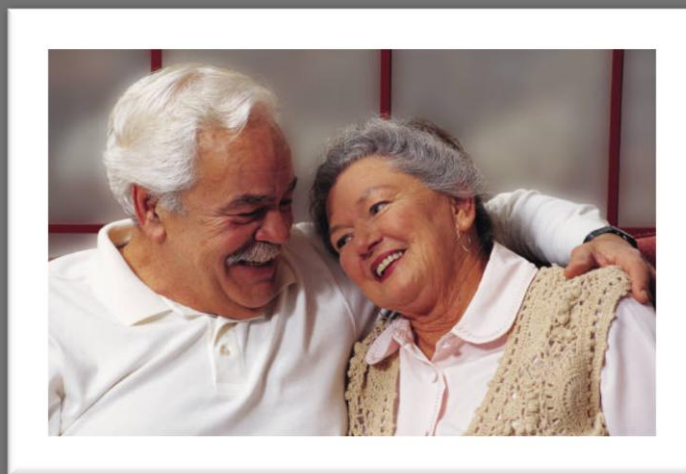


SUPPORTS AND SERVICES FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES STUDY

Final Report 2012



CRCB PDD commissioned this study to assist them in the development of community-based services for older adults with developmental disabilities as well as to contribute to provincial policy and research on this population and the ministry's framework on aging.

CRCB PDD is grateful to the parents, guardians, siblings, and individuals with disabilities who shared their views with us. CRCB PDD would also like to thank the disability services providers for their input, CRCB PDD personnel for their assistance, the research advisory committee for their advice, and the Steering Committee for their insights.

July 2012

The Study Steering Committee, convened by CRCB PDD to oversee the study, consisted of:

- Dr. Alex Hillyard (Committee Chair and Project Sponsor), Chief Executive Officer, CRCB PDD
- Jenia Tishkina-Norman, Senior Manager, Finance and Administration (PDD Project Manager)
- Pam Brown, Executive Director, Integrated Seniors Health, AHS, Calgary Zone
- Edward Burdon, Director, Calgary Society for Persons with Disabilities
- Ralph Hubele, Manager, Supportive Living Programs Unit
- Wayne Morrow, Chief Executive PDD Central Region
- Jeff Nish, Chair, CRCB PDD
- Erica Olsen, Policy Advisor, Policy and Planning, Housing
- Bruce Uditsky, Chief Executive Director, Alberta Association of Community Living (AACL)
- Dr. Tim Weinkauff, Senior Manager, Program Quality and Evaluation, PDD
- Valerie Wiebe, Executive Director, Addictions and Mental Health, AHS, Calgary Zone

This study was completed by Possberg & Associates Ltd. The team Possberg and Associates Ltd. assembled for the Supports and Services for Older Adults with Developmental Disabilities Study included:

- Dr. Matthew P. Janicki Research Associate Professor of Human Development at the Institute of Disability and Human Development at the University of Illinois at Chicago, Director for Technical Assistance for the Rehabilitation Research and Training Center in Aging with Developmental Disabilities–Lifespan Health and Function at the University, and formerly Director for Aging and Special Populations for the New York State Office for People with Developmental Disabilities.
- Dr. Sandra P. Hirst, RN, GNC(C) Director of the Brenda Strafford Centre for Excellence in Gerontological Nursing at the University of Calgary President of the Alberta Association on Gerontology and the Canadian Gerontological Nursing Association, Member of the Canadian Association on Gerontology, Board Member of the National Initiative for the Care of the Elderly.
- Mr. Derek Cook Research Social Planner in the Social Policy and Planning Division of The City of Calgary who has over 20 years of experience in the field of social work, research and community development. His work includes conducting statistical analysis, socio-economic research, trend analysis and social policy development.
- Dr. Chris MacFarlane Co-owner, Possberg and Associates Ltd., Registered Psychologist, an Assistant Adjunct Professor in the Department of Community Health Sciences at the University of Calgary and a Sessional Instructor in Disability Studies at Mount Royal University in Calgary.

The Research Advisory Committee, assembled by Possberg and Associates consisted of:

- Dr. Michael Jones Neurologist, Provincial Medical Advisor for Adults with Developmental Disabilities, British Columbia
- Dr. Aldred Neufeldt Professor Emeritus, Disability Studies, University of Calgary
- Mr. Stan Fisher President and CEO of St. Michael's Health Group, Edmonton, member of the Board of Directors of the Winifred Stewart Association for Mentally Handicapped, Edmonton
- Dr. Robert Schalock, Professor Emeritus from Hastings College, Adjunct Professor at the University of Kansas (Life Span Institute and the Beach Center on Disability), University of Salamanca (Spain): Chongqing Normal University (Mainland China), and University of Gent (Belgium) and President of Bob Schalock and Associates-Planning and Evaluation

Executive Summary

Calgary Region Community Board Persons with Developmental Disabilities (CRCB PDD) is responsible for the planning and allocation of resources for supports and service development for people with developmental disabilities. CRCB PDD's geographic area includes the city of Calgary as well as the territory encompassing Lake Louise, High River, Airdrie and Strathmore.

In 2009/10, there were 2,487 persons age 18+ with developmental disabilities receiving services based on CRCB PDD's funding in the Calgary Region. The majority (i.e., 91 percent) of the persons with developmental disabilities population lived within the urban area (e.g., Calgary). A smaller number (i.e., 219 people) resided in the rural communities within the Calgary Region.

The individual support needs of adults within this population are varied and diverse. Factors such as the age of the individual, their location, and the nature and degree of their presenting issues all impact the determination of the level of support they require.

CRCB PDD identified the development of appropriate services for older adults with developmental disabilities as an emerging issue in their region based on a series of focus groups, hosted by CRCB PDD in 2010 with families and guardians and from input received from disability service providers. Consequently, CRCB PDD commissioned a study to review the services and supports required for older adults with developmental disabilities, including those with dementia.

Vision: Communities and services will be able to support older adults with developmental disabilities so that they can continue to participate in their communities and live healthy and meaningful lives.

Study Design

The study's objectives are to provide:

- an understanding of the current service needs;
- an identification of the gaps between those service needs and current/future service availability;
- an outline of a planning framework that addresses the current and future service needs;
- an analysis of the best and promising practices in providing services and supports to older adults with developmental disabilities, as well as to their families;
- a summary of approaches for the identification of the onset of various age-related characteristics, including diseases and syndromes;
- a review of current research, government policies, services and supports, including natural and funded services and supports, available to adults with developmental disabilities ; and,
- an identification of areas of current and potential alignment, integration and collaboration of supports and services provided by community-based services and each level of government.

A mixed methods gap analysis study was completed by Possberg and Associates Ltd. The study included:

- an analysis of the current service recipients' data maintained by CRCB PDD;
- a review of the supports and services currently available in Calgary;
- focus groups with individuals with developmental disabilities and family members;
- interviews with health care and disability service professionals; and,
- three literature reviews including:
 - health issues and concerns that are unique to individuals with developmental disabilities as they age;
 - assessment tools and processes; and,
 - a summary of promising practices in supports and services.

Current Reality

The current reality is characterized by nine themes.

- 1. *The population is aging.*** In 2009/10, there were 2,487 individuals age 18+ with developmental disabilities receiving CRCB PDD-funded services in the Calgary Region. Approximately one thousand (i.e., 994) of these individuals were over the age of forty. An increasing percentage of individuals with developmental disabilities are living into late adulthood.ⁱ This is due to a number of factors including advances in medical and social services, advocacy of families and individuals with disabilities, and the movement away from institutionalization towards community living.
- 2. *Age restriction for services and supports.*** Although older adults with developmental disabilities are living longer, a small group of older adults with developmental disabilities, because of accompanying mental health concerns, including dementia or other health concerns are demonstrating the signs of aging at an earlier age (e.g., 50 years of age) than the general population. Unfortunately, older adults with developmental disabilities cannot access many generic services and supports for older adults developed by the federal, provincial, and municipal governments and non-profit organizations because eligibility is generally based on the chronological age of 65 years.
- 3. *Desire to aging-in-place.*** Generally, older adults with developmental disabilities want to age-in-place. This desire is supported by their families and their disability service providers. Aging-in-place is a philosophical and programmatic approach to supporting older adults that has been adopted by most developed countries.ⁱⁱ Studies indicate that aging-in-place for adults with developmental disabilities can occur if providers receive appropriate training, are assisted in making the necessary environmental modifications to the residences, and provided with responsive and flexible funding.ⁱⁱⁱ
- 4. *Mental health and dementia support needed.*** Individuals, who are dually diagnosed, including those with dementia, constitute a small subset of the population of older adults. This group has the highest level of support needs and requires multiple resources, from a number of ministries and community services, to support them. There appears to be a significant gap in appropriate service models and personnel for older adults with developmental disabilities and accompanying mental health concerns, including dementia. An individual in this group, according to family members, health and disability professionals, is likely to become either a “revolving patient” or a “delayed discharge” in emergency, psychiatric, and/or medical wards.

- 5. Workforce development required.** Disability and health service providers expressed a desire to receive more training in supporting older adults with developmental disabilities. Service providers expressed concern with a lack of knowledge on issues related to aging and/or developmental disabilities. The number of physicians, including psychiatrists, who are trained and/or willing to support older adults with developmental disabilities, is limited. Some administrators expressed concern with the lack of clarity at the provincial level regarding the roles and responsibilities of various ministries, departments, and professionals in supporting older adults with developmental disabilities. They have suggested that there is a lack of clear direction and clarity from respective ministries, exacerbated by changes or reductions to services and eligibility criteria resulting in major time and effort taken to sort out for individual clients what ministry is responsible for what services - particularly in complex situations.
- 6. Families support critical.** Consistently families and guardians expressed concern for the future of their adult with a developmental disability. Calgary families indicated they didn't know who to approach to get assistance with this planning. These families were concerned with who would advocate for service quality when they were no longer able to fulfill this role, whether the Office of the Public Guardian would be able to accommodate the demand for support, and where their family member would reside in the future. Studies indicate that there are a significant number of adults who access services for the first time, later in life, when their parents are no longer able to support them.^{iv v} This number could be equal to those currently receiving CRCB PDD services.^{vi} Identifying and assisting these families to complete future plans could result in the development of appropriate and cost-effective services for these adults (i.e., both the parent carers and the adult with the developmental disability).
- 7. Support networks needed.** Health and social services research over the last thirty years has demonstrated the significant role that well-developed social support networks have on mitigating the occurrence and effects of negative life conditions including poverty, depression, unemployment, sexual abuse, and health issues for people with and without developmental disabilities. Unfortunately, its identification as an over-riding best practice, and the efforts of funders, disability service providers, parents, guardians, advocacy groups, and academics, has generally only resulted in a lack of or an under-development of support networks for most people with developmental disabilities. The issues underlying the gap in the application of research into practice are multiple and complex. Calgary families indicated that older adults with developmental disabilities have networks that are dependent on families

and staff, which places them at risk of not receiving the emotional, financial, and instrumental support they require when their families are no longer able to support them.

- 8. Early identification of those at-risk of inadequate support needed.** Early identification of the specific individuals who are currently most at-risk of not being able to aging-in-place (e.g., those living at home with elderly parents, those in supportive roommate situations, those living alone or in semi-independent situations, those living without adequate support) would be critical so that long-term residential, legal, and financial planning can be completed and supports implemented.

- 9. On-going data collection will assist planning.** There are a number of suggestions for increasing the collection of statistical information for planning purposes. The number of individuals with Down syndrome is one example of the type of information that should be maintained. Completing a census on all known clientele served by Calgary region's providers who fall into the 40+ years age group would be advantageous. This census could collect data on: the age, sex, physical and mental status of adults, the capacity of family caregivers or other caregivers and the status of future plans for the individuals including the likelihood of the current caregiving duration. Also the completion of a broader census of older adults currently not in service, but known to someone or unknown and yet to be found by outreach measurement strategies. Both of these censuses would contribute to long-term planning.

Promising Practices

Ten practices have been identified which would enhance the likelihood of a greater number of older adults with developmental disabilities aging-in-place.

- 1. Develop social support networks.** Social scientists have long appreciated the positive role that community involvement and the presence of natural support networks (i.e., non-professional) plays in the promotion of well-being.^{vii} The results suggest that more work needs to be accomplished in the development of this very important asset for older adults with developmental disabilities. Post-secondary institutions and professional training groups such as the Alberta Council of Disability Services have a role in enhancing disability services personnel's skills in developing social support networks. The development, monitoring, and reporting of system-level indicators may also shed light on the strategies necessary to get increased traction on this issue.

- 2. Utilization of safe environment technology.** Using smart technology and other residential adaptations increases the likelihood of older adults with developmental disabilities aging-in-place. This technology can contribute to their ability to complete tasks while alerting them and others to potential unsafe activities. Maintaining linkages with their families and communities would also be facilitated with this technology.
- 3. Develop viable and walkable communities.** Livable and inclusive communities have affordable and appropriate housing, are supportive, and allow for ease in mobility and engagement in civic and social life. Supporting efforts to keep advocates, family members, and people with disabilities informed regarding municipal and provincial initiatives in housing and transportation policies which support the development of viable and walkable communities would benefit older adults with developmental disabilities.
- 4. Support the development of a network of health care providers knowledgeable in the issues of aging with a developmental disability.** Currently, individuals with developmental disabilities receive primary medical care from medical professionals throughout Alberta. The development of training sessions for family physicians and specialists such as psychiatrists would be advantageous. The exploration of other strategies to enhance medical services to older adults with developmental disabilities should be pursued.
- 5. Support workforce development.** The need for increased workforce development for disability, social work, health or allied health professionals is critical.^{viii ix x xi} Each of these professional groups has a particular area of expertise but the needs of older adults with developmental disabilities crosses professional boundaries. Also the nurturing of professional participation in aging and developmental disabilities networks assists in reducing language barriers and staff resistances while facilitating the likelihood of increased joint planning and working relationships between the two service sectors.^{xii} Exploring the development of these joint networks may prove to be an effective strategy to develop programs and professionals between the two sectors.
- 6. Support families, guardians and siblings.** Families and guardians of individuals with developmental disabilities have been a critical force in the development of progressive disability services. Families want increased access to information related to future planning for their adult with a developmental disability. This information includes estate and financial issues, as well as issues related to planning for

guardianship and trusteeship. Supporting parents with increased access to respite services may assist the older parent and the older adult with developmental disabilities to age-in-place together.

- 7. Provide on-going assessments and screening.** It is critical that baseline medical and functional assessments be completed before the older adult with developmental disabilities is 40 years of age so that it can be used as a measure of comparison to determine frailty related to aging in the future. The British Columbia Health Authority is currently using the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) and uses a “shared funding” model which allows them to contribute funding for personal care when the person’s decreased function becomes an issue. Working closely with Alberta Health Services to ensure these assessments are completed would be beneficial.

- 8. Develop outreach and service navigation teams.** Although training of professionals is a priority, the sheer number of these professionals, combined with the high turnover rates generally, may make the task of ensuring all the professionals have adequate skills costly and overwhelming. Another alternative suggestion^{xiii xiv} is to develop a regionally-based group of consultants and a pool of skilled support staff. This model has worked well in other countries.^{xv xvi} The consultant team would have expertise in older adults’ services and supports, as well as, those for individuals with developmental disabilities. This team would be available to provide assessments and consultations to both the disability and health sector and case manage particularly challenging situations.

- 9. Partner with older adults centres.** Exploring strategies to enhance partnerships with day centres for older adults in Calgary (e.g., Kerby Centre) would be advantageous especially if these strategies are combined with on-going workforce development in both sectors.

- 10. Develop flexible funding models.** It has been suggested that the absence of flexible funding in the disability sector means that all changes are viewed as age-related which results in inappropriate referrals and use of services for older adults.^{xvii} Janicki suggests that governments make funds available for service providers to meet the changing needs of that population whether or not they are associated with aging. The need for long-term planning, including the possibility of increased funding, as individuals with developmental disabilities age is essential.

