policy literature focuses on the dichotomy between medical diagnosis and the social implications of a physical or mental condition. For the purposes of this study, disability can be defined within the medical and disability models. Proponents of the medical definition concentrate on the diagnosis of the condition that led to the disability per se. Emphasis within the medical model lies within finding a "cure" for one's illness, thus not allowing for a societal response to the needs of the person to lead a "normal" life (Kaplan, Robertson). In this light, social policy initiatives are designed to find strategies for adapting to normalcy rather than to seek a greater understanding of the person's existing abilities (Blaser). To date, many

social programs have been based on the underpinnings of this approach. The disability model is based on the social, physical, attitudinal and economic barriers society has placed on the person with the perceived disability (Kaplan, Pfeiffer, 1998). In this model, disability is seen as external to the realities of the individual, and it places his fate solely on society to overcome barriers, to accommodate. This model is closely tied to the Independent Living (IL) movement that stresses the necessity for programming that facilitates dignity, participation and empowerment (Canadian Association of Independent Living Centres, 2007). Elements of both models can be observed in the definition given by the World Health Organization:

A disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (World Health Organization).

While these definitions come from different perspectives, both models stress the lifelong challenges and barriers that a person with a disability faces. Virtually all the literature points out that, like their "abled-bodied" peers, persons with disabilities are living longer because of better living conditions and health care (MacLellan, 2002; Bigby; Society of Manitobans with Disabilities, 2004). The issue that arises from this is the increased challenge a person with a disability must face as a result of living longer. The literature clearly demonstrates that policy and programming for persons with disabilities have been historically focused on childhood and young adulthood opportunities. Because older

persons with disabilities have not been the focus of research, policy and planning have not kept up with their growing needs. Limited service options leave people who are aging with a disability largely on their own (Zarb, 1993). For most Canadians, aging with a disability has become an undignified ordeal largely because services and programming are either inappropriate or non-existent. Further, like most other disability issues, the realities of the individual make a “one-size-fits-all” approach to programming extremely restrictive. The key to success lies within flexibility, choice and individualized planning (Bigby, September 2004).

A further complication is the language we use to determine what “aging” means. Most literature indicates that aging itself is not necessarily tied to chronological age, but is more of an individual journey along one’s life path. This journey is comprised of the psychological, biological, social, and environmental factors all impacting on the individual (Bigby, 2004). People age differently and at differing rates. Aging, like disability, is unique to every individual who experiences it.

Studies on the relationship between aging and disability pose a unique question that has policy implications for service delivery: Do the effects of the aging process eventually make disability irrelevant? Are not both aging and disability leading in the same direction? Upon first glance this seems to be a legitimate question. So why should there be a distinction between those who are aging with a life-long disability and persons who become disabled as part of their normal aging process? The normalization of disability into an established program or policy framework for seniors is not necessarily appropriate (Walker and Walker, 1998). In other words, while many seniors who have lived with a

life-long disability may have the same concerns as their “age-related disabled” peers, the service delivery options may come from a different point of entry. A practical example would be the distinction between people living with life-long hearing impairments and those who develop hearing loss during their senior years. As Kenopic graphically illustrates, the loss of culturally-specific implications of the language of signing, coupled with the loss of assistive technologies like TTYs, cuts off Deaf seniors from their social connections and profoundly impacts on their functionality within retirement homes (Kenopic, 2001). Despite the cultural underpinnings of the Deaf community, the research also shows that the psychological and practical effects of disability impact the individual differently at each stage of life. Persons with a childhood disability may see their lives from a forward perspective with a focus on loss of opportunity or providing services and tools that will allow them to lead an active life in spite of their condition, while people who develop disability through an aging process tend to view life from the past (Verbrugge and Yang, Spring, 2004). Such life perspectives will ultimately demand service providers to link age and disability, and yet have the ability to benefit from the apparent distinctions also.

Within Canadian health and social services, people with disabilities and older people are constructed as two distinct client groups. Separate organizations and departments provide services and support to each group. These two groups have remained distinct even though they share many commonalities. In terms of community participation as well as barriers and facilitators in the environment many of the needs are similar as well. There is a need to examine a more efficient use of community resources with the increase in these populations (Canadian Centre on Disability Studies, Discussion Paper, 2008).

One of the central themes throughout the literature on aging with a disability is the paradigm of “successful aging”. Indeed, successful aging has become a central theoretical

paradigm within the fields of geriatrics and gerontology. Much discussion within mainstream gerontology is devoted to the concept most widely associated with Khan and Rowe who point to the avoidance of chronic disease, maintaining mental and physical abilities, and continuing to engage in their communities (Khan and Rowe, 1998). This concept is certainly appealing from both a personal and policy standpoint. The image of the healthy, active, and happy senior is worth promoting with policy and programming (Seniors' Secretariat, 2005). While this image is very popular, critics have also suggested that the concept of successful aging is vague and does not account for persons who already live with issues relating to health, or those who "age successfully" by their own criteria (Bowling and Dieppe, December, 2005).

Taken one step further the concept of "successful aging" may be seen as another form of discrimination against those who are aging with a disability. As Minkler and Fadem point out, older persons with disabilities fall into a group largely marginalized already in society, economy, and health, and are thus seen as "aging badly" (Minkler and Fadem, 2002). Bigby argues that "successful aging" for persons with disabilities cannot lie outside the realm of proactive public policy. She notes, "...moving from general to the specific is a complex task that cannot occur in a vacuum and must take into account the existing context, policies and programs, culture and values within which aging people with disabilities are situated (Bigby, 2004a)." From a policy perspective, the nexus between aging and disability presents a unique opportunity to view programming through a "double lens" instead of the single lens now in use. The double-lens approach has been recommended by the Society for Manitobans with Disabilities and it advocates for programs to be developed for each group and shared when appropriate (Society of

Manitobans with Disabilities, 2004). In the final analysis, finding ways to integrate seniors and disability policy to provide the most effective and efficient programs and services will be the challenge.

As a starting point, and certainly from a best practice standard, Satariano (1997) points out that the new paradigm of disability suggests the importance of having public health professionals collaborate with architects, city planners, transportation experts, and engineers in the design of both indoor and outdoor environments that truly accommodate elders of diverse abilities and functional limitations.

The continued development and refining of conceptual approaches to research that stress optimal aging is consistent with the 'new paradigm of disability', which holds that a person with a disability 'should no longer be viewed as someone who cannot function because of an impairment, but rather as someone who needs an accommodation in order to function. (Bleecker, 2000, p. 1). **Referenced by Minkler and Fadem.**

However, for policy development to take place, both a body of knowledge and a voice of advocacy need to be heard. Interestingly, demographic and social realities of an older population have created a demand for increased research into aging with disability during the past decade but the literature is still quite limited. Like other disability issues documented in the literature, the true test of the facts will emerge in response to two main actions: 1) advocates within the disability community must increase their focus on these matters, and 2) agencies and governments must begin to respond realistically to the quality of life issues facing this population. While retirement planning and advertisements for RRSPs encourage the general population to become proactive in

etching their future, persons with disabilities either have not been included or have not focused their collective attention around issues of aging.

As Putnam notes, the issue of a political identity based on disability is constrained by a framework for a collective base for common issues (Putnam, 2005). While the notion of a collective political identity around disability is the ultimate goal, Kennedy notes that politicians and policy makers “fear” the mainstream seniors’ community because of its influence in electoral politics. Kennedy suggests persons with disabilities can have the same influence to effect policy change (Kennedy, Spring, 2002). Engaging the political process to advocate for change appears to be an obvious solution, but is it a reasonable expectation for this population group? As Priestly notes, persons with disabilities continue to face barriers to full citizenship and choice. He suggests that disabled persons are often perceived as “non-adults” incapable of self-determination, and without adult rights (Priestly, Spring, 2003). One conclusion is that people who are aging with disability are not included in the political process and therefore have no organized method for effecting change.

The other side of the issue is how disability and aging research has been conducted. A search of the literature reflects an asymmetrical interest in intellectual over physical disability. While there have been resources devoted to what persons with specific physical conditions can expect in older age, emphasis has been placed on the premature aging process relating to Down Syndrome and other developmental disabilities (Arcand; Janicki, 2000; Ballinger, June, 1991; Ballinger, 1978; Margano et al, June, 2007). This

focus on specific issues draws attention away from the development of an across-disability, consumer-centred policy framework (Drainoni et al, Fall 2006).

It is also interesting to note that Canadian literature and research in aging with a disability are scarce in comparison to those in other nations such as the United States, the United Kingdom, Australia and New Zealand which have active research programs and departments in this field. This current research will add the voice of Nova Scotians who are aging with disabilities to the larger framework of literature in Canada. It is the sincere hope of the authors that this work will contribute to the development of best practice standards, policy implementation and improvement, and enhanced services for people who are aging with disabilities.