Three models have been outlined for supporting older adults with developmental disabilities who have Alzheimer's or other forms of dementia. These models include aging-in-place, in-place progression, and out-placement. The in-place progression (i.e., continuum of residential environments that vary with regards to such features as the type of support provided, the safety features of the home, and the training of the professionals) has been shown in other jurisdictions to have some promise for ensuring the safety and dignity of each of the residents in the home.^{xviii}

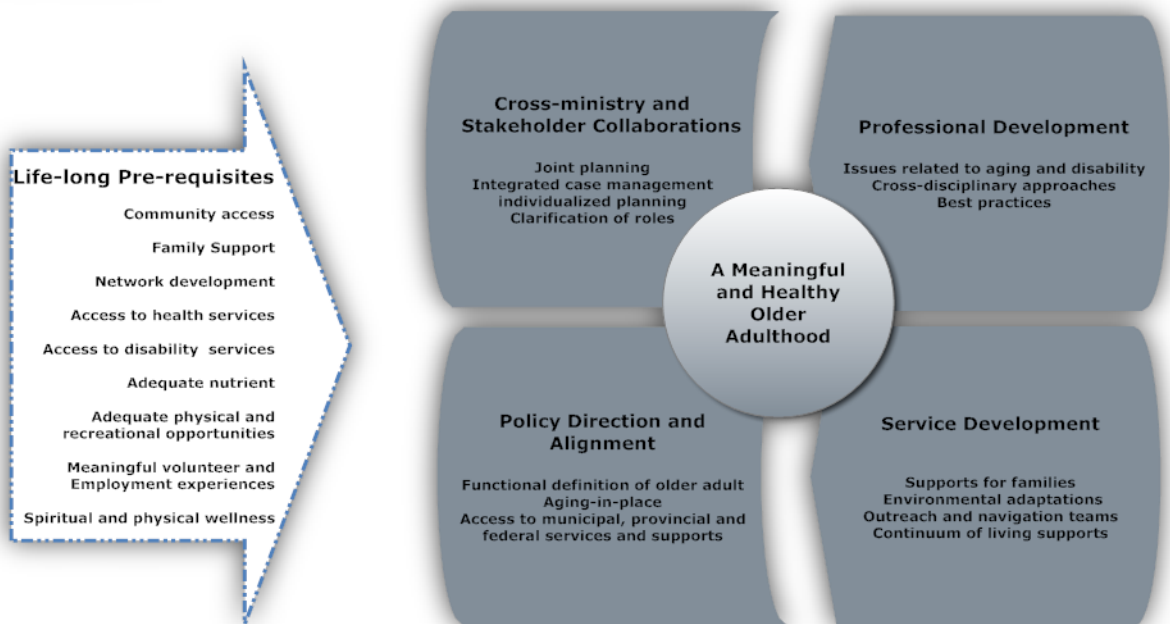
A number of financial supports and community services available to older adults in the general population, through the various levels of government, require the individual to be 55+ or 65+ years of age. Some older adults with developmental disabilities, due to the early signs of aging, may require these services before the stated age criteria for the services. Addressing these potential policy inequities will be necessary in developing supports and services for older adults with developmental disabilities.

A Framework for Awareness, Education, and Transformational Change

A Framework for Awareness, Education, and Transformational Change focused on improving services and supports for older adults with developmental disabilities is outlined. The framework identifies four intersecting and critical pillars. These four pillars are: cross-ministry and stakeholder collaborations; professional development; service and supports development; and, policy direction and alignment.

Key goals, the development of outcome measures, and an evaluation strategy that captures the systems level and program changes are proposed.

Supporting Older Adults with Developmental Disabilities Framework



CONTENTS

Executive Summary.....3

SECTION I: INTRODUCTION.....15

Background.....15

Calgary Region Community Board Persons with Developmental Disabilities (CRCB PDD)16

Study Design.....17

Objectives 17

Methodology..... 17

Underlying Assumptions..... 18

SECTION II: GUIDING PRINCIPLES AND VALUES.....21

Values and Principles for Service Delivery21

Rights of Individuals with Disabilities..... 21

Aging-in-Place 22

Reasonable Access 23

Systems Level Principles25

Common Agenda..... 25

Cross-Ministry Collaboration..... 26

Evaluation and Monitoring 26

Conclusion27

SECTION III: OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES IN THE CALGARY REGION –

Current and Projected Demographics29

Defining Older Adult for Individuals with Developmental Disability29

Chronological Definition..... 29

Functional Definition of Older Adult for Individuals with Developmental Disabilities 30

Demographic Projections31

Population Projections 31

Urban Area 32

Rural Area 33

Future Service Demand 33

Populations Requiring Special Consideration.....	34
<i>Older Adults with Mental Health Issues including Dementia.....</i>	35
<i>Older Adults Who Live Alone or Semi-independently.....</i>	35
<i>Older Adults Who Live in Support Homes</i>	36
<i>Older Adults Who Reside with their Parents.....</i>	36
<i>Older Adults without an Adequate Physical Environment.....</i>	38
<i>Older Adults without Adequate Staffing Support</i>	39
Conclusion	39
SECTION IV: SUPPORTING OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES.....	41
Promising Practices Supporting Older Adults to Age-in-Place.....	41
<i>Promising Practice #1: Develop Social Support Networks</i>	42
<i>Promising Practice #2: Use Safe Home Technology.....</i>	43
<i>Promising Practice #3: Promote the Development of Livable and Walkable Communities.....</i>	45
<i>Promising Practice #4: Support the Development of a Network of Health Care Providers Knowledgeable in the Issues of Aging with a Developmental Disability.....</i>	45
<i>Promising Practice #5: Support Workforce Development</i>	46
<i>Promising Practice #6: Support Families, Guardians and Siblings</i>	47
<i>Promising Practice #7: Provide On-going Assessments and Screening.....</i>	49
<i>Promising Practice #8: Develop an Outreach and Service Navigation Team.....</i>	49
<i>Promising Practice #9: Partner with Older Adults Centres.....</i>	50
<i>Promising Practice #10: Develop Flexible Funding Models</i>	51
Supporting Older Adults with Dementia.....	52
Financial Supports for Older Adults with Developmental Disabilities	53
Conclusion	54
SECTION V: FRAMEWORK FOR AWARENESS, EDUCATION, AND TRANSFORMATIONAL CHANGE.....	56
Framework for Awareness, Education, and Transformational Change.....	57
Outcome Measurements	57
Impact Assessment of Direction and Actions	58
Conclusion	58

**APPENDIX 1. Suggested Activities for the Development of Services and Supports for Older Adults
with Developmental Disabilities61**

REFERENCES68

ENDNOTES.....77

SECTION I: INTRODUCTION

Background

Older individuals with developmental disabilities are living longer due to a number of factors including advances in medical and social services, advocacy of families and individuals with disabilities, the adoption of de-institutionalization and normalization philosophies by most governments, and the development of community-based services with professionally-trained staff. In fact, most individuals with developmental disabilities have a life expectancy similar to that of other individuals without developmental disabilities, although individuals with Down syndrome tend to have a shortened lifespan when compared to other individuals with developmental disabilities and to individuals without developmental disabilities^{xx}.

Unfortunately, given the lack of focus on this population in the academic and policy literature until the mid-1980s^{xxi}, this group has largely been invisible.^{xxii} Consequently, older individuals with developmental disabilities have been at-risk of receiving fewer services than they need at the very time when they need them the most.^{xxiii} Individuals with developmental disabilities generally have social support networks which are typically limited to their family and staff. As they age, their parents are less able to care for them, as evidenced by the significant number of people who begin receiving services in their midlife.^{xxiv} Older adults with developmental disabilities also have less financial and personal resources than other older adults without developmental disabilities^{xxv} and are less resilient to the physiological changes associated with aging.^{xxvi} All of these factors contribute to their increased vulnerability as they age.

Historically, services and supports provided to this group have developed in reaction to an individual need, sometimes experienced as a crisis by family and staff. In many jurisdictions, including Australia, and Britain, placement in long-term care facilities designed for older adults has been a typical option for adults who have resided with their parents most of their lives.^{xxvii} Without adequate planning and development of residential options this could occur over time in Alberta.

Unfortunately, this has meant that these adults are residing with a significantly older population and being cared for by staff unfamiliar with supporting adults with developmental disabilities. Placement in these facilities is also counter-intuitive to the advocacy parents and others have historically engaged in to advance the inclusion of individuals with developmental disabilities into their communities^{xxviii} as well as being in sharp contrast to the aging-in-place discourse in progressive health policy.^{xxix}

Services and supports for adults receiving residential support from a disability services program for most of their adult years are also challenged in supporting these adults through the aging process, despite their desire to do so.^{xxx} These professionals do not typically receive training related to older adults and therefore are unfamiliar with the older adult-specific services that are available, the physical and psychological impact of the aging process, and the strategies for assessing and supporting these adults.

Administrators and policy personnel are also confronted with identifying which is the most appropriate department or organization to deliver and/or fund the services, what services should be available to this population, and how best to allocate resources effectively and efficiently while balancing other and sometimes competing priorities. Tasks such as ensuring adequate services and personnel to address the needs of a diverse population, dealing with perceptions of “double dipping” and inadequate resources, and being able to be responsive and flexible to individual needs while maintaining a long-term system’s perspective are challenging for any administrator or planning body.

Calgary Region Community Board Persons with Developmental Disabilities (CRCB PDD)

Calgary Region Community Board Persons with Developmental Disabilities (CRCB PDD) is responsible for the planning and allocation of resources for supports and service development for people with developmental disabilities. CRCB PDD’s geographic area includes the city of Calgary as well as the territory encompassing Lake Louise, High River, Airdrie and Strathmore. In 2009/10, there were 2,487 persons age 18+ with developmental disabilities receiving Persons with Developmental Disabilities (PDD) services in the Calgary Region. The vast majority (i.e., 91 percent) of the PDD population lived within the urban area (e.g., Calgary); while 219 people receiving PDD funding resided in rural communities within the Calgary Region.

The individual support needs of adults within this population are varied and diverse. Factors such as the age of the individual, their location, and the nature and degree of their presenting issues all impact the determination of the level of support they require.

CRCB PDD identified the development of appropriate services for older adults with developmental disabilities as an emerging issue in their region based on a series of focus groups, hosted by CRCB PDD in 2010 with families and guardians and from input received from disability service providers. Consequently, CRCB PDD commissioned a study to review the services and supports required for older adults with developmental disabilities, including those with dementia.

Study Design

The purpose of this study, conducted within the mandate and scope of CRCB PDD, is to review the services and supports that aging adults with developmental disabilities, including those with accompanying syndromes such as dementia, require so that they can continue to participate in their communities and live healthy and meaningful lives.

Objectives

The study's objectives are to increase awareness and understanding of the needs of this population and to inform the development of community-based services and supports, including community living, today and into the future. The study analyzes the characteristics specific to adults in the general population as they age and applies these findings to understand when and how these characteristics appear in the population of adults with developmental disabilities. An analysis of the demographics of the current population of adults with developmental disabilities in the Calgary Region has been completed to understand the composition today and how it will change in the future.

The study provides: a) an understanding of the current service needs; b) a clarification of gaps between those service needs and current/future service availability; and, c) an outline of a planning framework that addresses the current and future service needs of adults with developmental disabilities as they age. Analysis of the best and promising practices in providing services and supports to aging adults with developmental disabilities, as well as to their families is included in this study. Approaches for the identification of the onset of various age-related characteristics, including diseases and syndromes, are explored to understand their impact on models of support and service delivery. The current research, government policies, services, and supports, including natural and funded services and supports, available to adults with developmental disabilities as they age are examined. Finally, areas of current and potential alignment, integration and collaboration of supports and services provided by community-based services and each level of government are identified along with potential service model(s)/approaches are included in the planning framework.

Methodology

A mixed methods gap analysis study was completed by Possberg and Associates Ltd. The study included an analysis of the current service recipients' data maintained by CRCB PDD, a review of the supports and services currently available in Calgary, focus groups with individuals with developmental disabilities and family members, and interviews with health care and disability service professionals. Three reviews of the literature were completed. The first examined health issues and concerns that are unique to individuals with developmental

disabilities as they age, the second focused on assessment tools and processes, and the third provided a summary of promising practices in supports and services.

This report provides an analysis of this information. Outlined in this report are a number of concrete suggestions for consideration which focus on potential partnerships, models of support, and evaluation and information systems which will contribute to the delivery of quality supports and services for older adults with developmental disabilities.

Underlying Assumptions

This study is guided by the following assumptions:

- The term older adult is used to refer to adults over the age of 50 years of age who have accompanying functional challenges similar to other people in the general population who are experiencing physical decline because of the aging process. It does not imply that all adults with developmental disabilities over the age of 50 are physically, medically, socially, and/or psychologically at risk and requiring specialized services (e.g., institutional);
- People with developmental disabilities and their families need to be involved in designing services;
- Most individuals with developmental disabilities, similar to other adults without developmental disabilities, will be able to age-in-place in their homes with supports from disability and health services;
- A small group of older adults with developmental disabilities, because of accompanying mental health concerns, including dementia or other health concerns, are not receiving effective and efficient services now which has meant a reduction in their quality of life and an inappropriate use of scarce resources across government departments;
- The pre-requisites for healthy aging begin early in life. All people with developmental disabilities should be receiving quality services and supports throughout their life so that there is an increase in the number of “well-healthy” older adults with developmental disabilities in the future;
- The development of social support networks for people with developmental disabilities throughout their life span is critical;
- Cross-ministry collaboration is an essential element of any initiative addressing social issues. Supporting individuals with developmental disabilities as they age will require

the development of a committed and articulated cross-ministry process which is supported and marshalled by a legitimate and thoughtful champion;

- Key ministries and departments which will be primary stakeholders in the development of services and supports for people with developmental disabilities who are aging are: the Seniors Ministry including Persons with Developmental Disabilities, Supportive Housing, Aids to Daily Living, and the Office of the Public Guardian; and the Ministry of Health and Wellness Services including Integrated Seniors Health, Addictions and Mental Health Services;
- The integration of studies examining the support needs of people with developmental disabilities throughout their lifespan will be a critical on-going planning strategy; and,
- Continuous improvement and decision-making will be based on data-informed structures and self-correcting and adjusted systems. The design of these systems will have to be responsive and accommodate organizational changes, policy directives, socio-demographic factors, and changing needs requirements.



Carol¹

Carol is in her mid-sixties. She has been supported by PDD-funded and mental health agencies all her life. Carol has schizophrenia and recently has been diagnosed with Alzheimer's; she suffers from delirium, and is physically aggressive towards others. Currently she is either in hospital, where she has restricted movement or in her disability services group home in her bedroom generally which has a locked half-door so she will not wander or hurt others. The following is an excerpt from her sister's comments regarding what has happened to Carol in 2011.

It has been a hectic summer as Carol has had three admissions and is in the hospital now. There is a big gap between acute care and support in the community for almost all aging people but health seems to think that PDD-funded clients have the support. They don't seem to get that

it is not medical support. PDD staff are not trained or paid as personal care aides. Home care doesn't want to provide these services because they think you are double dipping.

My sister has had five emergency admissions in the last year and is on this merry go round of getting discharged too soon and/or with lack of follow through in the community. Her family doctor retired and it is really hard to find a new doctor, although lots of things could be addressed by a nurse or nurse practitioner, if they were available. This all necessitates more trips to urgent care or emergency. The staff will call me and say Carol hasn't opened her mouth for two days and doesn't want to get out of bed so we agree that they should take her to urgent care but I need to get there before the worker's shift ends at 3 (ideally sooner).

Carol's life journey is generously shared here by her guardian as an example of the complexity a small group of adults with developmental disabilities, those most at need, experience as they age and the necessity of multiple service systems collaborating to address their needs. Throughout the report there are other stories which reflect adults who would be considered either the well-elderly or those with marginal needs. The emerging trends and the theory of systems change outlined in the report are grounded in the need to continue to develop services for each of these groups.

¹ Carol's guardian who is her sister gave permission for this picture and the insert.

SECTION II: GUIDING PRINCIPLES AND VALUES

Clarification of the values and guiding principles that will underpin the development of services and supports for older adults with developmental disabilities, including those with dementia, is a critical first step in designing a system of support. These values and guiding principles become the framework for decision-making, resource allocation, evaluation, system reform, program implementation, and staff development.

This section outlines the values that have been the basis for the development of disability and older adults' services as stated in the literature and considers whether CRCB PDD needs to modify their stated values to support the future development of services and policies for older adults with developmental disabilities, including those with dementia.

Values and Principles for Service Delivery

Based on a review of the literature, a number of values and principles have been identified that have guided the development of services for older adults with developmental disabilities. These values include: respecting the rights of individuals with disabilities, aging-in-place, and reasonable access.

Rights of Individuals with Disabilities

The principles and values that have permeated the disability literature include: the respect for the dignity of the individual, the celebration of

Edinburgh Principles

1. Adopt an operational philosophy that promotes the utmost quality of life of people with ID affected by dementia, and wherever possible, base services and support practices on a person-centred approach.
2. Affirm that individual strengths, capabilities, skills and wishes should be the overriding consideration in any decision-making for and by people with ID affected by dementia.
3. Involve the individual, her or his family, and other close supports in all phases of assessment and services planning and provision for the person with ID affected by dementia.
4. Ensure the appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs and support the healthy ageing of people with ID affected by dementia.
5. Plan and provide supports and services which optimize remaining in the chosen home and community of adults with ID affected by dementia.
6. Ensure that people with ID affected by dementia have the same access to appropriate services and supports as afforded to other people in the general population affected by dementia.
7. Ensure that generic, cooperative and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with ID affected by dementia. (Wilkinson and Janicki, 2002, p. 280).

diversity, the valuing of personal autonomy, rights, and choice, and the development of community-based services, independent living, and natural supportive networks.

These values are reflected in the United Nation’s Convention on the Rights of Persons with Disabilities, which has been recently ratified by the Government of Canada in March, 2010.

These values are also reflected in the Edinburgh Principles. These principles, generated to guide the development and support of services for people with intellectual disabilities (ID) and dementia, were developed by a working group of international experts in 2001.^{xxxix} The values of quality of life, choice, consultation, and collaboration, are identified in these principles.

The Persons with Developmental Disabilities Community Governance Act, the legislation that governs the establishment and operation of the Persons with Developmental Disabilities Community Boards including CRCB, states the following:

- the people of Alberta honour and respect the dignity and equal worth of adults with developmental disabilities;
- it is important that adults with developmental disabilities have opportunities to exercise self-determination and to be fully included in community life;
- the individual needs of adults with developmental disabilities are most effectively met through the provision of services that are based on equitable opportunity, funding and access to resources;
- the Government of Alberta recognizes, values and supports the ability of communities to respond to the needs of adults with developmental disabilities. (Government of Alberta, 2011)

These values and principles are consistent with those identified in the older adults with developmental disabilities literature; therefore, there isn’t a need for a large shift in values, although potentially in policies and their applications (e.g., contracting, procurement, of services) and the delivery of all PDD services.

Aging-in-Place

Analysis of older adults’ accommodation policy in five countries (i.e., Canada, Ireland, Australia, United Kingdom, and United States) indicates that it is based on an “aging-in-place” philosophy.^{xxxix}

Deconstruction of the term “aging-in-place” reveals that it can have varied interpretations.^{xxxix} This approach sometimes refers to the older adult being assisted to live in their own home until at such time, due to medical and other concerns, they are required to move to a medical-based facility. This interpretation of aging-in-place would be similar to

the community independent living movement which has dominated the disability field for over forty years. On the other hand, aging in place in some jurisdictions, such as the Alberta Health Services, refers to receiving services as close to one's community as possible or "aging-in-the-right-place"^{xxxiv}, which in some respects is similar to a "continuum of service" approach commonly used in the mid-sixties in the disability field with examples of this approach still present in Alberta. It is recommended that CRCB adopt Alberta Health Services' interpretation of aging-in-place, given the importance of the partnership with this department and to communicate this policy position to all stakeholders.

It should be noted however that health services across Canada, and in particular Alberta, are attempting to support an increased number of older adults to reside in their homes for as long as possible. This policy is viewed as best practice as well as a cost-saving measure. Efforts to ensure this can occur for older adults with developmental disabilities could ultimately mean cost-savings for a number of ministries.

Families and advocates for adults with developmental disabilities, who have historically fought for deinstitutionalization and community inclusion may be suspect and even disheartened by any model that proposes congregated medically-focused care. The one exception would be for older adults with developmental disabilities who have dementia and need specialized medically-trained professionals and services.

Reasonable Access

What constitutes "reasonable access to services" is based in a myriad of values. Unfortunately, historically parents of children and adults have had to advocate, sometimes to the point of legal action, to clarify the meaning of "reasonable access", most notably in the reasonable access to academic settings.

In a similar manner, what constitutes "reasonable access" for older adults with developmental disabilities is also contestable territory rooted in values and rights. What an individual, organization, or ministry purports to believe about such ideals as the rights of individuals with developmental disabilities, the rights of older adults who are disabled and those who are not disabled, the role of society and their governments to support those who are at risk, the importance of specialization, efficiency, effectiveness, the role and expertise of various professionals and sectors will influence how "reasonable access" is defined for older adults with developmental disabilities.

If one believes that older adults with developmental disabilities have a right to access health care services in a manner similar to other older adults in their community, then the question around the issue of "reasonable access" becomes one of distinguishing between lifelong disability-related needs and health-related needs.

The adoption of an assessment tool^{xxxv} that distinguishes between frailty and disability may assist CRCB PDD and Alberta Health Services clarifying roles and responsibilities, and their complimentary nature, in relation to the older adult with developmental disabilities. These measures would involve self-report or third party input. The change in ability is a critical distinguishing characteristic between frailty and disability.

The appropriate age criterion for the delivery of older adults' services and supports is another area where the issue of "reasonable access" needs to be clarified. Based in a concern that "relatively small insults to functioning attributable to aging may have greater and earlier impact upon independence for persons with developmental disabilities "^{xxxvi} and that adults with Down syndrome have an earlier onset (e.g., 52 years of age), compressed course, and shorter duration of dementia,^{xxxvii} has challenged the commonly held belief, reflected in government policies, that an older adult is an adult who is at least 65 years of age. Some have suggested^{xxxviii}, consistent with the World Health Organization, that age 50 years and above be the criteria for aging, while others^{xxxix} have suggested that policy should be changed to permit persons with developmental disabilities access to aged care services after the age of 40 years.

It may be that establishing a chronological age, regardless of its amount, is an inappropriate strategy for determining "reasonable access". A functional assessment which separates a level of frailty from a lifelong disability might be more sensitive to the needs of the individual, given the heterogeneity of people with disabilities. This suggestion is also made in light of the one researcher^{xl} who noted that that today's 70-year old older adult with developmental disabilities was born in 1935 before advances in medicine and education, which might mean that the group of older adults now is an "exceptionally robust individuals, and it will be interesting to see if older adults in the future turn out to have a broader spectrum of support needs."

We are recommending that for planning purposes a person with a developmental disability who is 50+ years of age and who also has accompanying functional delays which can be attributed to aging, similar to other adults without disabilities, would be considered an older adult. We also recommend that a comprehensive functional and medical assessment be completed before the individual is 40 years of age so that a baseline can be established for comparison when assessments are required later in life.

Systems Level Principles

Three principles have been identified, based on a review of the literature, as underpinning the development of a system of services and supports for older adults with developmental disabilities. These principles include:

- acknowledging and establishing a common agenda in the development and review of policies and services for both older adults with developmental disabilities and those of the general population;
- ensuring cross-ministry collaboration; and,
- developing systems of evaluation and monitoring of the implementation of services, supports, and policies.

Common Agenda

A key question in the development of services for older adults with developmental disabilities in the Calgary Region and in Alberta is whether the Ministry of Health should be developing specialists' services for this population or is it the responsibility of the Ministry of Seniors. Given the lack of cost-effective, quality of life, and other evaluative studies on various service models that support older adults with developmental disabilities, the answers to this question and many others like it are difficult to answer. The Alberta solution, given the input from stakeholders, involves the development of complimentary but separate services based on PDD's and Alberta Health Services' individual mandates, as well as, the joint development of specialized services when the needs of this population cross ministry mandates.

Some^{xli} have suggested that those who advocate for different specialized services for each group believe that the life experiences of older adults and people with developmental disabilities are different and correspondingly their response to aging is different. Researchers in Australia tend to advocate for a distinct set of policy directions for older adults with developmental disabilities which reflect the "overarching principles of equal rights, choice and self-determination, the adoption of a leadership role by disability services, and systematic bridging of gaps between services."^{xlii}

The perception of "double dipping," which has been articulated by some professionals in the course of this study, is an expression of the position that there should be specialized provision of services to older adults with developmental disabilities, preferably funded by PDD, rather than an individual receiving both PDD and Alberta Health Services funded services.

Other researchers and policy advocates, particularly those in the Canada, United States and Ireland, acknowledge the "common agenda" between older adults and people with

disabilities. Some examples of Canadian provincial governments' actions which are consistent with a common agenda approach are provided in the table entitled Examples of a Common Agenda Approaches in Canada (see page 28).

Advocates of a common agenda approach have suggested that a "double lens" (i.e., disability and older adults) approach for the development and review of policies and services should be developed and implemented. There are numerous examples of policy lenses used to evaluate the implications of various policies and service developments. Currently, neither a disability nor older adults' lenses are being utilized in Alberta. The development of common lens between PDD and Health Services would be beneficial.

Cross-Ministry Collaboration

Cross-ministry collaboration is cited in the literature as a critical component in service delivery, policy development, and human resource development in relation to supporting older adults with developmental disabilities.^{xliii xliv} To be successful, collaborations need champions to move the agenda forward and keep all the parties focused on the joint goals. Collaborations also take dedicated time, energy, and resources and a strategic framework which has been articulated and endorsed by all the parties. Unfortunately, in the absence of these elements collaborations become an exercise in futility and a task relegated to the side of many professional's desk.

Although there are examples of national frameworks and agendas around the development of services for older adults with developmental disabilities, in particular Ireland and Australia, the work in these areas tends to be either directed by non-profit agencies or to be pilots without longevity and coordinated effort.^{xlv} National frameworks or regional plans need to be supported with a recognized overseeing body, a dedicated champion at the regional and provincial or state level, a concerted effort and commitment, and adequate funding. There are examples in Alberta of successful and unsuccessful cross-ministry collaboration focused on various issues.

Establishing a provincial agenda for older adults with developmental disabilities that frames the allocation of resources, establishes targets, reduces service gaps, and focuses efforts across provincial departments would be advantageous and consistent with promising practices identified in the literature.

Evaluation and Monitoring

In Alberta, most ministries subscribe to the values of efficiency, effectiveness, stability, and accountability. Unfortunately, there is a paucity of studies focused on the evaluation of service models for older adults with developmental disabilities, including those that

examining the social return. More work in this area is warranted as services and supports are developed in the Calgary region and across Alberta.

Conclusion

The CRCB PDD is well positioned philosophically to implement a system of supports and services, in partnership with their community-based agencies and other appropriate ministries to support older adults with developmental disabilities. There is the potential that as new models of support for older adults with developmental disabilities evolve, various PDD policies and their applications (e.g., contracting, procurement, of services) will need to be modified to reflect the needs of this population and the disability service providers supporting them.

Cross-ministry collaboration is critical in the development and delivery of supports for older adults with developmental disabilities. This collaboration should focus on a number of issues including, but not limited to, the development of:

- a common agenda or approach towards the development of policies and services in regards to this population;
- a dual lens approach (i.e., persons with developmental disability and older persons) in generating and evaluating policies;
- sector-specific services and when appropriate the development of cross-ministry services;
- an evaluation strategy; and,
- joint training opportunities for professionals in each sector.

Examples of a Common Agenda Approaches in Canada

- The **Manitoba** Government has recently embarked on a public consultation process which will contribute to legislation that will provide greater accessibility (i.e., to create “an inclusive society by eliminating the institutional and physical barriers faced by older adults and persons with disabilities”).
- The Ministry of Family and Community Services in **New Brunswick** has organized some areas of policy and service delivery as inclusive of adults with disabilities and older adults including Long Term Care Services for Adults and Older adults – one program for all adults focusing on functionality; Adult Protection Services are structured with a focus on older adults and adults with disabilities who are victims of abuse or neglect; and, Adult Victims of Abuse Protocols have been written to apply to and people with disabilities. (Society of Manitobans with Disabilities, 2004)
- The **Ontario** Partnership on Aging and Developmental Disabilities is an informal partnership of service providers in long-term care and developmental disabilities, eight regional committees, local cross-sector pilot projects, provincial associations, planning bodies, educational institutions, researchers and policy-makers. This group is dedicated to ensuring quality of life for older adults with developmental disabilities through transition planning that includes equal access to older adults' community and residential programs. They are involved in cross-sector planning, applied research, caregiver education, innovation in service delivery, and policy development.
- Health professionals in Vancouver Island, **British Columbia** are completing baselines using the Dementia Screening Questionnaire in Individuals with Intellectual Disabilities (DSQIID) on many of the adults with Down syndrome, in order to have more information and be proactive regarding signs of early onset of dementia. The health region is discussing how to fully implement the Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines (Sullivan, et. al., 2011), in particular, the recommendations regarding advanced care planning (i.e., discuss and record advance care planning annually) (Personal communication with professionals with BC Health Services, 2011).
- The **Alberta** Ministry of Seniors includes the older adults and the disability portfolios. Planning documents, including the *Aging Policy Framework Government of Alberta*, 2010) reflects goals and values consistent with needed to support older adults with DD. These older adults are not identified in the document, although it is assumed that the document applies to them as older adults as well.
- *Creating Connections: Alberta's Addiction and Mental Health Strategy* will create a more seamless system to ensure the best quality assessment, treatment and support services. The development of the strategy was co-led by Alberta Health and Wellness and Alberta Health Services. It involved 16 Government of Alberta ministries in recognition of the fact that many people with addiction and mental health issues are served by many government departments.

SECTION III: OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES IN THE CALGARY REGION – Current and Projected Demographics

Adults with Developmental Disabilities

Although individuals with developmental disabilities have many positive strengths, they also are characterized by lifelong mental or physical functional limitation that manifests early in life after birth.^{xlvi} Developmental disability describes the population of individuals with significant limitations in intellectual functioning and adaptive conceptual, social, and practical behaviour skills that commence before the age of 18 years^{xlvii} and commonly associated with neurological disorders such as cerebral palsy^{xlviii} and Down syndrome.^{xlix}

Defining Older Adult for Individuals with Developmental Disability

Chronological Definition

Although it is generally accepted that the chronological age of 65 years is the typical criteria for identifying an individual as an older adult, for men and women with developmental disabilities this is inappropriate. Most adults with developmental disabilities will age in a similar manner to other adults without developmental disabilities. As a group, older individuals with developmental disabilities have an increased frequency of thyroid disorders, heart disorders, and sensory impairments.^l The cumulative evidence suggests that older adults with developmental disabilities have rates of common adult and older age-related conditions that are comparable to and in some cases even higher than that of the general population.^{li}

Some individuals with developmental disabilities, due to their pre-existing neurological, functional, physical impairments, and complex needs demonstrate signs of aging in their 40s and 50s that the general population may not experience until 20 to 30 years later.^{lii liii} The majority of adults with Down syndrome are likely to experience premature aging with marked biological age-related changes occurring from about 40 years.

Given that the signs of aging occur at a much younger age in some adults with developmental disabilities than in the general population it has been recommended that the age of 50 years should be used as the criteria for identifying the individual as an older

adult.^{liv} To ensure that these older adults receive the necessary services and supports they require as well as to assist policy developers and service providers in planning for and delivering these services, an adjusted chronological age combined with a functional definition and assessment may be more appropriate.

Functional Definition of Older Adult for Individuals with Developmental Disabilities

Although a chronological age of 50 years may be useful in defining adults with developmental disabilities as older adults, for the development of policies and systems-level planning it will have limited usefulness for service providers and family members who are attempting to support the individual and anticipate and plan for their future needs. A functional definition of older adult is required.

The functional assessment needs to document the individual's current abilities and/or levels of support in relation to those they have demonstrated or required throughout their lifetime. This functional assessment should be based on observation, self-report, and third party input. Similar to other adults without developmental disabilities we would expect to see changes in four areas: mobility (e.g., strength, endurance, balance, reaction time, self-care), sensory ability (i.e., vision, hearing), overall physical health, and cognitive functioning (e.g., memory).

Appropriate screening would be imperative to ensure that the presenting changes in behaviour are not related to a non-age-related illness. Assessments that distinguish between frailty (e.g., loss of endurance and body weight, decreased balance, mobility and cognitive functioning, wasting muscle mass and strength, slowed performance, and relative inactivity) and disability will assist with differentiating age-related issues from disability issues.

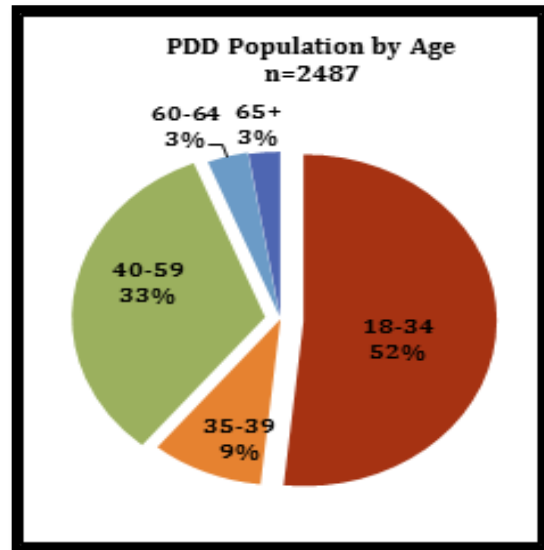
Middle age health surveillance should begin in the 40s, with special attention to adults with Down syndrome in this age group due to precocious aging.