References: Literature Review

- (2006). About Your House. Accessible Housing by Design (series) Ottawa, ON: *Canada Mortgage and Housing Corporation*. Socio-Economic CE 63b.
- Arcand, M. (n.d.). Wisconsin Council on Developmental Disabilities. Retrieved from Living and Aging with Cerebral Palsy: <http://www.wcdd.org/announcements.htm>.
- Ballinger, B. R. (June, 1991). People Aged Over Sixty-five Years Living in a Mental Handicap Hospital - Thirteen years on. *Mental Handicap* , 77-80.
- Ballinger, B. R. (1978). The Elderly in a Mental Subnormality Hospital: A Comparison with the Elderly Psychiatric Patient. *Social Psychiatry* 37-40.
- Bigby, C. (2004a). *Ageing with a Lifelong Disability*. New York: Jessica Kingsley Publishers.
- Bowling, A. a. (December, 2005). What is Successful Ageing and Who Should Define It? *British Medical Journal* 1548-1551.
- Canadian Association of Independent Living Centres
<http://www.ilcanada.ca/article/home-125.asp>

- Drainoni, M.-L. L.-H. (Fall, 2006). Cross-Disability Experiences of Barriers to Health-Care Access - Consumer Perspectives. *Journal of Disability Policy Studies* 101-115.
- (September, 2007). How Effective Are Bathtub Grab Bars For Stopping A Fall When You Lose Your Balance? Ottawa, ON: *Canada Mortgage and Housing Corporation*. Socio-Economic Series 07-016.
- Janicki, M. A. (2000). *Aging and Intellectual Disabilities Improving Longevity and Promoting Healthy Aging - Summative Report*. Geneva: World Health Organization.
- Kennedy, J. (Spring, 2002). Aging and disability--the advocacy and research agendas: An interview with J... *Journal of Disability Policy Studies* 280-283.
- Kenopic, C. (2001). *Keeping the Hands in Motion*. Ottawa, ON: Canadian Association of the Deaf.
- MacLellan, M. (2002). *Age Related Transitions: Older Parents Caring for Adult Sons/Daughters With Lifelong Disabilities*. Halifax: Mount Saint Vincent University.
- Margano, M. M. (June, 2007). Fifteen-year Follow-up of 92 Hospitalized Adults with Down's Syndrome: Incidence of Cognitive Decline, its Relationship to Age and Neuropathology. *Journal of Intellectual Disability Research* 463-477.
- Minkler, M. a. (Spring, 2002). "Successful Aging": A Disability Perspective. *Disability Policy Studies*, 229-225.
- Priestly, M. (Spring, 2003). Symposium on Disability and the Life Course. *Disability Studies Quarterly* .
- Putnam, M. (Winter, 2005). Conceptualizing Disability: Developing a Framework for Political Disability Identity. *Journal of Disability Policy Studies* 188-198.
- Rowe, J. a. (1998). *Successful Aging*. New York: Pantheon Press.
- Seniors' Secretariat. (2005). *Strategy for Positive Aging in Nova Scotia*. Halifax: Province of Nova Scotia.
- Society of Manitobans with Disabilities (2004, October). *Aging and Disability in Manitoba Converging Opportunities*. Retrieved from <http://smd.mb.ca/uploads/DoublelensreportFinal.pdf>.
- Statistics Canada (2006) *Participation and Activity Limitations Survey, 2006*. Ottawa: Social and Aboriginal Statistics Division.

Verbrugge, L. M.-s. (Spring, 2004). Aging with Disability and Disability with Aging. *Journal of Disability Policy Studies*, 253-267.

Walker, A. a. (Vol 1, no. 2, 1998). Normalisation and 'Normal' Ageing: The Social Construction of Dependency Among Older People with Learning Difficulties. *Disability and Society* 125-142.

Aging with Disability and Dignity

Limitations

The *Aging with Disability and Dignity* research project was originally designed to be conducted over an eighth month time period. Problems in the funding process resulted in a loss of time, leaving the research team with approximately four and a half months to accomplish a number of challenging goals. Further constraints to the research included: the geographical fragmentation of people aging with disabilities across Nova Scotia, and climatic considerations (the project ran between October 21, 2007 and March 31, 2008).

Method

This project utilized a community-based participatory action research approach. Using a research consent form (Appendix A) and a Needs Assessment Survey Tool (Appendix B), the research team designed and implemented a series of consumer focus groups to be conducted across the province. The tool was tested by having members of the Advisory Committee (Let Abilities Work Partnership Society) complete the surveys. The results of this test group were included in the final analysis. The first focus group was held on December 11, 2007 in Halifax, NS with six participants. In the debriefing session that

followed, the team concluded that they would be unable to obtain an adequate sample size using this format.

The coordinators decided to meet with the members of the Collaborative Partnerships Network on December 13, 2007 . This is a network of individuals and agency representatives who work with and provide services for people with disabilities in nine localities across the province. We asked for and received their generous support in setting up agency based focus groups within each of their respective regions. The coordinators attended each of these focus groups, distributing the consent form and needs assessment tool. In turn, agency representatives had consumers complete the documents and return them to the research team.

This is a casual research design and as such there were no controls for experimenter bias, or in this case interviewer bias. Further, the sample size was not a scientific representation of the population being researched. It is, however, a reasonable snapshot of the lives of Nova Scotians who are aging with disabilities, and the results are consistent with similar findings across Canada.

In addition to providing a snapshot of the experiences and needs of people aging with disability in Nova Scotia, project activities included: strengthening the partnerships among agencies and individuals who serve this population, conducting a relevant literature review with an eye to best practice standards, developing an educational package that could be used by each of the 28 Independent Living Resource Centres across Canada, and hosting a provincial Round Table where key findings and recommendations could be made available to decision makers.

Special Note: The research team attempted to obtain information from three First Nations communities in Nova Scotia. Agency recommendation forms were provided to members of the Health Centres but we did not receive any data back within the timeframe of the project; therefore, those results were not available for publication.

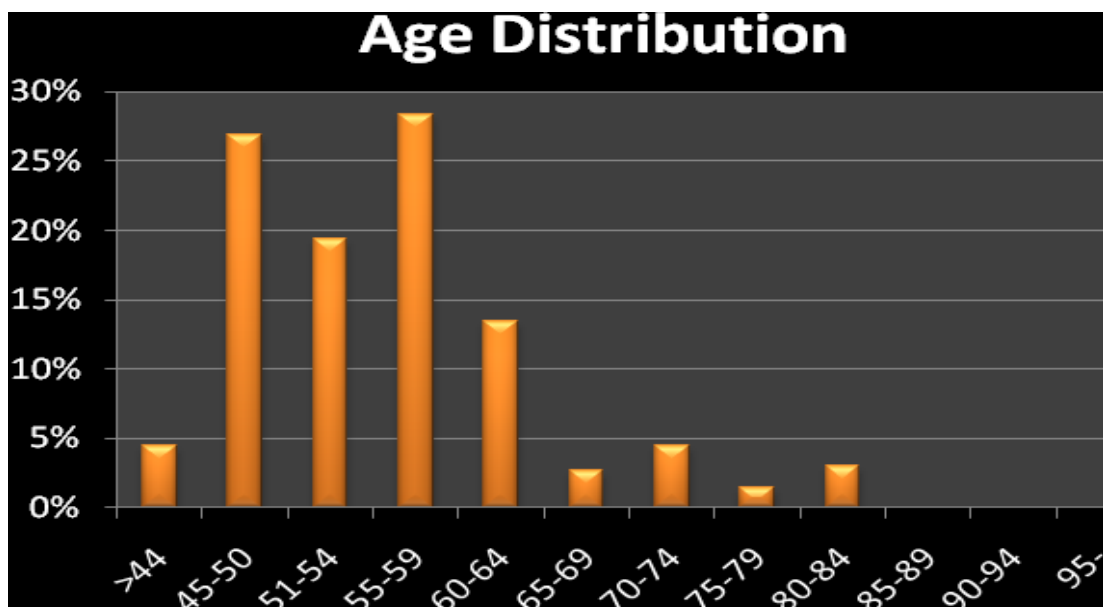
Key Findings

- Aging with a disability is expensive and there is a lack of support to assist with these costs.
- Many service providers do not have adequate funding to meet the needs of their clients.
- Transportation, housing and recreational needs for people aging with disabilities are not being met.
- Employment supports are inadequate to meet the needs.
- There is no central navigation system for people needing to access services.
- People who are aging with disabilities must be seen as an inclusive part of our communities.
- There is no system of evaluation for programs and services, nor any system for evaluating the needs of this population.
- There is a need for education to deal with the social stigma of disability; e.g., a wheelchair is a source of pride, independence and full participation for a disabled person, but is perceived to be a limitation or loss of capacity by the general public.

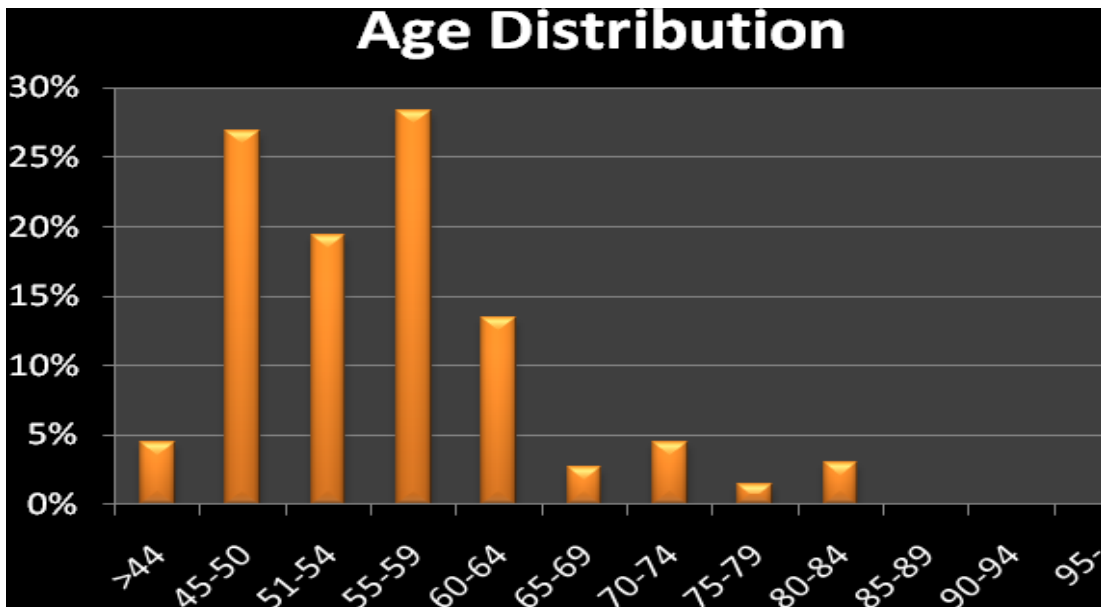
person, but is perceived to be a limitation or loss of capacity by the general public.