Adults with Down syndrome constitute approximately ten percent of developmental disabilities population and approximately sixty percent of the adults with Down syndrome develop Alzheimer. This population will be effected by Alzheimer at an earlier age (e.g., 52 years of age) than the general population and the course of the disease will have a shorter duration. It has been suggested that, consistent with the World Health Organization, that age 50 years and above be the criteria for aging^{lv}, while others have suggested policy should be changed to permit persons with developmental disabilities access to aged care services after the age of 40 years.^{lvi}

Demographic Projections

As part of this CRCB PDD study, a projection of the population of older adults with developmental disabilities in the Calgary Region was completed.^{lvii} Statistics Canada data from the 2006 Participation and Activity Limitations Survey (PALS) was used to develop a profile of the population of persons with developmental disabilities in the Calgary Metropolitan Area (CMA).

Population projections were developed using CRCB PDD Board administrative records to establish a current (2009/10) age profile of the PDD population as a basis for 3, 5 and 10 year projections. Population data was analyzed by gender and region. The Calgary Region was divided into its urban (Calgary) and rural components which were analyzed separately. Records were considered to be within the Calgary Region from the communities of Airdrie, Balzac, Banff, Bassano, Black Diamond, Blackie, Bragg Creek, Calgary, Canmore, Chestemere, Cluny, Cochrane, Crossfield, Dewinton, Gleichen, High River, Irricana, Langdon, Longview, Okotoks, Piddis, Rocky Ford, Rocky View, Strathmore, and Turner Valley. Records from outside the Calgary Region or of unknown location were excluded from the analysis.



Population Projections

In 2009/10, there were 2,487 persons age 18+ with developmental disabilities receiving PDD services in the Calgary Region. Males tended to be more prevalent than females, accounting for 57 percent of the client population. The vast majority (i.e., 91 percent) of the PDD population lived within the urban area (city of Calgary). The PDD urban population was 2,268, and the rural population was 219.

Approximately one thousand (i.e., 994) of these individuals were over the age of forty. Older adults (i.e., age 45+) accounted for 29 percent of the PDD population or 733 people, while those individuals 65 years of age or older accounted for just 2.7 percent. In 2009/10, there were 60 persons age 65+ with developmental disabilities in the city of Calgary, and 6 in the rural area.

The total number of PDD clients (i.e., age 35+) in the Calgary Region is expected to grow by 30.6 percent between 2010 and 2020. The population is projected to grow by 7.6 percent by

2013 to 1,336, and by 13.0 percent to a total of 1,393 by 2015. By 2020, the total population is projected to be 1,611.

The number of people who are 55+ years of age will increase from 289 in 2010 to 534 people in 2020. Given that age 53 is a typical time for the onset of Alzheimer’s for individuals with Down syndrome it would be advantageous to identify the number of individuals with Down syndrome in this population.

Population growth is expected to be most significant among those who are 65 years or older and older adults (i.e., age 55-64). Between 2010 and 2013, the number of older adult with developmental disabilities who are 65+ years is expected to grow by 44.5 percent from 66 to 95. By 2015, this group will have grown by 74.9 percent to 115 and by 2020 by 169.3 percent to 178.

Projected Age Distribution (#) of PDD Population, Calgary Region							
	2010	2013	2015	2020	Percentage Change		
					2010-13	2010-15	2010-20
35 - 44	500	493	527	680	-1.4%	5.4%	36.0%
45 - 54	444	475	453	397	7.0%	2.0%	-10.6%
55 - 64	223	264	298	356	18.3%	33.7%	59.6%
65+	66	95	115	178	44.5%	74.9%	169.3%
Total	1,233	1,327	1,393	1,611	7.6%	13.0%	30.6%

Urban Area

The PDD population in the urban area (Calgary) is expected to grow by 28.9 percent between 2010 and 2020 from 1,153 to 1,486. Between 2010 and 2013, the population will grow by 7.4 percent to 1,239 and by 2015 by 12.1 percent to 1,292. Population growth will be greatest among those who are 65 years or older. Between 2010 and 2013, the older adult population (i.e., 65 years of age or older) is expected to grow by 44.4 percent from 61 to 88, and by 79.2 percent by 2015 to 109. By 2020, the older adult population is expected to have grown by 168.7 percent to 164. Meanwhile, the population age 45 – 54 is expected to drop by 11.7 percent by 2020.

Rural Area

Within the Calgary Region, the rate of population growth will be highest in the rural areas. Between 2010 and 2020, the rural PDD population (i.e., age 35+) is projected to rise by 55.4 percent from 80 to 124. Over the forecast period, the senior PDD population in the rural area is expected to grow at a similar rate to that of the urban area, rising by 45.4 percent by 2013, by 22.8 percent by 2015 and by 177.2 percent by 2020. Unlike the urban area, however, the rural area is projected to experience significant growth in the younger age cohort (i.e., 35-44) which is expected to grow by 97.2 percent by 2020.

Future Service Demand

Service projections were developed by establishing usage rates for 10 year age cohorts for the population age 35+ based on 2009/10 administrative records. These age specific usage rates were then applied to the future population to estimate future service demand based on the projected population age structure.

Between 2010 and 2020, the greatest growth in demand among the PDD population age 35+ is expected to be for respite services, which will increase by 34.2 percent. Over that time period, the number of people utilizing such services is expected to rise from 238 to 320. Following respite services, demand increases will be greatest for supported independent living (i.e., +31.3 percent), community access (i.e., +31.2 percent) and overnight residential services (i.e., +30.6 percent).

Among those over the age of 65 years, demand is expected to rise significantly for all services, although community access supports will be more likely needed than employment services. Demand will continue to be greatest for overnight residential and community access services. It will be necessary to ensure enhanced support is available in these residences including appropriate personnel training and physical modifications to ensure the safety and health of these older adults.

In the rural areas of the Calgary Region, the greatest increase in demand for service for adults with developmental disabilities (i.e., age 35+) is expected to be for employment services. Between 2010 and 2020, demand for employment services is expected to rise by 62.8 percent, though the number of people requiring such services remains small. Given that older adults may be less likely to be seeking employment we may interpret these numbers as a significant increase in the demand for a day service. The demand for respite services and overnight / residential care is also expected to grow appreciably.

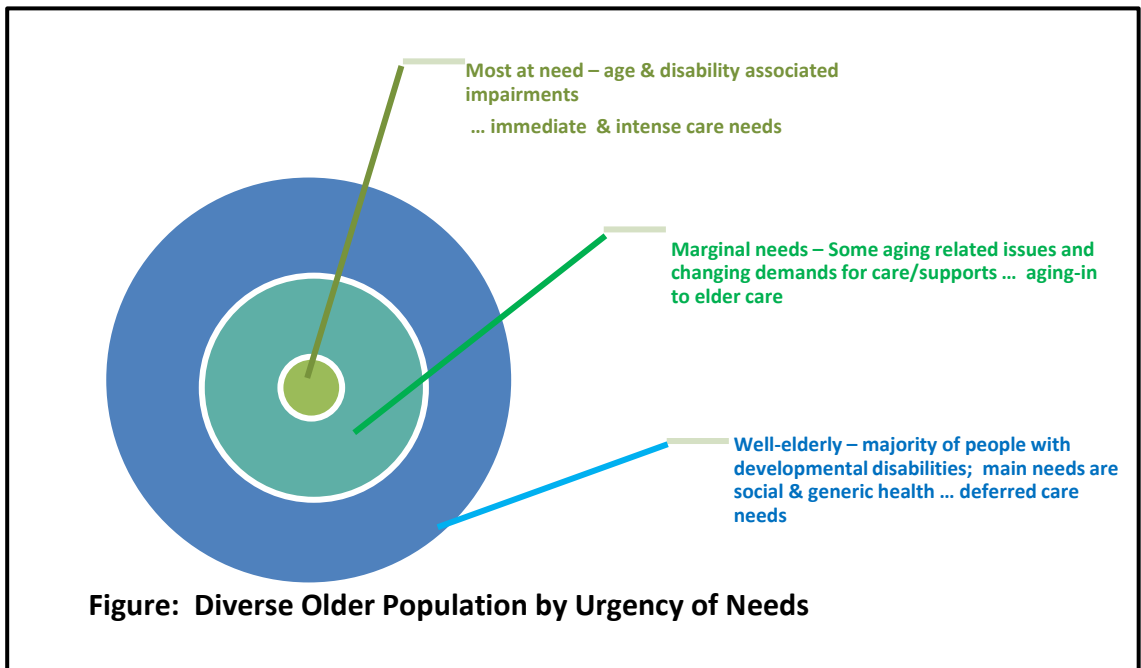
The number of older adults with developmental disabilities (i.e., age 65+) remains low in the rural area, so service demands also remain significantly below that of the urban area over

the forecast period. Demand will grow appreciably however for overnight / residential care as well as supported independent living services.

Populations Requiring Special Consideration

The service providers in Calgary interviewed as part of the study, gave several examples of individuals aging-in-place as well as examples of individuals actively engaging generic health-related facilities for other services. The latter occurred through a sharing of resources between CRCB PDD and Alberta Health Services (e.g., staff from the disability agency augmenting the residential support in the nursing home). A few adults have been transferred to older adult-specific services because their needs became too large for the agency to support. This currently is being done on a case by case basis without policies at the agency, regional, and provincial levels.

As indicated in the following schematic the majority of older adults with developmental disabilities will fall into the well-elderly category while a small group will be identified as most-at-need and require intensive and immediate support.



In this study we have also identified a number of situations that put older adults at-risk of not having their needs met as they age. These older adults are those:

- with mental health issues including dementia;
- who live alone or semi-independently;
- who live in support homes;
- who reside with their parents;
- without an adequate physical environment; and,
- without adequate staffing support.

Older Adults with Mental Health Issues including Dementia

Older adults with developmental disabilities and dementia are at particular risk of receiving inadequate services. Adults with Down syndrome constitute approximately 10 percent of developmental disabilities population and that approximately sixty percent of the adults with Down syndrome develop Alzheimer.^{lviii} This population will be effected by Alzheimer at an earlier age than the general population and the course of the illness will be shorter than what is experienced by the general population.

One author of this report, Dr. Janicki suggests that although staff may want to support the older adult to age-in-place, the deterioration in the person's ability, the decrease in their physical health, and the increase in their confusion, aggression, and wandering behaviours may put the older adult and possibly others in the house at risk. Relocation to an environment with differently trained staff and more environmental features to ensure the person's needs are addressed may be necessary. In Alberta this relocation may be to an environment funded by Alberta Health Services and/or Persons with Developmental Services.

Older Adults Who Live Alone or Semi-independently

In a similar manner to other older adults without developmental disabilities who live alone, older adults with developmental disabilities who live alone or semi-independently are at risk of not receiving the supports they need as they age.^{lix} These older adults have limited or no savings to augment the older adults' benefits and they would have limited or no social support networks to instrumentally, physically, and/or financially assist them as they age. Also the relationship these individuals have with a disability service provider would be limited and therefore subtle changes in their behaviours due to aging and/or dementia may go undetected.

The data analyzed for this CRCB PDD study (i.e., those currently receiving PDD services) does not indicate how many people live independently or semi-independently.

Older Adults Who Live in Support Homes

There is some evidence (i.e., interviews with service providers) to suggest that Calgary service providers have relied heavily on support homes as a residential model. In support homes the homeowner, who sometimes has disability-related training, is paid to provide a supported room and board situation.

In a number of these situations, the adult with developmental disabilities is not permitted to be in the house unless the home owner is present. This situation is problematic on a number of levels. First, it begs the question of whether this is a “home” or merely a shelter situation. Second, it runs counter to the goal of community inclusion, which has been embraced by progressive disability services and by the funder, CRCB PDD. Finally, as the individual ages and no longer is involved in employment training or actual employment, the individual is not able to use his “home” as a base from which to meet and entertain his neighbours, be involved in the local community association and age-related community groups, nor relax and enjoy his or her home and garden as other older individuals without developmental disabilities do as they age.

Currently, in the majority of situations the home owner is not required to provide physical care for the individual. As the person with developmental disability ages their physical care needs will change and they will require access to their residences during the day which may make a number of these current situations inadequate.

Home owners themselves, who have been providing these room and board situations, are also aging and may be unable to provide a living situation and/or advanced physical care for the person with developmental disabilities as they age.

Given the reliance on this model of residential support for adults with developmental disabilities in Calgary and the potential challenges it presents for older adults with developmental disabilities we recommend that this population and their support needs become a priority in planning. We also recommend that this use of this model for adults with developmental disabilities in the Calgary region be reviewed, evaluated, and strengthened to reflect the goals of community inclusion for all adults.

Older Adults Who Reside with their Parents

Non-Canadian studies (i.e., Britain and Australia) indicate that most individuals with developmental disabilities live with their parents until midlife when they are transitioned to another living situation (e.g., group home, nursing home) because of their parents’

advancing age.^{lx} ^{lxi} This trend is a result of parent preference and a high level of unmet accommodation need.

In Alberta, the historical development of disability residential services and the recent efforts by some advocacy groups to support home ownership initiatives does provide greater options for families planning for the future needs of their sons, daughters or siblings. Ensuring this type of information is accessible for families would be an important strategy towards assisting families to plan for a residential option of aging-in-place for the adult with a developmental disability.

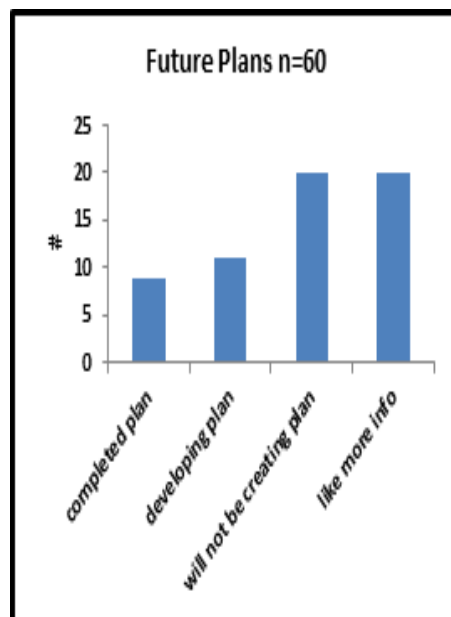
Others have also noted that the definition of 'carer' and 'cared for' need to be questioned.^{lxii} ^{lxiii} They suggest that there is a need to take into consideration the interdependence and mutual support of elderly care givers and their sons and daughter when developing future plans for residential support. These “two-generation” families will need to be planned for, identified, and supported. We recommend that CRCB PDD develop information packages that could be circulated by home care providers and other generic senior services to these two-generation families not connected to CRCB PDD services.

Nine percent of the older adults in care facilities for seniors in Australia are individuals with developmental disabilities. CRCB PDD does not have data on the number of adults with developmental disabilities currently residing in facilities for seniors or the number of individuals who are currently residing with their parents. This information would be helpful for cross-ministry future planning.

Sixteen adults with developmental disabilities over the age of 45 began receiving services from CRCBPDD in 2010 for the first time. PDD data does not specify the reason for this late entry into disability services (e.g., out of province, out of region, not wanting or needing service historically). It is conceivable that the number of people coming into service for the first time after the age of 45 years may increase in the future. This premise is based on the following two observations:

- there are statistically significantly more adults with developmental disabilities in Calgary than the number who are receiving CRCB PDD funding; and,
- as adults with developmental disabilities age they are at greater risk of losing their typical supports networks (e.g., parents, work situation).

Although a number of families in Calgary have developed future plans for their children, including purchasing them a residence, there are families that need assistance with future planning. As part of this CRCB PDD study, approximately 90 parents, siblings and guardians participated in focus groups. Parents expressed a need for more accessible and consistent information for future planning. These parents suggested that their ability to plan for the future was hampered by what they viewed as poor quality services and professional personnel currently providing support to their sons and daughters combined with a lack of adequate funding and respite services.



CRCB PDD’s recent development, the Family-Managed Supports Centre, is ideally positioned to assist parents with this long-term planning. In Calgary as well, PLAN, an organization devoted to supporting and assisting parents with long-term planning is available. Families are required to pay a fee to be involved which may discourage some families.

Older Adults without an Adequate Physical Environment

Ensuring that older adults are as mobile, independent, and safe as possible in their homes contributes to them avoiding a referral to a long-term care facility. Residences need to be modified as the person ages with environmental modification including the installation of wall bars, entrance ramps, and the removal of rugs and slippery floor surfaces. Various federal and provincial health organizations, over the last several years, have marshalled public health campaigns on the impact of falls on older adults’ health and have provided information on prevention strategies.

Unfortunately, falls prevention information has not been targeted to older adults with developmental disabilities, their families nor their support staff. In fact, public health information is generally not being used with older adults with developmental disabilities, although it would contribute to their health.^{lxiv} This would include the education of the adults, their service providers, and family members of what constitutes a healthy lifestyle for the older adult with developmental disabilities. This lifestyle information would include information on diet and exercise given the incidence of obesity and the lack of exercise in adults with developmental disabilities.^{lxv} Health promotion materials designed for individuals with developmental disabilities and on-going education of health professions that addresses attitudinal, communication, programmatic, and physical barriers experienced

by individuals with developmental disabilities accessing the health care system is also necessary.

Older Adults without Adequate Staffing Support

Although older adults may have staff supporting them, this support may be inadequate because they do not have the requisite skills to support someone who is an older adult. The development and training of disability, social work, health and allied professionals is essential.^{lxvi lxxvii lxxviii lxxix}

It will be necessary to work with agencies to develop procedures regarding the assessment, planning, and funding of possible transfers or other supports for older adults who need medical supports.^{lxxx} It has been recommended that assessment procedures and protocols need to be improved, mixed models of service provision be developed, flexible funding be made available, as well as joint staff training and work to retirement transition planning occur.^{lxxxi}

Conclusion

Early identification of the specific individuals who are currently most at-risk of not aging-in-place (e.g., those living at home with elderly parents, those in supportive roommate situations, those living alone or in semi-independent situations, those living without adequate support) would be critical so that long-term residential, legal, and financial planning can be completed and supports implemented.

There are a number of suggestions for increasing the collection of statistical information for planning purposes. The number of individuals with Down syndrome is one example of the type of information that should be maintained. Completing a census on all known clientele served by Calgary region's providers who fall into the 40+ years age group would be advantageous. This census could collect data on: the age, sex, physical and mental status of adults and the capacity of family caregivers and the status of future plans for caregiving duration. Also the completion of a broader census of older adults currently not in service, but known to someone or unknown and yet to be found by outreach measurement strategies would contribute to long-term planning.



Joan²

Joan, a 55 year old woman, had been the same day program since 1991. The following is a description from the disability service day service provider on the last two years of Joan's life when her guardian and others were working towards supporting Joan to age-in-place in a residence of her choice.

In the last two years, she began displaying symptoms of aging such as circulatory problems, hip problems and increased seizures. As a result she seemed to be communicating through her behaviour that she did not want to ride on Access Calgary to come into or leave our day program. She often appeared to be in pain. Climbing in and out of the cab or Handibus was a struggle. In the

last year of her life, her residential care provider was changed twice because each residential service was unable to meet her needs. Because of this, the day program worked to accommodate her changing needs in order to keep the disruptions in her life to a minimum. This meant offering more sedentary activities onsite with socialization. Two staff assisted her with any walking so she wouldn't fall and her doctor ordered her to keep her feet up as much as possible so the day program got a recliner chair for her. There was a discussion amongst her guardian and support staff, about her retiring and aging-in-place through wrap-around services. Sadly, this past summer, she passed away before this could be put into place.

Joan's story highlights the need for flexible and responsive systems of supports between all those involved in supporting adults with developmental disabilities, especially those whose support needs change rapidly and sometimes unpredictably. The reasons for these changes can be related to various factors including aging, chronic physical and/or mental health issues, and/or the loss of a supportive family member. Systems of funding and of service delivery need to be able to adjust quickly to ensure comprehensive and consistent support for these individuals.

² Pseudonym and different picture; story provided by a disability service provider

SECTION IV: SUPPORTING OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

This section focuses on the supports and services needed to support older adults with developmental adults. The section considers strategies to assist older adults with developmental disabilities to age-in-place. Also outlined in this section are strategies to support older adults with developmental disabilities and accompanying Alzheimer's or some other forms of dementia be supported in residences that provide the type of physical care they require in the later stages of their life.

Promising Practices Supporting Older Adults to Age-in-Place

Consistent with the community inclusion philosophy promoted by CRCB PDD, older adults with developmental disabilities should be supported to age-in-place, if they and their families and/or guardians prefer and are able to support this option whether it is with their parents and/or living with some form of staffing support. There are situations, previously referred to in this report, where the option of aging in the person's current residence is not the person's or their guardian's preferred choice. Also there are situations where various issues make the option of aging-in-place (i.e., their current home) not possible. These issues could include, but are not limited to:

- a support home operator is retiring;
- the parents of the older adult wanting to reside in their home alone or sell their home, as they themselves age;
- the accommodations such as bachelor suites being too small to accommodate a support worker as the adult with disability ages;
- the landlord nor willing to make necessary adaptations to the home (e.g., bars in the bathroom, ramps); and,
- the person has reached the final stages of dementia.

There are a number of promising practices that would enhance the opportunity for an older adult with a developmental disability to age-in-place. These include the following ten practices:

1. develop social support networks;
2. use safe environment technology;
3. develop viable and walkable communities;
4. support the development of a network of health care providers knowledgeable in the issues of aging with a developmental disability;
5. support workforce development;
6. support families, guardians and siblings;
7. provide on-going assessments and screening;
8. develop an outreach and service navigation team;
9. partner with older adults centres; and,
10. develop flexible funding models.

Promising Practice #1: Develop Social Support Networks

Social scientists have long appreciated the positive role that community involvement and the presence of natural support networks (i.e., non-professional) plays the promotion of well-being.^{lxxii} For instance, one study^{lxxiii} which involved extensive review of the literature on community involvement indicated that:

Research in the disciplines of sociology and community psychology has ascertained that involvement in groups and organizations leads to several positive outcomes, including reduction in psychological distress, enhancement of subjective well-being, increased feelings of self-esteem, and the promotion of personal happiness and life satisfaction. At the neighbourhood and societal level, active participation in groups and organizations has been associated with higher levels of social and communal benefits and increased political participation.^{lxxiv}

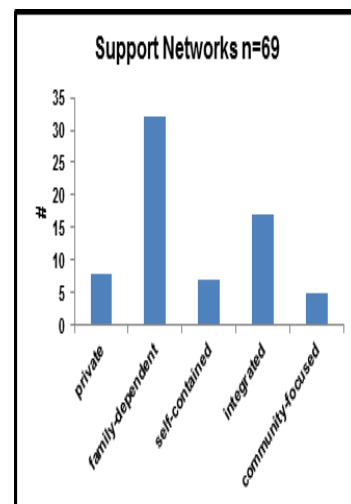
Although community participation does not guarantee the development of positive social support networks for older adults it is the first step in the likelihood of their development. Some older adults may be isolated from their communities because of their limited income. Participation in community events may involve fees, and/or transportation making them inaccessible for these older adults.

Unfortunately, there has been research to indicate that professionals working with adults do not work to strengthen their inclusion in their communities nor work to strengthen their support networks.^{lxxv} They found that most staff disagreed on the meaning of inclusion or felt these residents were too different for it to be meaningful. Others have observed that

staff do not understand the importance of social networks, do not believe that the individuals they are supporting could have friends or that non-paid individuals might be interested in spending time with the person. Organizational policies can interfere with the development of friendships and social networks for older adults. Fears regarding the agency's possible liability if an adult's friend or volunteer were to harm or threaten the adult have caused some agencies to shy away from inclusion efforts. The lack of knowledge, the devaluing of adults and their families, and the organizational issues will need to be addressed for adults with developmental disabilities.

Families in Calgary were asked during the focus group sessions to describe the type of social support network their older adult with a developmental disability experienced. They were asked to pick one of the following alternatives:

- Private – small and primarily composed of family members living far away.
- Family – small and primarily composed of family members living nearby and staff.
- Self-contained – small and primarily composed of staff and families members who live some distance away.
- Integrated – larger and include close relationships with family, friends, neighbours, individuals with and without disabilities and staff.
- Community – larger than average and primarily made up of friends living close by, family members living far away, neighbours, individuals with and without disabilities and staff.



The results, summarized in this figure, suggest that more work needs to be accomplished in the development of this very important asset for older adults with developmental disabilities. Post-secondary institutions and professional training groups such as the Alberta Council of Disability Services have a role in enhancing disability services personnel's skills in developing social support networks. The development, monitoring, and reporting of system-level indicators may also shed light on the strategies necessary to get increased traction this issue.

Promising Practice #2: Use Safe Home Technology

The use of Smart Technology appears to have promise in supporting and maintaining the safety of people who are vulnerable including older adults with developmental disabilities and adults with developmental disabilities and accompanying complex service issues.

Bal, Shen, Hao, and Xue^{lxxvi} in a recent paper summarizing the use of Smart Technology in homes for seniors provide the following definition of Smart Home technology.

The Smart Home is most easily described as a collective term for information and communication technology in homes where components communicate through a local network. The smart home technologies have been derived from the main concept of home automation, which makes use of:

- *sensors to collect data regarding the state of home environment and activity of any living being inside,*
- *controllers to analyze collected data and decide on actions;*
- *actuators to produce actions, operate home devices, generate consumable services; and network communication systems to integrate devices, components and exchange information with external units/systems. Smart home may also be referred to as other terms ; and,*
- *forms such as: smart space, aware-house, changeable home, attentive house and collaborative ambient intelligence. (p. 482)*

These researchers note that Smart Homes for elderly or disabled have the capabilities of:

- 1) monitoring the activities of the householder and the living environment to ensure the safety of residents,*
- 2) detecting the physiological and mental condition of the householder in order to maintain the health and wellness in addition to safety,*
- 3) automating tasks that a householder is unable to perform,*
- 4) alerting the householder of potentially dangerous activities and preventing the householder from dangerous activities,*
- 5) alerting informal caregivers (family members), formal caregivers (nurses, doctors or superintendents) or first responders if the householder is in difficulties (through a linkage with a local community service scheme),*
- 6) facilitating in the rehabilitation of householders (by using auditory and visual prompts), and*
- 7) linking them to the families and communities through audio-visual units (speakers, monitors, display devices, TV, etc.) (p. 482)*

Recent papers^{lxxvii lxxviii} have also explored the use of telemonitoring to monitor the safety of older adults who do not for various reasons want others sharing a space with them. This technology could be used to maintain the safety and quality of life of older adults with developmental disabilities age-in-place.

Although smart technology^{lxxxix} and environmental changes make it easier for all older adults, including those with developmental disabilities, to age-in-place there is some evidence that these changes may be challenging for staff, without training on implementation. One research study indicated that there is a lack of awareness of the need for these environmental changes and that they are not being used properly when they are installed.^{lxxx} The creation of an environmental assessment coordinator who would complete assessments and ensure they were correctly implemented would be advantageous. On-going staff training on environmental safety in residences and awareness of the possible avenues for funding to support these changes would also be warranted.

The Federal and the Alberta governments both have grants to assist home owners with the cost of these installations. According to the disability personnel interviewed as part of this study, the total amount awarded annually in these grants is inadequate to meet the community demand. Advocacy for more funds or targeted funds for older adults with developmental disabilities may facilitate the possibility of them residing in their homes for a longer period of time.

Promising Practice #3: Promote the Development of Livable and Walkable Communities

As part of a review of international trends in the care of individuals with disabilities and the care of older adults^{lxxxix} concluded that, “Policy literature in the USA by both older people and disability organizations has focussed on the idea of ‘livable communities’.” This reference is to community design principles for cities and is not in reference to segregated communities for people with disabilities. Livable and inclusive communities have affordable and appropriate housing, are supportive and allow for ease in mobility and engagement in civic and social life. Ensuring that families and advocates of people with disabilities are aware and involved in the developments and policy discussions surrounding livable cities would increase the likelihood that older adults with developmental disabilities will age-in-place.

Promising Practice #4: Support the Development of a Network of Health Care Providers Knowledgeable in the Issues of Aging with a Developmental Disability

House-care zones or home-service zones are being used in the Netherlands as a possible model to support older adults. The Dutch Government is promoting aging-in-place with formal and informal supports as evidenced by the following:

The focus in the Netherlands is on building assisted-living complexes. . . . Complexes include a day centre for those needing structured support, as well as physical therapy space. . . .Older people with dementia are accommodated in small-scale housing groups in ordinary neighbourhoods. Both types of housing are part of what is called a ‘house-care zone’ or

'home-service zone'. These zones cover over 10,000 inhabitants, with a central multifunctional building containing core services and high-support accommodation, and accommodation for people with varying levels of need radiating outwards from this facility.^{lxxxii}

The types of supports for older adults including home care, assisted and long-term facilities that Alberta Health Services (AHS) has put into place are similar to the model being developed in the Netherlands.

The Primary Health Care Networks (PHCN) operating in Calgary also cover a large geographic area and number of clients, similar to the house-care or home-care zones in the Netherlands with the exception that, in the Netherlands medical services are located in buildings offering high-support accommodation and multiple services for older adults.

The current Primary Health Care Networks developed in Alberta could become a source of on-going medical support to people with developmental disabilities in an intentional and strategic manner. Currently, individuals with developmental disabilities receive primary medical care from individual physicians throughout Alberta. These physicians generally work in isolation and receive little or no training in the medical needs of individuals with developmental disabilities, in particular those who are aging.

The development of training sessions for family physicians and specialists such as psychiatrists would be advantageous. The exploration of other strategies to enhance medical services to older adults with developmental disabilities should be pursued. For example, CRCB PDD and Alberta Health Services might consider jointly funding a disability services specialist to work as part of a Primary Health Care Network in Calgary. An evaluation of any pilots would be warranted.

Promising Practice #5: Support Workforce Development

As was previously mentioned, the need for increased workforce development for disability, social work, health or allied health professionals is critical.^{lxxxiii lxxxiv lxxxv lxxxvi} Each of these professional groups has a particular area of expertise but the needs of older adults with developmental disabilities crosses professional boundaries. Professionals need training in supporting someone with developmental disabilities as well as working with someone who is older. The focus of the training varies depending on the skills of the professional groups targeted and issue to be addressed.

Completing valid assessments which inform service needs and health care supports would be a critical area for professional training. There is a need for carers (e.g., family and staff)

to be trained in how to proactively assist in the assessment process.^{lxxxvii} Agencies and families utilizing family-managed supports funding need support to develop procedures regarding the assessment, planning and funding of possible residential placement or other supports for older adults who need medical supports.^{lxxxviii}

Promising Practice #6: Support Families, Guardians and Siblings

Families and guardians of individuals with developmental disabilities have been a critical force in the development of progressive disability services. They also have been a significant source of physical, social, and financial support that, in their absence would have to be assumed by the state. Families of older adults with developmental disabilities have issues that are unique to their situation which need to be addressed in the development of services for older adults with developmental disabilities.

Some studies have indicated that a significant number (e.g., 75 percent) of care givers do not make future plans for their son or daughter that addresses issues such as legal, financial, and long-term accommodation.^{lxxxix} This can occur for various reasons including a desire to not face their own aging, an avoidance of the anxiety caused by thinking about the adult having to live with someone else, and according to one study, an expectation that siblings will continue the care in their absence. It should be noted that according to one study this expectation for the role of the sibling is rarely discussed with the family members including the adult with developmental disability.^{xc}

Unfortunately we do not know the state of future plans in Calgary, although during the family focus groups, people who participated expressed concern over the lack of information on the topic. The majority of these families did not have plans in place. A number of siblings

Family and Guardian Focus Group Themes

- **Ensure adequate wages for quality staff.**
- **Provide staff education and training programs, with scholarships allotted through agencies for up-grading.**
- **PDD monitor services closely.**
- **Create an ombudsman for parents and guardians of disabled persons.**
- **Create a joint task force between Alberta Health Services and PDD.**
- **Increase access to transportation services.**
- **Make information accessible; use technology to get information to families and guardians as well as to provide agencies with best practice information.**
- **Provide information on how to age-in-place.**
- **Provide a registry of respite service providers.**
- **Increase funding for respite services.**
- **Engage siblings in the planning process and support them in assuming responsibility.**
- **Work with the Public Guardian's and Trustee's office to plan to support this population.**

attended these sessions. A few of them expressed concern that they were going to be assuming the financial, advocacy, and support activities that their parents had historically completed.