Consumers: Quantitative & Qualitative Results

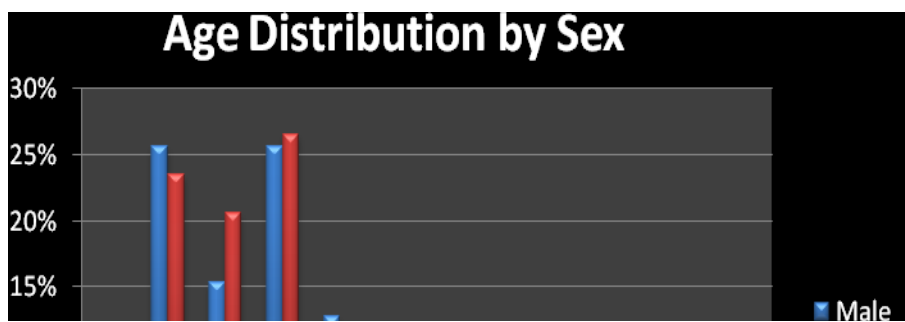
Basic Demographics



This graph illustrates the age range of the 74 people who participated in the research.

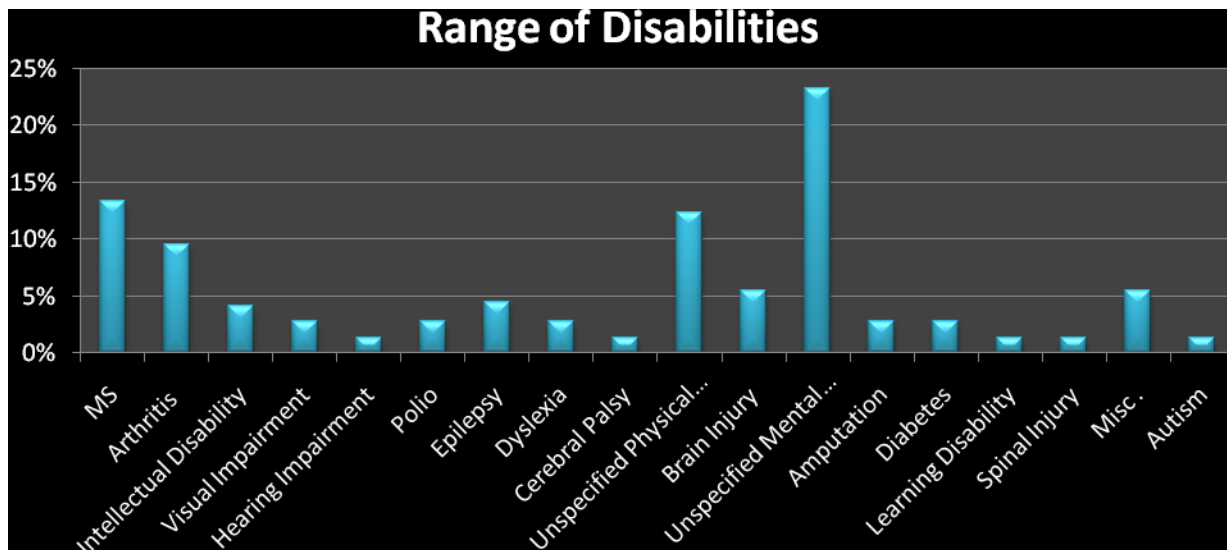


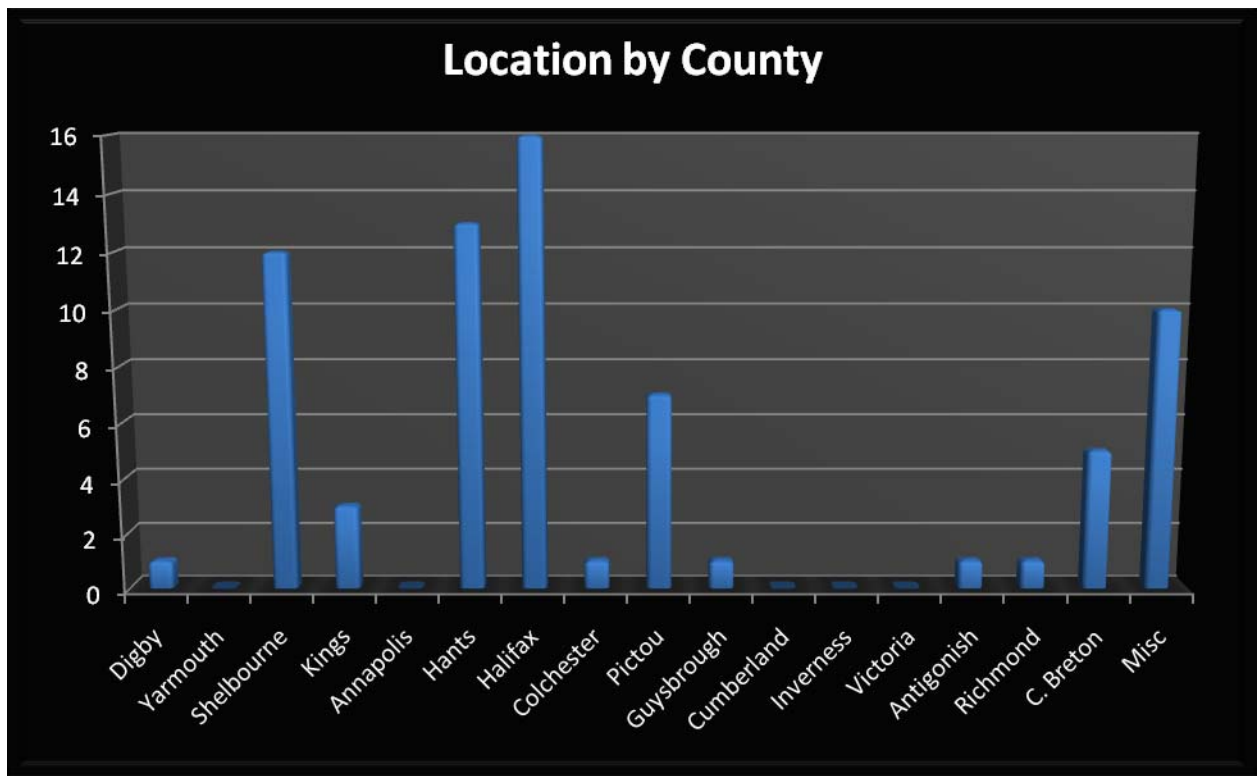
This graph illustrates the age range of the 74 people who participated in the research.



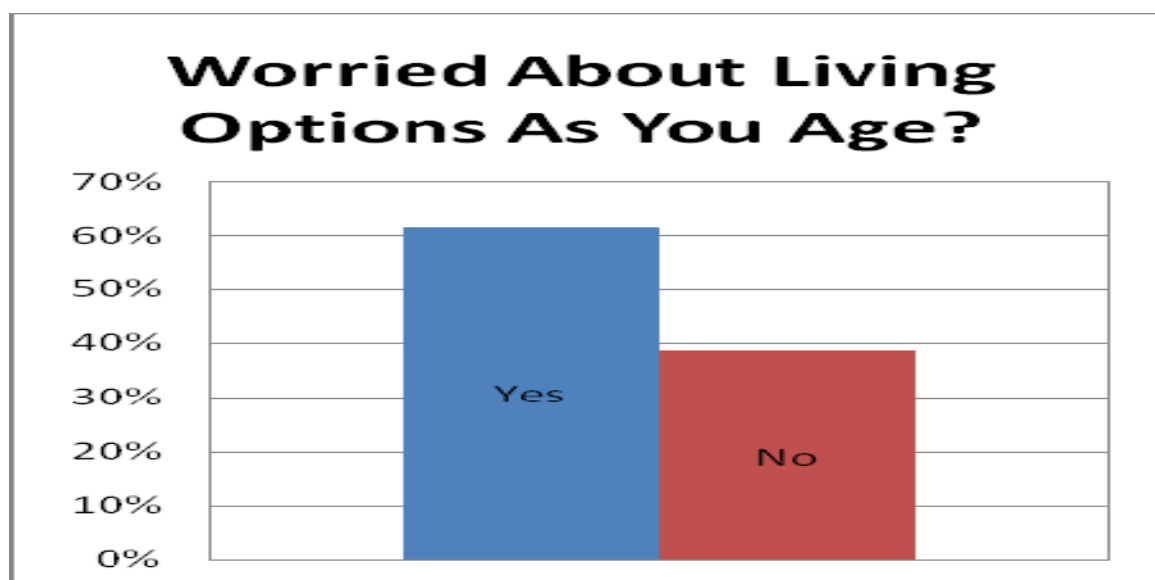
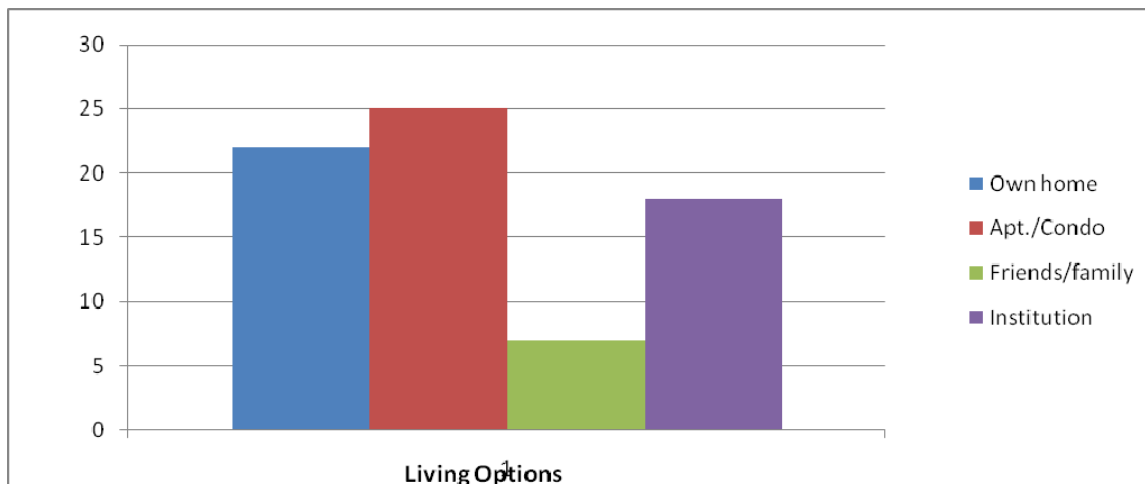
This graph illustrates the age range of the 74 people who participated in the research.