Being involved in annual planning with disability agencies does not guarantee that families will have these plans completed. Depending on the sophistication of the agency, their beliefs and model of individual planning, their model of intervention (e.g., individual-centered vs family-centred), their confidence in broaching what may be viewed as a sensitive topic, their relationship with the family, their lack of awareness of the importance of this type of planning, or their assumptions about the roles and responsibilities of the family (e.g., legal and financial planning is the family's domain) this topic may never be addressed. Whatever the reason, this type of planning is critical to have in place given the significant role families play in supporting adults with developmental disabilities.

Some research indicates that older parents of individuals with developmental disabilities are less stressed than younger parents and those parents of individuals with developmental disabilities are considerably less stressed than other caregivers.

Assuming that because someone is the parent or a close relative of an individual with developmental disabilities equips them to be physically, financially, or psychologically able to care for an adult with a disability, may be creating an undue hardship for both parties. Several siblings in the focus groups, which were held as part of this study, indicated that they were unable to carry the extra financial costs of supporting the individual with a developmental disability, which their parent had historically assumed. They also expressed that given the demands of their own family and careers they would not be in a position to advocate for their brother or sister in the same way their parents had done. They acknowledged that this could result in a reduced quality of services for their brother or sister but they felt that it was an unrealistic expectation.

An examination of the literature^{xci} for the period of 1970-2008 on adult siblings over the age of 21 found that although siblings are often expected to assume care giving roles, including living with the person, only approximately 10 percent of adults lived with their sibling. Predictors of the sibling assuming the care giving relationship included sex of the sibling (i.e., female siblings were more likely to be the primary care giver), the desire of the sibling, the health of the parent, the level of disability of the adult, and the current relationship with the parent and the person with the disability. Engaging siblings earlier in the future planning processes and assisting them to be knowledgeable about the current and future needs of their sibling who has a disability would benefit both parties.

There is some evidence^{xcii} that a significant number of aging families caring for an older adult with developmental disabilities are not connected to formal services for adults with developmental disabilities. These families generally approach non-disability focused services (e.g., Meals on Wheels, centres supporting older adults) for assistance in times of crisis.^{xciii} It will be critical to work closely with these organizations in identifying and supporting families who are not involved in formal disability services.

Promising Practice #7: Provide On-going Assessments and Screening

Although there are a number of assessment tools available to assess the health care and support needs of older adults, these tools have generally not been normed on older adults with developmental disabilities.^{xciv} The British Columbia Health Authority is currently using the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) and uses a “shared funding” model which allows them to contribute funding for personal care when the person’s decreased function becomes an issue.^{xcv}

It is critical that baseline assessments be completed before the older adult with developmental disabilities is 40 years of age so that it can be used as a measure of comparison to determine frailty related to aging in the future.

There appears to be a significant gap in appropriate service models and personnel for older adults with developmental disabilities and accompanying mental health concerns, including dementia. Health professionals have stated that the efficacy of the service for older adults with developmental disabilities and accompanying mental health issues, including dementia, tends to be poor because health care providers are not knowledgeable in supporting someone with a developmental disability.

Promising Practice #8: Develop an Outreach and Service Navigation Team

Although training of professionals needs to be a priority, the sheer number of these professionals, combined with the high turnover rates generally, may make the task of ensuring all the professionals have adequate skills costly and overwhelming. Another alternative suggestion^{xcvi xcvi} is to develop a regionally-based group of consultants and a pool of skilled support staff. This model has worked well in other countries.^{xcviii xcix} The consultant team would have expertise in older adults’ services and supports, as well as, those for individuals with developmental disabilities. This team would be available to provide assessments and consultations to both the disability and health sector and case manage particularly challenging situations.

The support staff would be trained in supporting older adults with developmental disabilities and be available to provide short-term hands-on support to community-based programs. This support may involve providing increased staffing until an assessment can be completed

and funds released for increased staffing, assisting in the completion of environmental and individual assessments, and hands-on training and coaching of agency personnel.

A comparison of an agency-based to a government-based case management service was conducted.^c The agency-based program was specialized and focused on families with older adults with developmental disabilities in the home. The program was designed to assist parents in keeping people in their home, to assist families to plan for the future, and to facilitate the acquisition of skills of the adult. The program, which was agency-based had funding for .6 FTE of a case manager, \$40,000 in discretionary funds and administrative and travel money. The government-based case management program was designed to address generic case management needs for children and adults with developmental disabilities.

The researchers did not find a significant difference in the age of the parents in the two services, or in the skills of the case managers. They did find that the specialist program spent 75 percent of their funds on accessing services for the families while the mainstream service only spent 25 percent of their funds. The specialized service also put more emphasis on outreach and finding families while the mainstream waited for families to self-referral. The specialized service also spent time in future planning while the mainstream tended to deal with immediate needs therefore resulting in more emergency planning. This study demonstrates the benefits of a specialized outreach team for individuals and their families who are older.

The Central Persons with Developmental Disabilities Region is implementing a pilot to evaluate the introduction of an outreach team supporting five group homes that each has one or more, older adults with developmental disabilities as residents. This team will be involved in training the group home staff and consulting with them.

Promising Practice #9: Partner with Older Adults Centres

Older adults centres or day services, whether in rural or urban settings are evolving to address the needs of a new population of older adults (e.g., healthier, younger, more individually focused) and becoming more of a hub for older adults services. Based on interviews with 32 older adult centres in the US it was concluded that the trends that are developing in the older adult centres may have a negative impact on the intergenerational and community culture of these centres.^{ci} The trends identified including: a tendency to market to younger older adults, and an emphasis on individualized choice and lifestyle approaches. This may or may not have a positive impact on individuals with developmental disabilities, depending on whether disability service providers can pick up on this trend and use it.

A recent examination of older adult centres in rural communities in the United States^{ci} indicated these centres are critical because of the lack of services in a rural community but found that they tended to only provide recreational and social services rather than becoming hubs for a number of services older adults would need. The author of the study advocated for older adult centres to evolve into hubs of activity for older adults.

A number of disability services have used the Kerby Centre in Calgary as a source of day activities for some of the older adults in their residences. Nondisabled older adults have had mixed reactions to this idea. The Executive Director of the Kerby Centre has expressed an interest in supporting the integration of older adults with disabilities into the Kerby Centre.

Janicki, recently in Calgary, described a project that was implemented in New York to integrate people with developmental disabilities into the older adult centres. Funds were given to the centre to pay for the extra time spent on facilitating the integration. Exploring strategies to enhance partnerships with day centres for older adults in Calgary (e.g., Kerby Centre) would be advantageous.

Janicki also noted that professional participation in aging and developmental disabilities networks assists in reducing language barriers and staff resistances while facilitating the likelihood of increased joint planning and working relationships between the two service sectors.^{ciii} Exploring the development of these joint networks may prove to be an effective strategy to develop programs and professionals between the two sectors.

Promising Practice #10: Develop Flexible Funding Models

It has been suggested that the absence of flexible funding in the disability sector means that all changes are viewed as age-related which results in inappropriate referrals and use of aged services.^{civ} Further, funding mechanisms and a desire to not shift responsibility from one sector to another can lead to inappropriate service provision. Janicki suggests that governments make funds available for service providers to meet the changing needs of that population whether or not they are associated with aging.

The need for long-term planning, including the possibility of increased funding, as individuals with developmental disabilities age is essential. Older adults with developmental disabilities who have dementia will need significant staffing increases in the initial stages of dementia.^{cv} When the individual progresses to the later stages of dementia the staffing needs reduces. With this knowledge a long-term individual budget could be projected to assist the region in the allocation of resources.

Supporting Older Adults with Dementia

Janicki and his colleagues identified three models of accommodation for individuals with developmental disabilities and dementia.^{cvi} The models are:

- aging-in-place – Older adults are provided a number of supports so that they can remain in the home and community until their health requires them to be placed in a health facility.
- in-place progression – In this model, a series of group living situations are developed in a continuum fashion to allow for the older adults to be grouped based on similar needs or stages of dementia. An older adult is moved to the appropriate location (e.g., house, unit) as their dementia progresses. Efforts are made in this model to design identical physical layouts in each location to reduce any confusion experienced by the older adult.
- out-placement – In this model, the older adult receives services from traditional older adult residential services (e.g., nursing homes.) when their medical needs warrant more care than can be given by a staff-living situation or family home.

These researchers did determine that agencies can adapt to supporting older adults with developmental disabilities with dementia provided they:

prepare for the fiscal implications of unreimbursed changes in level of care and the impact on staff of facing recurrent deaths or significant decline after years of demonstrated independence by persons with ID now experiencing dementia. They will also need to know more about how to adapt their physical plant (to increase safety, access, and independence), to increase administrative preparation in terms of planning, fiscal management, and resource allocations (to provide a supportive administrative environment for clinical services, to adapt best practice models for staff training (to ensure staff readiness and capability), and to recruit and train staff for dementia capable environments (to maintain a workforce familiar with dementia related care).^{cvi}

Janicki has also suggested that, based on his experience, an aging-in-place residential model for older adults living in group settings (e.g., group home) will naturally evolve into an in-place progression model for older adults with developmental disabilities and dementia. He suggests that although staff may want to support the older adult to age in place, the deterioration in the person's ability, the decrease in their physical health, and the increase in

their confusion, aggression, and wandering behaviours may put the older adult and possibly others in the house at risk.

Although the out-placement model is consistent with the normalization principle ascribe to in the disability field (e.g., similar roles and life styles to that of the general population) it is not the ideal option for older adults with developmental disabilities and dementia. Older adults with developmental disabilities and Alzheimer's are younger than older adults without disabilities, when they begin to show signs of Alzheimer's. Placement in a long-term care facility, with considerably older adults, being cared for by nursing personnel who have not been trained to work with individuals with developmental disabilities, and being away from their familiar routines and environments places the older adult with developmental disabilities at risk of isolation and increased deterioration.

Unfortunately, there were few evaluations of these models available in the literature surveyed. One Canadian study did compare the quality of life of individuals with Down syndrome residing in 10 group homes to those residing in 10 special care facilities (e.g., nursing homes) across Canada.^{cviii} The study included interviews and a survey with agency directors or managers, quality of life measures which involved staff, programming, environmental characteristics, and a review of the organizational philosophy of care. It was concluded from the study group home environments overall provide better quality of life. This study also suggested, consistent with Janicki's findings that homes will need to increase their staff training and their staff ratios to support individuals with developmental disabilities who also have dementia. This may be challenging for disability service providers in Calgary, given the variable economic climate and their constant challenge to attract and maintain well qualified staff.

A number of agencies in Calgary have been exploring the possibility of developing services for older adults with developmental disabilities.

Financial Supports for Older Adults with Developmental Disabilities

There are a number of financial supports and community services that are available to older adults through the Government of Canada, the Alberta Government, and the City of Calgary. Some of these benefits and grants are not available until the individual is 55+ years of age (e.g., Community Based Snow Removal Programs) or even 65+ years of age (e.g., Old Age Security).

Some adults with developmental disabilities demonstrate limitations in their functional ability at a younger age than other adults without developmental disabilities, but because of

the age criteria associated with these financial and community services they are not accessible to these adults. The lack of awareness of family members and/or disability service personnel of the existence of these resources also contributes to these resources not being fully utilized by older adults with developmental disabilities. Further, some individuals with developmental disabilities may not have been employed sufficiently to qualify for some of these benefits (e.g., Canadian Pension Plan) nor do they have access to sufficient funds to apply for some of the benefits (e.g., Canada Disability Savings Grant) which require a contribution from the financial benefit recipient. Adjusting the qualification criteria for supports and services for older adults with developmental disabilities should be examined.

Conclusion

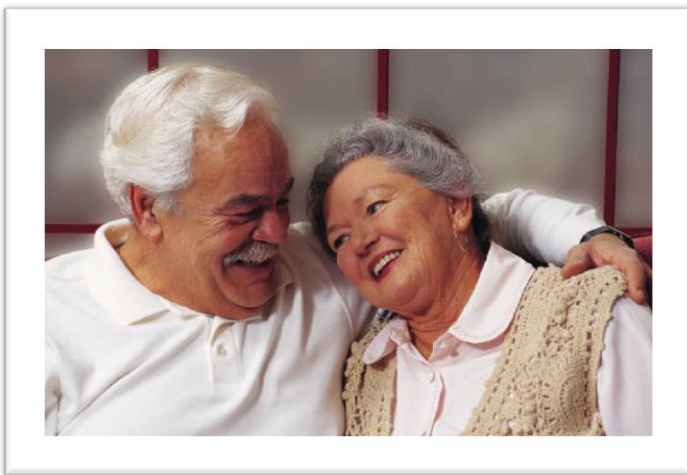
Older adults with developmental disabilities want to age-in-place. Generally their parents, siblings and/or guardians, and the professionals working with them want this residential option for older adults with developmental disabilities as well. There are circumstances that make this option difficult to achieve for some individuals. Ten promising practices were provided which would enhance the likelihood of a greater number of older adults with developmental disabilities aging-in-place. These promising practices include:

1. development of social support networks;
2. utilization of safe environment technology;
3. development of viable and walkable communities;
4. support the development of a network of health care providers knowledgeable in the issues of aging with a developmental disability;
5. support for workforce development;
6. support for families, guardians and siblings;
7. provision of on-going assessments and screening;
8. development an outreach and service navigation team;
9. partnering with older adults centres; and,
10. development of flexible funding models.

Three models have been outlined for supporting older adults with developmental disabilities who have Alzheimer's or other forms of dementia. These models include aging-in-place, in-place progression, and out-placement. The in-place progression (i.e., continuum of residential environments created that vary with regards to such features as the type of support provided, the safety features of the home, and the training of the professionals) has been shown in other jurisdictions to have some promise for ensuring the safety and dignity of each of the residents in the home.^{cix}

A number of financial supports and community services available to older adults in the general population, through the various levels of government, require the individual to be 55+ or 65+ years of age. Some older adults with developmental disabilities, due to the early signs of aging, may require these services before the stated age criteria for the services. Addressing these potential policy inequities will be necessary in developing supports and services for older adults with developmental disabilities.

Karen and Mark³



Karen and Mark met and fell in love in their twenties and have been together ever since. Both lived with their parents and attended a university-based program. A few years ago Mark's parents bought them a home as a wedding gift. The following is a description from the disability service day service provider.

Recently, Karen and Mark have been showing signs of aging and not wanting to attend a day service. They are comfortable living in her home and their parents have arranged for them to get 25 hours a week support. They both are involved in their community.

Ken and Mark's story provides an example of adults with developmental disabilities living-in-the-right-place. This situation evolved because of forward planning, adequate resources, and involvement of a positive support network.

³ Pseudonym and different picture; story provided by a disability service provider

SECTION V: FRAMEWORK FOR AWARENESS, EDUCATION, AND TRANSFORMATIONAL CHANGE

The purpose of this study, conducted within the mandate and scope of CRCB PDD, is to review the services and supports that older adults with developmental disabilities, including those with accompanying syndromes such as dementia, require so that they can continue to participate in their communities and live healthy and meaningful lives. This report summarizes the results of this study.

Seven other reports were completed by the study team as part of this study. These reports include:

- *Aging with a Developmental Disability: A Health Perspective;*
- *Projections of the Population of Older Persons;*
- *Assessing the Health of Older Adults with Developmental Disabilities;*
- *Family and Guardian Focus Groups Summary Report;*
- *Individual Financial Support for Older Adults with Developmental Disabilities;*
- *Guidelines for Using the Supports Intensity Scale (SIS with Older Adults with Developmental Disabilities; and,*
- *Six Critical Factors Organizations Need to Think about when Providing Services and Supports to Older Individuals with Developmental Disabilities.*

This final report summarizes these reports and provides additional material on promising practices in the development of services and supports for older adults with developmental disabilities.