	Male		Female
Totals		39	34
Average	55.1	53%	47%





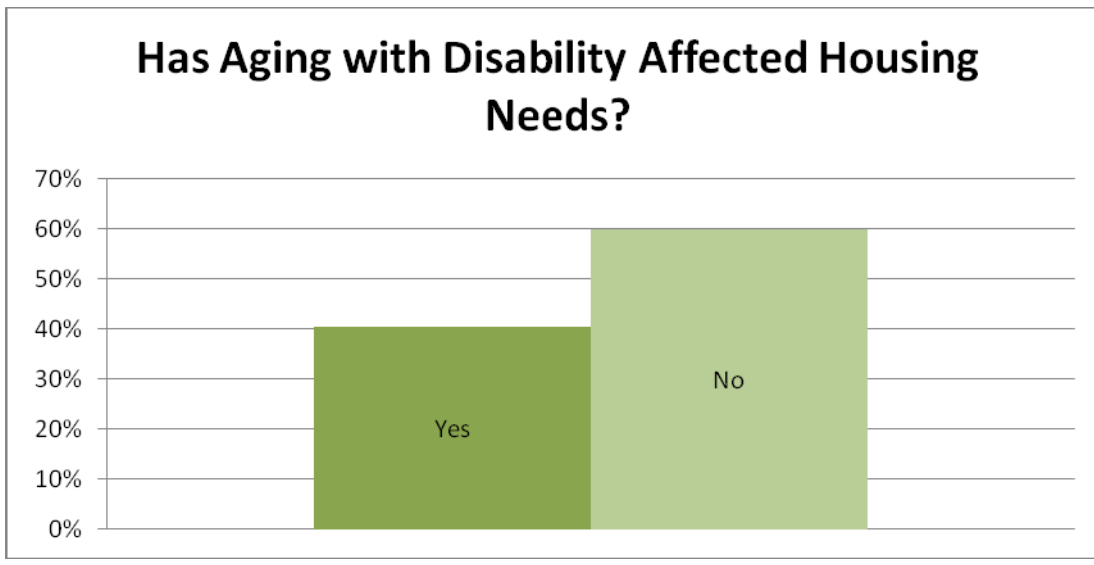
Living Options



“How will I be able to cope when I am unable to get from room to room?”

“As my condition worsens with time, there will be a time when I will no longer be able to care for my house or myself. The only option will be a nursing home.”

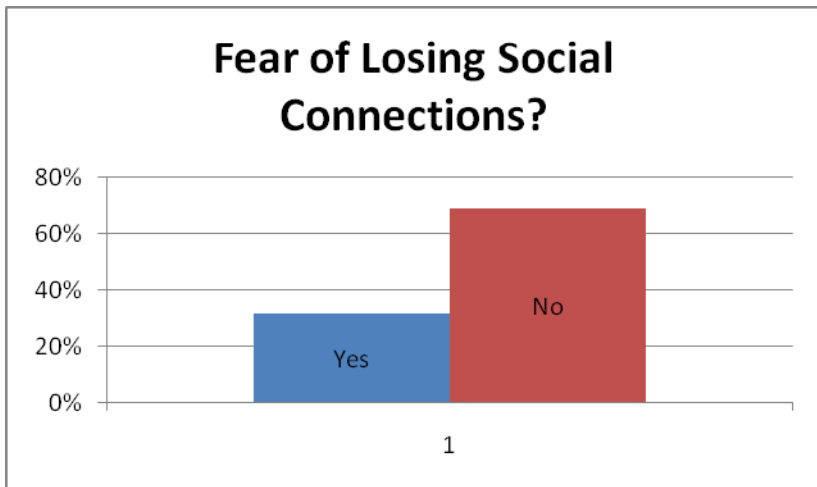
“Old age or pension income is not sufficient to pay for my own apartment and medication.”

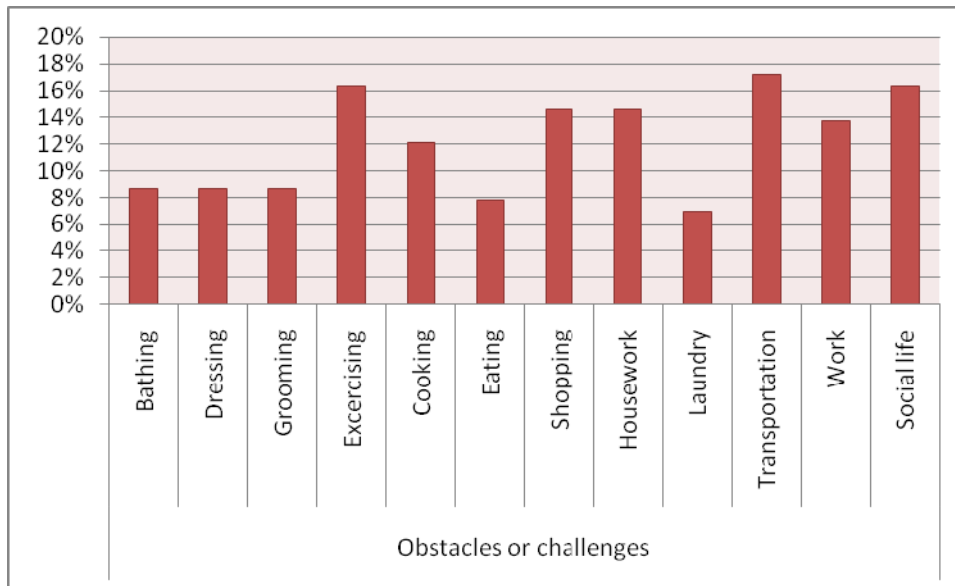


“I did live in my own home, waited so long for a grant and had to leave. Would much sooner be in my own home. Would be so much more comfortable.”

“Budgetary restraints require that I spend a lot of time alone unsafely.”

”Well, like me, the house is aging too.”





“I would like to take in more social activities but transportation is not always available.”

“I can’t rejoin the workforce because of drowsiness from my medication.”

“I will need help with snow removal, gardening, home maintenance and general help with wood heat in the future.”

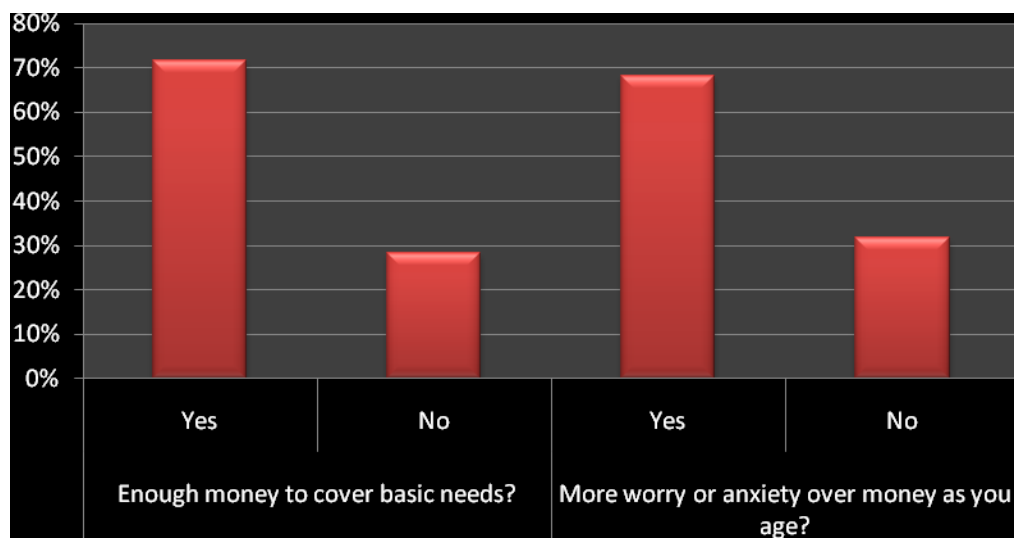
It is worth noting that Canada Mortgage and Housing Corporation (CMHC) has created a policy paper for developing the knowledge and capacity to improve housing and support for people with long-term disabilities who are aging. They have developed a model for assisting seniors/disabled community who are homeowners with their choices and options for hiring contractors when considering building, remodeling, or renovating. The model is designed to bring together the Chamber of Commerce, community seniors, members of

the disabled community, building material suppliers, and the local homebuilders' association. It is a model which could be used to success in most communities.

Financial Concerns

	Q. of Life	Male	Female
Total Averages	6	38	34

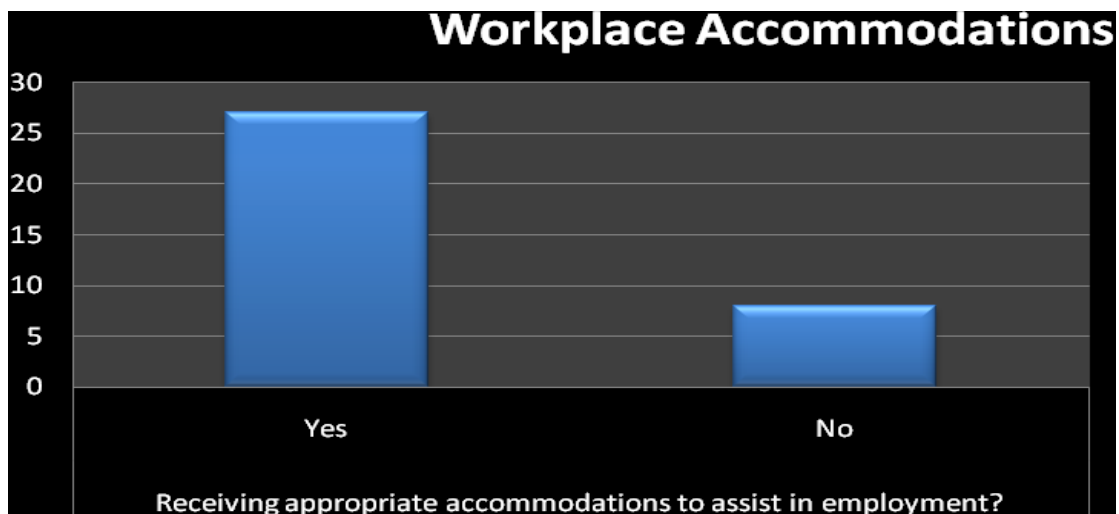
**Income (Monthly)
Average
\$967.90**

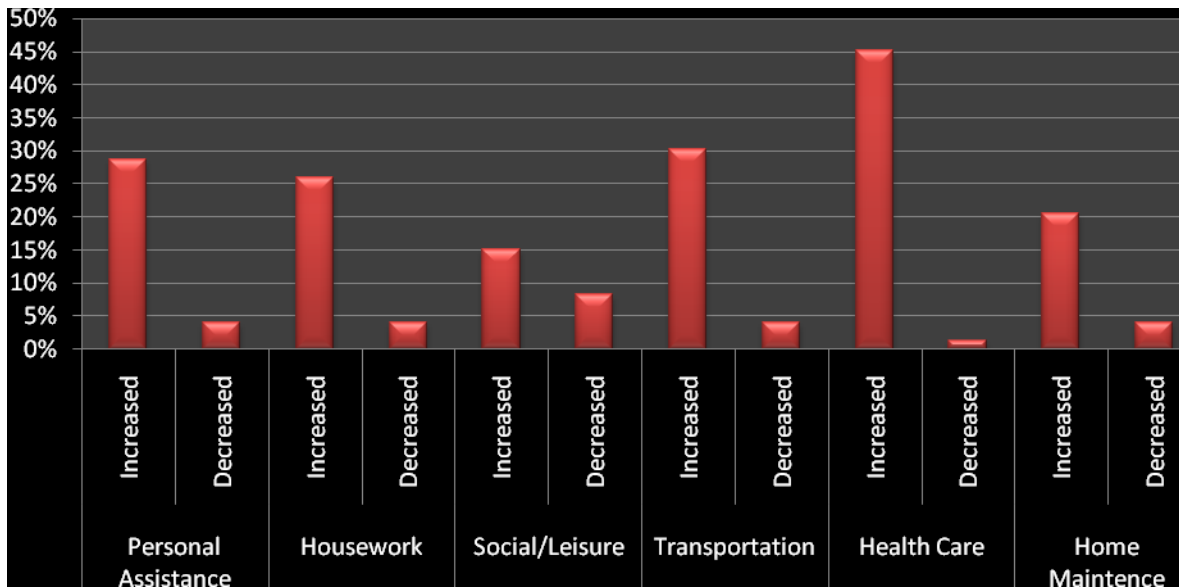


“I am very careful about money and don’t have luxuries like vacations or entertainment.”

“I am unable to buy them (medications).”

“Income tax deductions for disabled people who must pay for shoveling, plowing and general maintenance would help.”





“My sister takes care of all the house maintenance for me (spouses often provide full household support).”

“I am developing illness brought on by the stress of just living.”

“I had to leave home. I waited 10 years for a grant to put in a bathroom downstairs.”

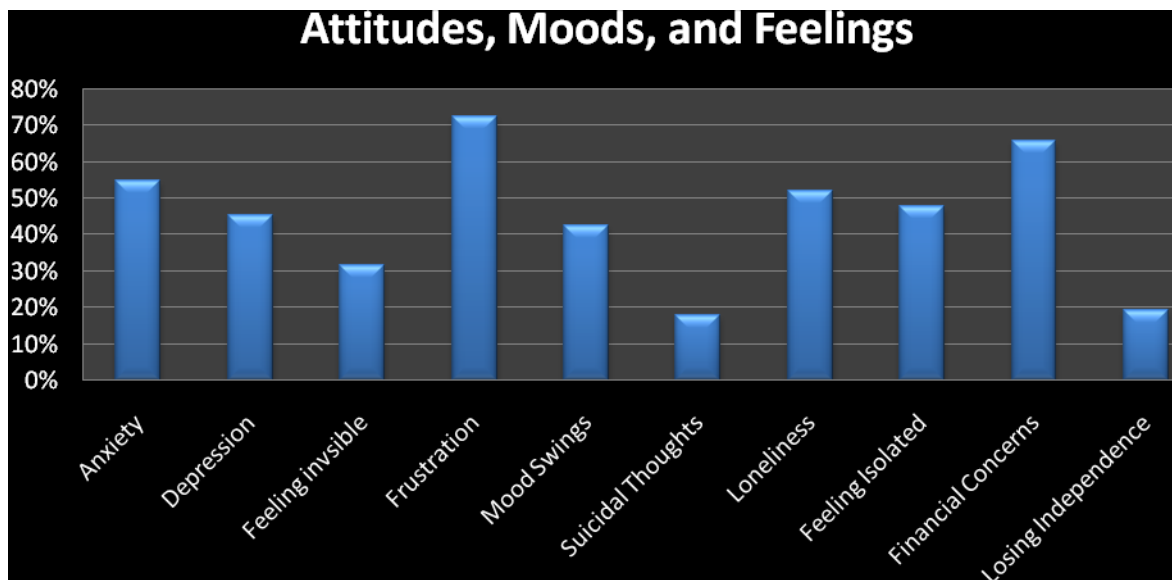


“Governments largely ignore the needs of disabled people; they haven’t got a clue.”

“Again, affordable housing and medical services like dental, eye care, drugs. I know of people who can’t afford to take the drugs they require so thus live an isolated and painful existence.”

“All levels of government need to embrace financially and legally the full Rights of Persons Living with Disabilities.”

Attitudes, Moods, and Feelings: Increase as you age with a disability



“I want to gain my independence. I’m trying to gain my independence. I have been feeling more depressed, anxious and frustrated but I think this is because I want it to happen faster than it can.”

“Loneliness, feeling isolated, drinking too much.”

“I need better medical health services.”

Key Agency & Research Project Recommendations

- **Accessible and Affordable Housing**

- Periodic assessment regarding housing needs

- Home maintenance assistance

- **Accessible Transportation Options**

- Transportation strategy in regard to employment, medical appointments, shopping, recreation, and isolation reduction.

- **Person-Centered Disability Supports**

- Resources that allow someone to age in place

- System navigation services to help guide people through the variety of services

- Employment needs of persons with disabilities that are not currently being addressed.

- **Central Access to Service**

- Such as a 1-800 service, or online website

- **Disability Act for Nova Scotia**

- With funding to support the promotion of and compliance with the act

- A Provincial Evaluation Council to evaluate programs/services for the disabled

- **Investment in Agencies that serve Persons with Disabilities**

- Interpretation costs, educational needs

- Tax-based relief for costs related to living with a disability

- **An expanded Disabled Persons Commission**

- An office in each region of the province

- An expanded mandate

- **A Double-Lens Approach to Service Delivery**

- Policy implementation and improvement need to be applied using a “double-lens” approach to seniors and persons aging with disabilities. The points of entry may be different but these groups share a large portion of service needs.

- **Greater Commitment to Full Citizenship and Inclusion**

- Lost in the shuffle of retirement planning and a wealth of expert advice, this subgroup of the seniors’ community continues to ask, “What about us?” Largely dependent on charitable organizations, they are not treated with inclusion within most social institutions within our society. They need a political identity.

- **Greater Awareness of Policy Implications**

- There is a need for further research and knowledge about the impending social implications of this research.

- **Development of Best Practice Standards**

Implications for Future Research

The constraints and findings inherent in this project have implications for future research and follow-up work.