Framework for Awareness, Education, and Transformational Change

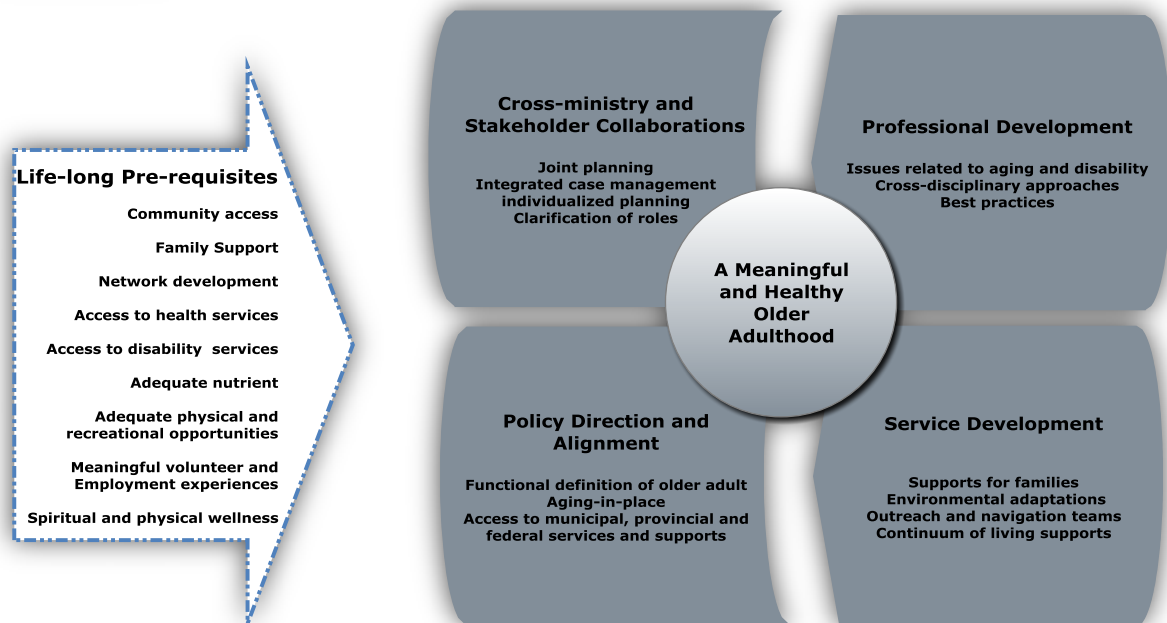
The preceding sections of this report identify guiding principles and values, current and projected demographic information, and promising practices in supporting and providing services for older adults with developmental disabilities. Based on this information, four intersecting and critical pillars have been identified. These pillars are:

- **cross-ministry and stakeholder collaborations;**
- **professional development;**
- **service and supports development; and,**
- **policy direction and alignment.**

The following graphic outlines the Framework for Awareness, Education, and Transformational Change, including the four pillars and suggested goals.

Figure: Framework for Awareness, Education, and Transformational Change

Supporting Older Adults with Developmental Disabilities Framework



Outcome Measurements

The implementation of these goals will result in a number of measurable outcomes. It has been suggested in this study that individuals with developmental disabilities and their

families work with other stakeholders to identify their desired outcomes for the development of supports and services for older adults with developmental disabilities. The following are suggested as initial outcomes of the implementation of the proposed framework for change:

- the quality of life of older adults with developmental disabilities is enhanced;
- increased number of older adults with developmental disabilities in ‘well elderly’ group;
- families and guardians are satisfied that appropriate planning and long-term supports and services are in place that ensure the health, safety, and life quality of their older adults with developmental disabilities;
- disability services and health personnel are well-trained to support older adults with developmental disabilities; and
- cross-ministry and stakeholder collaboration enhances the development of cost effective services and supports.

Impact Assessment of Direction and Actions

An impact assessment of the directions and actions suggested in this report to fully understand the resource needs and challenges presented (e.g., integration of cross-ministry collaboration, housing considerations). An on-going evaluation of the implementation of these recommendations should also be designed and implemented. This could include a social return on investment aspect to the assessment of impact.

Conclusion

This study was completed under the auspices, mandate, and scope of CRCB PDD. Current services and supports for older adults with developmental disabilities were reviewed in context of promising practices. A Framework for Awareness, Education, and Transformational Change is outlined which articulates the four pillars and suggested goals.

In the completion of this study we heard many voices and perspectives on how to move forward in developing services and supports for older adults with developmental disabilities. The observations and suggestions made in this report are based on these perspectives and a review of the literature. The suggestions and observations are also made based on a commitment to provide quality services and supports which reflect a respect for the dignity and choice of the individual, the importance of the involvement of parents and guardians, and a commitment to community living and community inclusion.

CRCB PDD's mission and beliefs are aligned with a social model of disability. None of the suggestions and observations made in this report supports a return to a medical model of disability. Interviews with senior personnel and board members of CRCB PDD reflect their belief that every effort should be made to support people with developmental disabilities, throughout their life span, to live a full and inclusive life which is free of abuse, neglect, and isolation. These individuals and the authors of this report have not indicated a desire for congregated settings for older adults with disabilities; needless assessments for administrative purposes; nor have they identified group home residences as safer and better models than other residential models. The suggestions in this report do not support the premature labelling of a person with a developmental disability as "older." The report suggests that every effort should be made to support individuals who are demonstrating the behavioural, physical, and cognitive changes commonly associated with advancing years and that these developments not be overshadowed and ignored because of the individual's developmental disability.

The findings of this report do suggest that:

- older adults be supported to live in the residence of their choice (e.g., aging-in-place) in a similar manner to other older adults without developmental disabilities;
- some adults, because of the tenuous nature of their current residential support, their limited social network, and the lack of future planning, are at risk of isolation, neglect, and poor quality care in the future;
- a small number of adults with developmental disabilities who have dementia, be provided with the medical and physical care they need so that they pass through the final stage of their life with dignity and adequate support;
- the parents who are themselves aging and the siblings of the older adult with a developmental disability be provided with the support they need;
- disability services and health personnel receive adequate training so that older adults with disabilities are safe, healthy, and involved in their communities;
- the ministries and departments (e.g., seniors, PDD, AHS, transportation, housing) work together to develop the types of policies and services that would support older adults with developmental disabilities;
- that medical and physical screening occur throughout the person's life so that their medical and physical needs are addressed and that in the event that this screening has never occurred on an ongoing basis it occurs at least once before they are 40 years of age so age-related issues can be addressed and not be overshadowed and neglected; and,

- the ten promising practices identified in this report (e.g., use of safe home technology) be implemented, monitored, and evaluated in the development of services and supports for older adults with developmental disabilities.

In summary, in the development of supports and services for older adults with developmental disabilities will require:

- a review government policies related to older adults;
- the securing of a government-level champion(s);
- a review of the demographics and needs of older adults (i.e., 45+ years of age);
- collaboration with other ministries and service providers;
- development of a continuum of effective, relevant and relevant services and supports; and,
- the articulation of desired outcomes by families and other stakeholders of the relevant outcomes.

A list of suggested activities that could be implemented in a region or jurisdiction planning for services for older adults with development disabilities is outlined in Appendix 1.

APPENDIX 1. Suggested Activities for the Development of Services and Supports for Older Adults with Developmental Disabilities

The following are some suggested strategies based on this approach which may be helpful in developing an action plan to move forward on the development of services and supports for older adults with developmental disabilities. These suggested activities are divided into four areas:

- Cross-ministry and stakeholder collaborations
- Professional development
- Service and supports development
- Policy direction and alignment

1.0 Cross-ministry and stakeholder collaborations

1.1 Develop a provincial agenda for older adults with developmental disability, which frames the allocation of resources, establishes measurable targets and outcomes, reduces service gaps, and focuses efforts across provincial departments.

- Adopt the Edinburgh Principles on supporting older adults with developmental disabilities and dementia and revise them to encompass a larger population.
- Adopt an aging-in-the-right-place philosophy.
- Align and bridge policy across departments to reflect this agenda.
- Establish inter-departmental funding structures to support this agenda.
- Identify provincial and regional champions in the departments of health, seniors, housing, and PDD to ensure the implementation of the provincial agenda.
- Consider the development of a secretariat on aging and developmental disabilities to oversee the implementation.

1.2 Develop a long-term regional and provincial evaluation strategy.

- Work with families, service providers, and other stakeholders to articulate outcomes.
- Develop measures and benchmarks for each outcome.
- Monitor and report outcomes on an annual basis.
- Articulate the desired outcomes for each services and supports at a regional level.

1.3 Promote the use of an operational definition of the term “older adult” when applied to adults with developmental disabilities.

- Consider using a multi-facet definition (e.g., 50+ years of age and accompanying demonstrated frailty, not directly related to their developmental disability or a non-age-related illness).

- Complete middle age health surveillance beginning in the 40s, with special attention to adults with Down syndrome in this age group due to precocious aging issues.
- In conjunction with other ministries identify an effective and efficient means of assessing physical and mental health status in older adults with developmental disabilities.
- Consider having PDD complete Supports Intensity Scale (SIS) measures on adults 40+ years of age, as a baseline of their support needs.

1.4 Create a committee of multiple stakeholders to oversee the implementation of the plan.

- Identify stakeholders and appropriate representatives.
- Develop committee mandate.
- Develop process for implementation of study recommendations.
- Develop evaluation of collaborative process.

1.5 Provide timely and comprehensive information and support to families and guardians to complete future care plans for older adults with developmental disabilities.

- Post on the appropriate government department website a template for future planning. For families.
- Provide information on professionals, including lawyers and financial planners, who specialize in estate planning for individuals with disabilities.
- Consider the potential of partnering with systems supporting other individuals (e.g., aging parents, partners of stroke victims, parents of individuals with severe mental illness) to develop joint support and planning sessions for families.
- Review respite services for families, in particular those families supporting an older adult with developmental disabilities.

1.6 Support the development of ‘walkable and liveable’ cities that enhance the quality of life of older adults and adults with disabilities to increase their ability to ‘age-in-place’.

- Ensure advocates of older adults with developmental disabilities are involved in working committees at the municipal level focused on planning for older adults in the general population..
- Develop a communication system to keep advocates, family members, and people with disabilities informed about developments in municipal and provincial housing and transportation planning and policies.
- Work with government departments responsible for housing to ensure that at least ten percent of the new affordable housing spaces being created are physically accessible.

1.7 Work with organizations serving older adults and home care professionals to identify and support two-generation families.

- Develop fact sheets and informational material useful for families caring at home for an adult with developmental disability who is not engaged in any formal services and distribute them via generic older adult services.
- Work towards appropriate placement of older adults with developmental disabilities by:
 - identifying older adults with developmental disabilities in long-term care facilities who may be more appropriately placed in an alternative site;
 - developing planning tools for family members and the older adult with developmental disabilities so that aging-in-place is facilitated.
- Identify and support the older adults with developmental disabilities, who for various reasons (e.g., living alone, living semi-independently, residing with their parents, residing in a supportive roommate situation, those who come to the attention of adult protective services, homeless support organizations, and other social welfare groups) are at-risk of inadequate service provision as they age.
- Ensure future planning, which focuses on legal, health and accommodation issues and support needs, is completed and monitored for all individuals who are 40+ years of age.
- Collaborate and plan with other government departments to develop a system of service/case management to assist these individuals as they age.

2.0 Professional development

2.1 Promote the development of a competent and confident workforce to assist older adults with developmental disabilities.

- Meet with the individual agencies and any interagency service providers groups to discuss their future plans for staff training.
- Complete an assessment of the needs for professional training in disability services and health sectors.
- Identify other community partners who have the resources to offer training to service providers.
- Offer joint professional development sessions with other government departments.
- Fund, where necessary, the development and offering of professional development activities including the development of on-line training sessions.

2.2 Develop a regional network of service providers focused on older adults with developmental disabilities.

- Create a common website or portal for information on best practices in supporting older adults with developmental disabilities.
- Identify community partners who have the resources to offer training to service providers.
- Meet with service providers interested in supporting older adults with developmental disabilities.
- Map out resources for supporting this group of individuals among these service providers, identifying gaps and possible redundancies.
- Develop a plan for development and support of the service network.

3.0 Service and supports development

3.1 Undertake two censuses of middle-to-older age adults with developmental disabilities.

- Complete a census on all known clientele served by a region's providers who fall into the 40+ years age group. Collect data on: the age, sex, physical and mental status of adults and the capacity of family caregivers and the status of future plans for caregiving duration.
- Complete a broader census of older adults currently not in service, but known to someone or unknown and yet to be found by outreach measurement strategies.
- Develop projections of the nature of the older population of adults with developmental disabilities for purposes of forward planning, budgeting, and expectations of needs for specific services.

3.2 Develop initiatives on health targets to increase the number of older adults in 'well elderly' group.

- Initiative education campaigns on aging, wellness, and optimal supports and services for disability services working with people with developmental disabilities as they age.
- Explore collaborative arrangements among providers to optimize supports and services.
- Ensure adults with developmental disabilities are receiving health, lifestyle, and dementia screening and advice.

3.3 Develop outreach teams or collaborate with existing outreach teams focused on older adults, to enhance service provider expertise in aging and developmental disabilities.

- Provide health and disability professionals and families supporting older adults with developmental disabilities with information, training, coaching, and assessment.

- Explore the possibility of various stakeholders contributing resources to the development of these teams.
- Link the outreach teams to local universities and other resources to enhance visibility and expertise.

3.4 Make the development of social support networks for all adults with developmental disabilities a regional priority.

- Develop agency and systems-level indicators.
- Provide staff training in the development of social support networks.
- Monitor and report annually on an individual, agency, regional, and provincial level outcomes.

3.5 Organize specialty medical/health assessment resources.

- Complete dementia and mild cognitive impairment assessments on older adults when appropriate.
- Provide training for professionals working in these centres so that they can work with older adults with developmental disabilities.
- Ensure that disability services personnel are aware of these services.
- The adoption of a workable and useful functional screening instrument would help staff and families establish baseline data and subsequently identify significant changes in function that would speed referral to appropriate evaluators and diagnosticians.
- Provide training to disability services personnel regarding the early signs of dementia and the role in supporting and assessing the individual including environmental and technological changes that need to occur in the residence to support the individual.

3.6 Create long-term multi-year plans for older adults with developmental disabilities.

- Develop long-term plans, with their family and other caregivers, for increased support if necessary, after the older adult reaches forty years of age.
- Develop mechanisms (e.g., pre-identified thresholds or funding-triggers that allow for flexible and responsive funding arrangements as the older adult's needs change.

3.7 Develop appropriate supportive living for older adults with developmental disabilities and accompanying mental health concerns, including dementia.

- Ensure these supportive living arrangements are small (e.g., 3-5 people).

- Ensure personnel are trained in working with older adults with developmental disabilities who have accompanying mental health issues including dementia, attendant health care skills, and end-of-life issues.
- Ensure adequate environmental and technological modifications have been made to the supportive living arrangements to ensure the individuals' needs are met in a safe environment.

4.0 Policy direction and alignment

4.1 Develop a process among various government departments which outlines how they will collaborate and plan how they will each respond and support older adults with developmental disabilities.

- Incorporate a “double lens” perspective (i.e., older adults and individuals with disabilities) in the review of policies and programs
- Outline roles, responsibilities, mandates, clientele, and funding arrangements for supports and services for older adults with developmental disabilities.
- Agree to work closely together to ensure older adults with developmental disabilities get adequate and timely service.
- Identify pressure points between the systems as it related to older adults with developmental disabilities.
- Offer joint professional development sessions.

4.2 Work with disability and health providers to develop, implement, and maintain protocols for regular assessments of older adults with developmental disabilities.

- With the government responsible for health services articulate a plan to develop and adopt a standardized protocol or screening/assessment instrument for providers and local planning authorities.
- Clarify, with service providers, the type of information that needs to be maintained on aging adults with developmental disabilities.
- Provide training to facilitate the consistency in client information being documented and for enhance awareness and skill development of health and disability professionals.
- Screen older adults with developmental disabilities to determine if mild cognitive impairment (MCI) or dementia is present.

4.3 Advocate and work towards ensuring that older adults with developmental disabilities have access to adequate benefits and services.

- Work with appropriate funding department (e.g., AISH) to recommend changes to health benefits for adults with developmental disabilities 65+ years of age so they

are able to maintain their health benefits at the level prior to turning 65 years of age.

- Work collaboratively with department responsible for aids (e.g., Aids to Daily Living) to review current funding criteria to ensure it is reflective of the needs of an older adult with developmental disabilities, in particular those with complex physical and/or mental health concerns.
- Advocate for an increase the total regional funds available in the Residential Access Modification Program (RAMP). Provide key influencers and decision makers with sufficient information (e.g., research findings, economic impacts, case studies, and policy positions) regarding the need to lower the age criteria so that older adults with developmental disabilities can have access to supports and services for older adults in the general population.