1. More funding over a longer period of time is needed to get a representative sample of consumers across Nova Scotia.
2. The research tool was too long for most participants and future researchers would be advised to use a shorter version of the tool used here.
3. Budgeting for future research of this nature must take into consideration the vast geography, the isolation of many communities, and the need to utilize regular mail in addition to the electronic media.
4. There is need for extensive follow-up as in giving briefings to political parties, government bureaucrats, community leaders, agency representatives and consumer groups, and lining up regular media spots. If we are to move the voice a step forward we need to communicate, coordinate, collaborate and build community.
5. The research team recommends that the ILRC based in Halifax take the lead in moving forward the issue of aging with disability, and seek national recognition as a “centre of excellence” in this field. We recommend, as a first step, that the ILRC pursue a “phase II” project to create a detailed, comprehensive program plan for a new array of services that will support Nova Scotians with disabilities to “age in place”.

6. The research team also recommends a greater media awareness campaign highlighting the issues of aging with a disability in Nova Scotia as part of an expanded research project.

Provincial Round Table: Outcomes

On March 18th, 2008 approximately 80 people attended a Round Table presentation and discussion in regard to the findings of this research project. Those in attendance participated in an exercise to generate ways in which they could take the recommendations from the research and put them into action. The following is a breakdown of what the participants plan to do:

Spheres of Influence in Work/Professional life

- Insist as employees that our workplaces be accessible
- Provide Start Making Abilities Count (SMAC) sensitivity training for all employees
- Switch Roles – have people switch roles with a person with a disability (as an educational tool)
- Bring awareness and accessibility issues to projects and issue
- Use services such as Voiceprint to provide information in a broadly accessible manner

Spheres of Influence in Personal Life

- Talk to family about disability-related issues
- Educate family (and friends) that they don't need to jump in to help until asked

Influences to Promote Change in all Spheres of Influence

- Make ourselves visible doing everyday things/be a role model
- Clarify the message and appropriate message around ability
- Be a self-advocate
- Realize that groups don't appeal to everyone – personal connections important
- Provide access to interveners and interpreters
- Respect human rights –treat all with dignity

Influence Changes to Government/Public Policy

- Make suggestions to retailers/service-providers on how to make their premises/services accessible and inclusive
- Use media to educate about disability, and be educated about disability
- Regarding affordable housing – Look through the “Double Lens”, aging and disability, to ensure that responsive and accessible programs, services and policies are in place to support changing needs
- Encourage development of 211 and database of resources
- Identify individuals who may require service
- Recognize a real difference between what is available in city compared to rural

Changes Within the Disability Community

- Be proactive in educating the community
- Unite as a “cross-ability” community
- Offer centralized service – groups getting to know each other
- Promote reassessment earlier

Evaluation of the Provincial Round Table

Evaluations of the Round Table event were overwhelmingly positive. Two areas of significance worth noting are: the entire audience scored 3.9 out of 5 in feeling that the event improved their skill, knowledge and understanding of people who are aging with a disability, and 4.2 out of 5 in their motivation to take the information and use it to effect change in their personal and public spheres of influence. This is significant because it is an indication that this workshop has made a positive contribution towards improving the lives of people who are aging with disability in Nova Scotia. (The Round Table Agenda, Exercise, Evaluation Form and complete results of the evaluation are located in Appendix C).

A Word About Best Practice Standards

Best practice standards are in a “putting the cart ahead of the horse” situation in this country and as such are the cart. There is no Disability Act in Nova Scotia (horse). We believe having such an act would enhance the ability to set best practice standards, develop policy and procedures and set treatment standards. At present, best practice standards for persons living with disability are inconsistent across agencies/services and are developed on an individual agency/service basis as opposed to a universal or national standard.

Canada Mortgage and Housing Corporation is an excellent example of some of the good work that is being done in this country (CMHC, 2007). They have produced eight detailed publications on building homes that are flexible and accessible; e.g., *Accessible Housing by Design, Lifts and Residential Elevators, Ramps, and Kitchens* (CMHC, 2006). They also have a research division that not only conducts meaningful studies on living with disabilities, but also publishes the findings which include best practice standards on issues such as the placement and use of grab bars.

It is beyond the scope of this report to make an exhaustive list of best practice standards for people who are aging with disabilities. However, the recommendations do serve to inform the setting of such standards.

Annotated Bibliography

This bibliography and publication list are designed to support participatory action research currently underway regarding aging with disability and dignity in Nova Scotia.

This document is divided into sections for easy access of the researcher. Online source material will have a hyperlink provided. Access dates will not be provided as it will be assumed that the researchers have checked the continued availability of the site.

One note about online sources... The internet has become a collage of material and while much attention has focused on on-line document creditability, the World Wide Web has become a crucial tool in research. This list focuses on source material provided through accredited educational institutions, health and social science researchers, recognized government and media publications, and social/public policy institutions.

Arcand, Maureen. “*Living and Aging with Cerebral Palsy*,” Wisconsin Council on Developmental Disabilities. Available: <http://www.wcdd.org/announcements.htm>.

This is a brief overview of two studies on aging with CP conducted in Wisconsin. The research focused on the changes in physical abilities and health conditions of persons with CP through the aging process. Because CP affects everyone differently the researchers found difficulty in developing a baseline for comparison. With this in mind, both persons with CP and service providers alike indicated further research was crucial.

Ballinger, Brian R. (1978) “The Elderly in a Mental Subnormality Hospital: A Comparison with the Elderly Psychiatric Patient” in *Social Psychiatry*, vol. 13, 37-40.

“Approximately 6% of the patients in a mental subnormality hospital were over the age of 65, in contrast of 61% of patients in a psychiatric hospital. The mean time spent in institutional care was 46.4 years for the mentally handicapped individuals. The levels of self care of the mentally handicapped patients were generally better than that of psychiatric patients. 39% of the mentally subnormal showed psychiatric symptoms when assessed by a standard interview and 42% did not appear to be in need of hospital care.”

Ballinger, Brian R. and Ballinger, C. Barbara. (June 1991) “People aged over sixty-five years living in a mental handicap hospital – Thirteen years on.” in *Mental Handicap*. Vol. 19, 77-80.

This article is a follow-up of a study completed in 1976 to survey the level and need of care for people who were aging in a psychiatric hospital. The study noted

a general similarity of care, abilities and treatment with the earlier study, and concluded that over half of the patients could be placed in non-hospital residential care.

Bendall, Lisa. (Winter, 1998) "Silver Linings" in *Abilities Magazine*. Issue 37, pp. 46-48. Available: <http://abilities.ca/seniors/article.php?pid=&cid=&subid=&aid=547>.

This article first appeared in the Winter 1998 issue of *Abilities Magazine*. It looks at the problem of elder abuse, especially in relation to disability. Bendall chronicles the experiences of seniors who are confronting financial abuse by scams and family neglect, and dealing with strategies to overcome abuse.

Bigby, Christine (2004) *Aging with a Lifelong Disability: A Guide to Practice, Program and Policy Issues for Human Services Professionals*. London: Jessica Kingsley Publishers.

Bigby presents a policy framework for program and service delivery for persons with lifelong disabilities in Australia. Her work focuses on perspectives of aging with a disability, physical and psychological needs and the social dimensions of aging. She also considers the challenges of older parents caring for their adult children. Bigby concludes by offering policy development options for service delivery. The book includes a collection of "vignettes" telling the life stories of older Australians living with a lifelong disability.

Bigby, Christine. Balandin, Susan. Fyffe, Chris. McCubbery, Jeffery and Gordon, Meg. (September 2004) "Retirement or just a change of pace: an Australian national survey of disability day services used by older people with disabilities," in *Journal of Intellectual and Developmental Disability*. Vol 29, No 3, pp. 239-254.

This Australian research study looked at participation by persons with intellectual disabilities over age 55 in day support programming. The mail survey was sent nationally to day service providers, and indicated that most aging people who attended individualized programs were regarded as most successful. The study also pointed to weaknesses in the understanding of aging and disability, and financial constraints in service delivery.

Bowling, Ann and Dieppe, Paul. (December, 2005) "What is Successful Ageing and Who Should Define It?" in *British Medical Journal* (BMJ) Vol. 331, 24-31.

This article explores the often controversial assumptions made in Rowe and Kahn's successful aging theory. Specifically, Bowling and Dieppe explore the limitations of successful aging being used as an unrealistic benchmark for all. Instead, they argue for a broad understanding of the concept to strive for, rather than a measure of success or failure.

Butler, Samantha. MacLellan, Marlene and Humble, Aine (November 2006) *The Next Stage: Retirement Planning for Older Persons with Disabilities*. Halifax: Nova Scotia Community College.

Funded by the Public Health Agency of Canada, this study explored the interface between the disability and aging sectors, and promoted social inclusion for older persons with intellectual disabilities. The study included a “needs assessment” arising from data collected from focus groups of both persons with intellectual disabilities and service providers. The main objective was to solicit opinions on expectations, aspirations and planning for retirement. Service providers were asked about current planning services and the capacity of social inclusion in program delivery.

The conclusions from this study settle on the desire for persons with intellectual disabilities to be in control of their own retirement planning with an emphasis on social inclusion and resource security. It also challenges the disability and aging sectors to promote education about issues of retirement pertaining to persons with intellectual disabilities. The report’s 14 recommendations focus on the areas of transitional planning from work to retirement, capacity building within the disability and aging sectors and policy recommendations for both the Nova Scotia Seniors Secretariat and the Disabled Persons Commission.

Butler, Samantha (2007). *Retirement Planning Resource Guide for Older Adults with Developmental Disabilities, Families, Friends and Service Providers*. Halifax: Nova Scotia Community College.

This guide is part of the NSCC’s project *The Next Stage* (see above) and is meant to provide a listing of resources and agencies providing information and services for persons with intellectual disabilities reaching retirement age. Topics range from community advocacy to acquiring basic services, to finances and planning. The listing contains provincial, national and international organizations of interest.

Community Living Research Project (2007) *Services for Seniors with a Developmental Disability*. Vancouver: University of British Columbia, School of Social Work and Family Studies. Accessed:
http://www.arts.ubc.ca/fileadmin/template/main/images/departments/Community_Living/documents/Services_for_Seniors_Report_April_2007.pdf

This report (and its plain language summary companion) studied issues, supports, and services available to people with intellectual disabilities that are aging. The report dealt with issues of formal and informal supports, programs to address grief and loss, access to assistive technology, as well as models of supports. The project offered recommendations for future practice, including family-based planning for needs and encouragement of self-determination strategies.

Disabled Peoples' International, (2005) Aging with Disability. Accessed.
http://v1.dpi.org/lang-en/resources/topics_list?topic=1

This source is a compilation of information from the Rancho Los Amigos National Rehabilitation Center on the effects of aging and disability. Set up as an information package, this site explores the relationship between disability and aging in terms of increased life expectancy, medical problems, functional problems and psychosocial changes that persons with disabilities face later in life. The site also suggests possible causes of secondary health issues.

Drainoni, Mari-Lyn. Lee-Hood, Elizabeth. Tobias, Carol. Bachman, Sara S. Andrew, Jennifer and Maisels, Lisa (Fall, 2006). "Cross-Disability Experiences of Barriers to Health Care Access – A Consumer Perspective" in *Journal of Disability Policy Studies*. Vol. 17, no. 2, 101-115.

This research considers the differences in access to health care from a life-long, cross-disability perspective. Using parameters established by the Institute of Medicine barriers of health care, the researchers conclude that while most consumers spoke of similar barriers, some disability groups reported more pronounced experiences than others. They conclude that a broader scope of focus is needed in policy formulation and implementation.

Hammel, Joy and Nochajski, Susan eds. (2000). *Aging and Developmental Disability: Current Research, Programming, and Practice Implications*. New York: Haworth Press.

This publication was co-published as Physical and Occupational Therapy in Geriatrics, Volume 18, Number 1. The collection explores current research and policy implication of those aging with a developmental disability. Specifically, the papers considers the dichotomy between "disability and aging" and "aging with disability" research, as it pertains to increased risk of loss of functional abilities and community participation. Other articles focus on the awareness of specific needs of women with intellectual disability, recommending practical terms of reference for therapists and clinicians. The articles also discuss the impact of assistive technology, life planning strategies, and the challenges associated with aging in place. This volume includes a listing of web-based resource material.

Hunsberger, James. Shaw, Lynn. Schweitzer, Ann and Burns, Sarah. (September/October 2005) "Aging with a disability: Strategies for enabling occupational transitions," in *OT Now*. Available:
http://www.caot.ca/otnow/Sept05/Sept05OTNow_Aging.pdf

This article is an introspective journey on the road of aging and disability. Hunsberger tells the story of partnering with his therapist team to prepare for new physical and psychological changes in his life in his retirement. The authors offer a personalized set of "best practices" to cope with aging with a disability.

Janicki, MP and Breitenbach, N. (2000) *Aging and Intellectual Disabilities – Improving Longevity and Promoting Healthy Aging: Summative Report*: Geneva: World Health Organization.

With the global increase of life expectancy of people with intellectual disabilities, the WHO commissioned this report to encompass the findings of four smaller studies conducted by the International Association for the Scientific Study of Intellectual Disabilities, and argues for the adoption of global standards in health care. Topics include physical health, women's health, biobehavioral and aging and social policy issues.

Kandel, Issack. Schofield, Patricia and Merrick, Joav. (2007) *Aging & Disability: Research and Clinical Perspectives*. Victoria, BC: International Academic Press.

This book is based on clinical research and practitioners' perspectives on aging and disability. It attempts to bridge the gap between what is often regarded as the two disciplines by common perspective, experience and research. Topics in this volume range from physical and mental health issues specific to aging and disability, to policy concerns.

Kennedy, Jae (Spring, 2002). "Disability and Aging – Beyond the Crisis Rhetoric" in *Disability and Social Policy Studies*. Vol. 12, no. 4, 226-228.

In this introduction for this special issue Kennedy outlines the broad issues facing older persons with disabilities. While seeing the current policy limitations in meeting the needs of an aging population with a disability, he challenges the "apocalyptic" assumptions made by policy researchers. Instead, he suggests that policymakers must take stock of both the strengths and weaknesses of current programming with a view to building on existing programming.

Kenopic, Chris. (2001) *Keeping the Hands in Motion*. Ottawa: The Canadian Association of the Deaf.

This report considers the unique challenges faced by Deaf seniors, especially living in nursing home settings. The project focused on the need for technical aids used for communications and made recommendations to smooth the transition to residential living. The research subjects were all linguistically and culturally Deaf, signing from childhood. The report draws from a comprehensive analysis of the project survey and makes recommendations about access to technology, retirement planning, and rights education.

MacLellan, M., Norris, D., MacPherson, K., and Flowerdew, G. (2002) *Age Related Transitions: Older Parents Caring for Adult Sons/Daughters With Lifelong Disabilities*. Halifax: Mount Saint Vincent University.

This is the final report of a joint study by Mount Saint Vincent and Dalhousie Universities to understand the challenges, needs and concerns of older parents responsible for the care of their adult children with a disability. The research was undertaken throughout Atlantic Canada and used both quantitative and qualitative research methodologies. The literature review and research data focused upon the increased demands and experiences of both child and parent encountering the aging process. The report also made recommendations for care support, especially the adoption of family-inclusive decision-making processes.

Margano, ML., Moore, PD., Kay, DWK., Perry, RH., Reid, BE., Berney, TP., and Tyrer, SP. (June, 2007) "Fifteen-year Follow-up of 92 Hospitalized Adults with Down's Syndrome: Incidence of Cognitive Decline, its Relationship to Age and Neuropathology" in *Journal of Intellectual Disability Research*. Volume 51, Part 6, pp 463-477.

This article outlines clinical research findings of the relationship between dementia and Down Syndrome. It has been long established that people living with DS are more susceptible to developing Alzheimer's Disease and other forms of dementia related conditions earlier than those in the general population. Assessments of 92 people were conducted between 1985 and 2000, measuring both cognitive and behavioral deterioration. Testing was done using the Prudhoe Cognitive Function Test (PCFT) and Adaptive Behavioral Scale (ABS). The occurrence of dementia increased to 50% by age 60. A follow-up study concluded that 21% (between the ages of 55 and 74 years) developed dementia during the follow-up period.

Minkler, Meredith and Fadem, Pamela (Spring, 2002) "Successful Aging: A Disability Perspective" in *Journal of Disability Policy Studies*. Vol, 12, no 4. 229-235.

"Minkler and Fadem examine the successful aging paradigm in gerontology and the problems it poses when applied to the growing population of people who are aging with substantial physical disabilities. They review Rowe and Kahn's (1998) three characteristics of successful aging and explore their relevance and limitations when applied to people with disabilities."

Morris, Chris (November 5, 2007) "Who will take care of them?" 'Living' in *The Halifax Chronicle-Herald*

This newspaper article tells the story of aging parents of adult children with disabilities and their frustration and fears. It explores the issue of institutional care, especially when parents are no longer able to care for their children. Underlying this problem is the lack of care facilities and government support programs.

Morrow, Marina (2000) *The Challenges of Change: The Midlife Health Needs of Women with Disabilities*. Vancouver: British Columbia Centre for Excellence for Women's Health. Available: <http://www.bccewh.bc.ca/publications-resources/documents/challengesofchange.pdf>.

This study was commissioned to understand the changing physical and emotional issues facing women with disabilities as part of the aging process. Trends lead to a greater lifespan within the general population, with women living longer than men. As such, the rationale of this study was to identify specific issues within this subsection of the population largely overlooked in disability studies. The research stresses traditional strategies toward empowerment for women within this age group are often inappropriate for women with a disability. The research indicates the necessity of further medical exploration of the relationship between menopause and disability, as well as further methodological study on the operational definition of disability and specific issues facing women with developmental disabilities.

National Advisory Council on Aging (2004) *Seniors on the Margins: Aging with a Developmental Disability*. Ottawa: Public Works and Government Services Canada.

This is one of a series of policy papers on marginalized sectors of the aging community in Canada. The document outlines NACA's position on those who are aging with a developmental disability, specifically outlining key health, economic and social issues. It documents key challenges and outlines recommendations.

National Council on Ageing and Older People and the National Disability Authority (February, 6, 2006) *Proceedings of the Seminar: The Interface Between Ageing and Disability*. Wendy Cox, ed. Seminar at Burlington Hotel, Dublin. Available: <http://www.ncaop.ie/newsevents/disabilitysemprocs.pdf>

This conference explored the intersection of issues within Ireland's National Council on Ageing and Older People and the National Disability Authority as part of a three step initiative to explore issues of disability and aging. The seminar focused on the rolling-out of a joint policy paper for stakeholder feedback.

Priestly, Mark (Spring 2003) "A Life Course Approach" in *Disability Studies Quarterly*. Vol. 23, no. 2. Available:

This article was originally an introductory address to an international symposium on disability and "life course". The author draws from both theory and cultural attitudes towards disability and aging. He argues that that both disability and aging within academic study have been viewed through individual life experiences and socially constructed attitudes. Both an "individual/biographical" approach and the structural-normative offer a comprehensive picture of the economic, political and social conditions impacting the individual.

Putnam, Michelle (Winter, 2005) “Conceptualizing Disability: Developing a Framework for Political Disability Identity” in *Journal of Disability Policy Studies*. Vol. 16, no. 3, 188-198.

Putnam studies the often controversial notion of disability identity as a means for political engagement. She considers six identity models used by other groups to have a voice. The differing views of social, psychological and political constructs of disability identity are discussed, and she offers a “conceptual framework” to clearly examine disability identity.

St-Maurice, Linda. (1995) *Seniors with Disabilities Abuse Prevention Model: An Approach to Independent Living in Rural Communities*. Ottawa: Canadian Association of Independent Living Centres.

This resource material was prepared to promote a model of abuse prevention through an independent living lens. Set in a resource manual format, this material is comprised of four volumes dedicated to procedures and resistance, profiling abuse, socio-demographic profiles, facilitator’s tools, and media tools.

School of Public Health and Health Professions. *Aging with Disability: A Life Course Perspective*. University of Buffalo. Available:
http://codi.buffalo.edu/graph_based/aging/.conf/.references.htm

This “cornucopia of disability information” is a source and bibliographical listing that is geared towards disability and aging. Although published in the 1990s, the list contains information on living with stroke and heart disease, material on caregiver stress, and personal stories of aging with a disability.

Society for Manitobans with Disabilities (October 2004). *Aging and Disability in Manitoba: Converging Opportunities*. Accessed:
<http://smd.mb.ca/uploads/DoublelensreportFinal.pdf>.

This report commissioned by the Society of Manitobans with Disabilities considers the social and policy impact on an aging population of persons with disabilities in Manitoba as in other jurisdictions; the demographics suggest seniors with disabilities are part of a growing population trend. Current projections within this subgroup are expected to grow to 68%. In this light, the Society recognizes a converging set of realities in the once separate spheres of disability and seniors’ issues. The Society advocates a “double lens” approach in addressing and formulation policy options, when appropriate, and outlines initiatives in other provinces.

-----, (2005) *Strategy for Positive Aging in Nova Scotia*. Halifax: Province of Nova Scotia.

Although this document does not address specific issues of disability and aging, it provides the framework for an aging strategy for the general population in Nova Scotia. Demographics suggest that the province has the oldest population in Canada, and by 2026 the seniors population in the province will grow by 80%. The strategy is a resource guide for current and future seniors' policy. Advancing the concept of positive aging as a lifelong process that encourages inclusion, activity and personal choice, the message is that aging no longer has to be a dreaded experience. Therefore, social policy must reflect the positive contribution seniors make to the life of the province.

The report contains a summary of issues for seniors, setting out specific goals and listing "best practices" in terms of good news stories.

Verbrugge, Lois and Yang, Li-shou (Spring, 2002) "Aging with a Disability and Disability with Aging" in *Disability and Social Policy Studies*. Vol. 12, no. 4, 253-267.

Verbrugge and Yang explore the similarities and differences of those who live with a childhood disability and those who become disabled through the aging process. They use indicators such as health, social demography and social participation to measure differences between the two groups. While health issues tend to bind the two groups together, the authors argue those who age into disability usually have a higher frequency of social participation.

Walker, Alan and Walker, Carol (1998) "Normalization and Normal Ageing: The social construction among older people with learning difficulties" in *Disability and Society*. Vol. 13, no. 1, 125-142.

Walker and Walker explore the issue of normalization as it pertains to older people with learning disabilities in the UK. They argue that programs for seniors and those with learning disabilities have taken distinct policy tracks. As such, people who are living longer and requiring specialized programming are lost between the two realms of service delivery. They question the use of normalization in this context, suggesting that what is normal for the group might not be for the individual. They advocate policy and programming designed specifically for this group and not discriminating by age.

Zarb, Gerry (1993) *Ageing With A Disability in Residential Care*. The Leonard Cheshire Foundation. Available:

<http://www.leeds.ac.uk/disability-studies/archiveuk/Zarb/CHESHIRE.pdf>

This is a companion briefing paper to Zarb and Oliver's research, *Aging with Disability: What do they Expect After All These Years* (see below). Zarb's

attention in this document centres on gaining support and funding for residential care homes such as the Leonard Cheshire Foundation in the UK. However, the briefing paper does provide a comprehensive overview of the researchers' methodology as well as results from quantitative and qualitative research from participants living in residential care facilities.

Zarb, Gerry and Oliver, Mike (1993) *Aging with Disability: What Do They Expect After All These Years*. London: Greenwich University Press. Available: <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/ageing%20with%20disability.pdf>

This was the first study on aging and disability in the UK. The main thread throughout the document is that persons with disabilities entering their older years feel excluded from their own long-term care planning. This disempowerment is especially felt by women and members of visible minority groups who especially live in isolation and dependence, and feel their voices are lost in the effort to secure supports and services. The authors argue the need for "defined rights and entitlements" to address this growing social policy challenge in the UK. The study is designed for government and disability advocacy groups, and meant to be a call for awareness and positive change.

Websites of note

Advancing the Inclusion of Persons with Disabilities 2005

Human Resources and Social Development Canada

<http://www.hrsdc.gc.ca/en/hip/odi/documents/advancingInclusion05/chap1.shtml>

Canadians are living longer. As we age, the chance of having a disability increases. Disability affects people of all ages. After age 65 about one in three of us have developed a disability, and that likelihood continues to increase as we grow older. What are the implications of aging with a disability?

Aging and Disability Resource Center (ADRC)

<http://www.agingcarefl.org/ADRC>

The Area Agency on Aging of Pasco-Pinellas, Inc. has been designated to serve as one of three Aging and Disability Resource Centers in the State of Florida as of August 1, 2005.

Canada Mortgage and Housing Corporation

<http://www.cmhc.ca>

Canada Mortgage and Housing Corporation (CMHC) is Canada's national housing agency. It is committed to helping Canadians access a wide choice of quality, affordable homes, while making vibrant, healthy communities and cities a reality across the country. CMHC works to enhance Canada's housing finance options, assist Canadians who cannot afford housing in the private

market, improve building standards and housing construction, and provide policymakers with the information and analysis they need to sustain a vibrant housing market in Canada.

Canadian Association of Independent Living Centres

<http://www.ilcanada.ca/article/home-125.asp>

CAILC and the Independent Living movement have a compelling vision of a Canada that is able to tap into this incredible resource offered by persons with disabilities. CAILC works to empower people with disabilities and to remove barriers so that responsible, self-reliant people with disabilities can assume risks, make choices and contribute as they wish.

Canadian Centre on Disability Studies

<http://www.disabilitystudies.ca/index.htm>

The Canadian Centre on Disability Studies is a consumer-directed, university affiliated centre dedicated to research, education and information dissemination on disability issues.

CDiHP –Aging with Disability

<http://www.cdihp.org/aging.html>

In March, 2003, the Center for Disabilities and the Health Professions partnered with the Rehabilitation Research and Training Center on Aging with a Disability to present: "Aging with a Disability: Putting Research into Practice and Education." Presentations included an overview of medical issues by Laura Mosqueda, MD, Musculoskeletal and Functional Issues by Lilli Thompson, PT, and Caregiver/Support Issues by Bryan Kemp, PhD.

Growth in disability rates from 2001 to 2006

Statistics Canada

<http://www.statcan.ca/english/freepub/89-628-XIE/2007002/growth-en.htm>

Between 2001 and 2006 the number of persons who reported having a disability increased by three-quarters of a million people (+21.2%), reaching 4.4 million in 2006. At the same time, the non-disabled population experienced lesser growth, increasing by 3.3% to reach 26.2 million people. As a result, the national disability rate increased 1.9 percentage points from its level of 12.4% in 2001 to reach 14.3% in 2006.

Independent Living Resource Centre, Halifax, NS

<http://www.ilrc-halifax.ns.ca/main.htm>

This is the only Resource Centre for Independent Living in Nova Scotia. The Centre helps persons with disabilities gain skills necessary for living independently in the community, and helps them find the services and agencies they need.

Ontario Partnership on Aging and Developmental Disabilities

<http://www.opadd.on.ca/>

This partnership ensures that the general and special needs of persons with a developmental disability who are aging are identified and addressed effectively to ensure quality of life.

Rehabilitation Research and Training Center on Aging with a Disability

<http://www.agingwithdisability.org/>

The center investigates the impact of aging on people with a disability, and examines issues such as health changes, psychological reactions, family needs, and job accommodation. The center specializes in new research on aging with disability and providing training to physicians, direct service professionals, and consumers. Types of impairments included in the research are polio and post-polio syndrome, rheumatoid arthritis, cerebral palsy, spinal cord injury, stroke and others.

Rights and Dignity of Persons with Disabilities, United Nations

<http://www.un.org/disabilities/>

The Convention on the Rights of Persons with Disabilities and its Optional Protocol are serviced by a joint Secretariat, consisting of staff of both the United Nations Department of Economic and Social Affairs ([DESA](#)), based in New York, and the Office of the High Commissioner for Human Rights ([OHCHR](#)) in Geneva.

Texas Department of Disability and Aging Services

www.dads.state.tx.us

From the Texas Department of Disability and Aging Services. This site explains programs and services for both seniors and persons with disabilities. Of note is the department's vision to promote individualized program delivery options.

Note that all states in the US have similar departments.