REFERENCES

- Ailey, S. H., O'Rourke, M., Breakwell, S. and Murphy, A. (2008). Supporting a community of individuals with intellectual and developmental disabilities in grieving, *Journal of Hospice and Palliative Nursing*, 10(5), 285-292.
- Alexander, L. M., Bullock, K. and Maring, J. R. (2008). Challenges in the recognition and management of age-related conditions in older adults with developmental disabilities, *Topics in Geriatric Rehabilitation*, 24(1), 12-25.
- Anderson, P. (2005). Data Brief: Some trends in the use of accommodation support services for people with intellectual disabilities in Australia, *Journal of Intellectual and Developmental Disabilities*, 30(2), 120-124.
- Ansello, E. F. and O'Neill (2010). Abuse, neglect, and exploitation: Considerations in aging with lifelong disabilities, *Journal of Elder Abuse and Neglect*, 22, 105-130.
- Aronow, H. U. and Hahn, J. E.(2005). Stay well and healthy! Pilot study findings from an inhome preventative healthcare programme for persons ageing with intellectual and/or developmental disabilities, *Journal of Applied Research in Intellectual Disabilities*, 18, 163-173.
- Baumbusch, J. (2010). Adults with intellectual disabilities becoming older adults citizens: new Frontiers in aging, Vancouver: University of British Columbia.
- Barnhart, R. C. (2001). Aging adult children with developmental disabilities and their families: Challenges for occupational therapists and physical therapists, *RightsLink*, 69-81.
- Barnhart, R. C. and Connolly, B. (2007). Aging and Down syndrome: Implications for physical therapy, *Physical Therapy*, 87(10), 1399-1406.
- Berry, M. (2010). Alzheimer's and individuals with intellectual and developmental disabilities, *Impact*, 23(1), 26-27.
- Bigby, C. (2002). Aging with a lifelong disability: Challenges for the aged care and disability sectors, *Journal of Intellectual and Developmental Disabilities*, 27(4), 231-241.
- Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.

- Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- Bigby, C. and Balandrin, S. (2005). Another minority group: use of aged care day programs and community leisure services by older people with lifelong disabilities, *Australian Journal on Aging*, 24(1), 14-18.
- Bigby, C. and Haveman, M. (2010). Aging A continuing challenge, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 1-2.
- Bigby, C. and Ozanne, E. (2004). Comparison of specialist and mainstream programs for older carers of adults with intellectual disabilities: Considerations for service development, *Australian Social Work*, 57(3), 273-287.
- Bigby, C. Webber, R., Bowers, B. and McKenzie-Green, B. (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria, *Journal of Intellectual Disability Research*, 52(5), 404-414.
- Botsford, A. L. (2000). Integrating end of life care into services for people with an intellectual disability, *Social Work in Health Care*, 31(1), 35-48.
- Botsford, A. L. and Rule, D. (2004). Evaluation of a group intervention to assist aging parents with permanency planning for an adult offspring with special needs, *Social Work*, 49(3), 423-431.
- Bowey, L. and McGlaughlin (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning, *British Journal of Social Work*, 37, 39-54.
- Bradley, V. J. (2000). Changes in services and supports for people with developmental disabilities: New challenges to established practice, *Health and Social Work*, 25(3), 191-189.
- Brehmer, B. and Weber, G. (2010). Frailty vs. disability distinctions in people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 49-58.
- Bittles, A.H., Petterson, B.A., Sullivan, S.G., Hussain, R., Glasson, E. J., & Montgomery, P.D. (2002). The influence of intellectual disability on life expectancy. *Journal Gerontology A Biological Science Medicine Science*, 57, M470-M472.
- Britton, A., Shipley, M., Singh-Manoux, A. and Marmot, M. G.(2008). Successful aging: The contribution of early-life and midlife risk factors, *Journal of the American Geriatric Society*, 56, 1098-1105.
- Campbell, J. E. and Herge, E. A. (2000). Challenges to aging in place: The elder adult with MR/DD, *RightsLink*, 75-90.

- Chance, P. SG. The mental health needs of older adults with learning disabilities, *Reviews in Clinical Gerontology*, 15, 245-253.
- Cheek, P., Nikpour, L., R., Nowlin, H. D. (2005). Aging well with smart technology, *Nursing Administration Quarterly*, 29(4), p. 329-338.
- Chou, Y-C, Lee, Y-C, Lin, L-C, Chang, A-N, and Huang, W-Y. (2008). Social services utilization by adults with intellectual disabilities and their families, *Social Science and Medicine*, 66, 2475-2485.
- Chicoine, B., McGuire, D., Herbein, S. and Gilly, D. (1995). Use of the community-oriented primary care model for a special-needs population: a clinic for adults with Down syndrome, *American Journal of Public Health*, 8, 869-870.
- Chicoine, B. McGuire, D. and Rubin, S.r. (1999). Speciality clinic perspectives. In M.P. Janicki and A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities* (PP. 278-291). USA: Taylor and Francis.
- Clement T. and Bigby, C. (2009). Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 22, 264–275.
- Connolly, B. H. (2001). Aging in individuals with lifelong disabilities, *RightsLink*, 23-47.
- Conroy, P. and Mangan, I (2006). Ageing and disability: A discussion paper. Dublin: National Council on Ageing and Older People.
- Courtenay, K., Jokinen, N. S. and Strydom, A. (2010). Caregiving and adults with intellectual disabilities affected by dementia, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 26-33.
- Dillenburg, K. and McKerr, L. (2009). "40 years is an awful long time": Parents caring for adult sons and daughters with disabilities, *Behavior and Social Issues*, 18, 155-174.
- Doka, K. J. and Lavin, C. (2003). The paradox of ageing with developmental disabilities: Increasing needs, declining resources, *Ageing International*, 28(2), 135-154.
- Edwards, C. and Imrie, R. (2008). Disability and the implications of the wellbeing agenda: Some reflections from the United Kingdom, *International Social Policy*, 37(3), 337-355.
- Essex, E. L. (2002). Mothers and fathers of adults with mental retardation: Feelings of intergenerational closeness, *Family Relations*, 51(2), 156-165.
- Fisher, K. and Kettl, P. (2005). Aging with mental retardation: Increasing population of older adults with MR require health interventions and prevention strategies. *Geriatrics*, 60, 26-29.

- Giles, L. C., Metcalfe, P. A., Glonek, G. F. V., Luszcz, M. A. and Andrews, G. R. (2004). The effects of social networks on disability in older Australians, *Journal of Aging and Health*, 16(4), 517-538.
- Gaventa, B. (2010). Aging and end of life: Helping the spiritual tasks of people with disabilities come alive, *Impact*, 23(1), 8-9.
- Gottlieb, B. H. (Ed.), (1981). Social networks and social support (pp. 69–96). Beverly Hills, CA: Sage.
- Government of Scotland (2007). All our futures: Planning for a Scotland with an ageing population summary report and action plan. Accessed from: <http://www.scotland.gov.uk/Publications/2007/03/08125028/1>
- Hahn, J. E. and Cadogan, M. P. (2011). Development and evaluation of a staff training program on palliative care for persons with intellectual and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 42-52.
- Hall, J. M. and Thomas, M. J. (2008). Promoting physical activity and exercise in older adults with developmental disabilities, *Topics in Geriatric Rehabilitation*, 24(1), 64-75.
- Hammel, J., Lai, J-S., and Heller, T. (2002). The impact of assistive technology and environmental interventions on function and living situation status with people who are ageing with developmental disabilities, *Disability and Rehabilitation*, 24 (1), 93-105.
- Happe, F. and Charlton, R. A. (2010). Aging and Autism Spectrum disorders: A mini-review, *Gerontology*, 1-9.
- Harrington, C. and Kang, K. (2010). Personal care services utilization by individuals with developmental disabilities, *Family Relations*, 59, 136-151.
- Haveman, M., Heller, T., Lee, L., Maaskant, M. Shooshtari, S. and Strydom (2010), A. Major health risks in aging persons with intellectual disabilities: An overview of recent studies, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 59-69.
- Haveman, M., Perry, J., Salvador-Carulla, L., Noonan Walsh, P., Kerr, M., Van Schroyen Lantman-de Valk, H., Van Hove, G., Berger, D. M, Azema, B., Buono, S., Cara, A. C., Tossebro, J. and Weber, G. (2011). Ageing and health status in adults with intellectual disabilities: Results of the European POMONA II study, *Journal of Intellectual and Developmental Disabilities*, 36(1), 49-60.
- Havir, L. (1991). Older adult centres in rural communities: Potentials for serving, *Journal of Aging Studies*, 5(4), 359-374.
- Healthy Aging and Wellness Working Group of the Federal/Provincial/Territorial (F/P/T) Committee of Officials (Seniors)(nd). Healthy aging in Canada: A new vision, a vital

- investment A discussion brief prepared for the Federal, Provincial and Territorial Committee of Officials (Seniors), author.
- Heller, T. (2010). People with intellectual and developmental disabilities growing old: An overview, *Impact*, 23(1), 2-3.
- Hellar, T., Caldwell, J. and Factor, A. (2007). Aging family caregivers: Policies and practices, *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 136-142.
- Heller, T., Janicki, M. P., Marks, B., Hammel, J., and Factor, A. (2008). Brief Report State of the Scientific Symposium on Aging and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 386-388.
- Heller, T. and Arnold, C.K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 16-25.
- Henderson, C. M., Acquilano, J. P., Meccarello, J. C., Davidson, P. W., Robinson, L. M., and Janicki, M. P. (2009). Health status and activities of daily living and walking in older people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 6(4), 282-286.
- Hewitt, A., Lightfoot, E., Bogenschutz, M. McCormick, K. Sedlezky, L. and Doljanac, R. (2010). Parental caregivers' desires for lifetime assistance planning for future supports for their children with intellectual and developmental disabilities, *Journal of Family Social Work*, 13, 420-434.
- Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., & Working Group (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva, Switzerland: World Health Organization.
- Hostetler, A. J. (2011). Older adult centers in the era of the "Third Age:" Country clubs, community centers, or something else?. *Journal of Aging Studies*, 25(2), 166-176.
- Hutchings, B. L., Olsen, R. V. and Moulton, H. J. (2008). Environmental evaluations and modifications to support aging at home with a developmental disability, *Journal of Housing for the Elderly*, 22(4), 286-310.
- Independent Living Resource Centre in Halifax, Nova Scotia (2008). What about us? Aging with disability and dignity, Accessed from www.ilrc-halifax.ns.ca/news/aging.doc .
- Jaeger, P. T. and Xie, B. (2009). Developing online community accessibility guidelines for persons with disabilities and older adults, *Journal of Disability Policy Studies*, 20(1), 55-63.
- Janicki, M. P. (2009). The aging dilemma: Is increasing longevity among people with intellectual disabilities creating a new population challenge in the Asia-Pacific region?, *Journal of Policy and Practice in Intellectual Disabilities*, 6(2), 73-76.

- Janicki, M. P. (2001). Toward a rationale strategy for promoting healthy ageing amongst people with developmental disabilities, *Journal of Applied Research in Intellectual Disabilities*, 14, 171-174.
- Janicki, M. P., Dalton, A. J., McCallion, P., Davies Baxley, D. and Zendell, A. (2005). Group home care for adults with intellectual disabilities and Alzheimer's disease, *Dementia*, 4, 361-384.
- James, A. and Shireman, T. I. (2010). Case manager' and independent living counselors' perspectives on health promotion activities for individuals with physical and developmental disabilities, *Journal of Social Work in Disability and Rehabilitation*, 9, 274-288.
- Jamieson-Craig, R., Scior, K. Chan, T., Fenton, C. and Strydom, A. (2010). Reliance on carer reports of early symptoms of dementia among adults with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 34-41.
- Jokinen, N. (2005). The content of available practice literature in dementia and intellectual disability, *Dementia*, 4, 327-339.
- Kandel, I. and Morad, M. (2004). Policy Briefs: Health needs assessment report: People with learning disabilities in Scotland, *Journal of Policy and Practice in Intellectual Disabilities*, 1(2), 113.
- Kerins, A. (2004). Irish Times –Opinions and Analysis, National Disability Strategy result of hard-fought struggle and unprecedented consultation process, 09/22/2004.
- Krassioukova-Enns, O. and Ogaranko, C. (2008). Project Description: Development of a Comprehensive Knowledge-based Framework to Address the Needs of Canadians with Long-term Disabilities who are Aging. Canadian Centre on Disability Studies.
- Laws, J., Parish, S., Scheyett, A. M., and Egan, C. (2011). Preparation of social workers to support people with developmental disabilities, *Journal of Teaching in Social Work*, 30, 317-333.
- Levy, J. M., Botuck, S. and Rimmerman, A. (2007). Examining outpatient health care utilization among adults with severe or profound intellectual disabilities living in an urban setting: A brief snapshot, *Journal of Social Work in Disability and Rehabilitation*, 6(3), 33-45.
- Lifshitz, H. and Merrick, J. (2004). Aging among persons with intellectual disability in Israel in relation to type of residence, age, and etiology, *Research in Developmental Disabilities*, 25, 193-205.
- Lifshitz, H. and Merrick, J. and Morad, M. (2007). Health status and ADL functioning of older persons with intellectual disability: Community residence versus residential care centres, *Research in Developmental Disabilities*, 29, 301-315.

- Llewellyn, G. McConnell, D., Gething, L. Cant, R. and Kendig, H. (2010). Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample, *Research in Developmental Disabilities*, 31, 1176-1186.
- Long, T. and Kavarian, S. (2008). Aging with a developmental disability, *Topics in Geriatric Rehabilitation*, 24(1), 2-11.
- MacLellan, M. (2009). Building Bridges between the Aging and Disabilities Communities in Nova Scotia. Accessed from <http://www.opadd.on.ca/News/documents/WorkshopB2-MarleneMacLellan.pdf>.
- Marks, B. A. and Heller, T. (2003). Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities, *Nursing Clinics of North America*, 38, 205-228.
- National Advisory Council on Aging (2004). Older adults on the margins: Aging with a developmental disability. Ottawa: Minister of Public Works and Government Services Canada.
- McCallion, P. and Nickle, T. (2008). Individuals with developmental disabilities and their caregivers, *Journal of Gerontological Social Work*, 50(Suppl #1), 245-266.
- McCarron, M. and Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland, *Aging and Mental Health*, 7(6), 413-417.
- McCarron, M. McCallion, P., Fahey-McCarthy, E., Connaire, K. and Dunn-Lane, J. (2010). Supporting persons with Down syndrome and advanced dementia: challenges and care concerns, *Dementia*, 9, 285-298.
- Morad, M. and Merrick, J. (2004). Policy Brief: The cost of triple jeopardy: Aging, developmental disabilities, and Ohio's impending care shift, *Journal of Policy and Practice in Intellectual Disabilities*, 1(2), 114.
- Murphy, K., O'Shea, E., Cooney, A., and Casey, D. (2007). The quality of life of older people with a disability in Ireland. National Council on Ageing and Older People.
- Patti, P., Amble, K. and Flory, M.(2010). Placement, relocation and end of life issues in aging adults with and without Down syndrome: A retrospective study, *Journal of Intellectual Disability Research*, 54(6), 538-546.
- Parish, S. L. and Lutwick, Z. E. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities, *Social Work*, 50(4), 345-354.
- Post, S. G. (2002). Down syndrome and Alzheimer disease: Defining a new ethical horizon in dual diagnosis, *Alzheimer's Care Quarterly*, 3(3), 215-224.
- Pruchno, R. A. (2003). Enmeshed lives: Adult children with developmental disabilities and their aging mothers, *Psychology and Aging*, 18(4), 851-857.

- Putman, M. (2010). Perceptions of difference between aging and disability service systems consumers: Implications for policy initiatives to rebalance long-term care, *Journal of Gerontological Social Work*, 54, 325-342.
- O'Donvan, A. (2005). Paper 18: Disability and Ageing: A social policy perspective. Dublin: National Disability Authority.
- Rosenzweig, L. Y. (2008). Serving the aging developmentally disabled population, *Topics in Clinical Nutrition*, 23(2), 98-101.
- Salvatori, P., Tremblay, M., and Tryssenaar, J. (2003). Living and aging with a developmental disability: Perspectives of individuals, family members and service providers, *Journal of Developmental Disabilities*, 10(1), 1-19.
- Service, K. P. and Hahn, J. E. (2003). Issues in aging The role of the nurse in the care of older people with intellectual and developmental disabilities, *Nursing Clinics of North America*, 38, 291-312.
- Singer, G. H., Biegel, D. E. and Ethridge, B. I. (2010). Trends impacting public policy support for caregiving families, *Journal of Family Social Work*, 13, 191-207.
- Silverman, W. (2009). Our children's "Golden Years", *EP Magazine*, 82-84.
- Simmons-Romano, M. (2011). Elderly individuals with developmental disabilities and the office visit, *Clinical Geriatrics*, May, 52-56.
- Society for Manitobans with Disabilities (2004). Aging and Disability in Manitoba: Converging Opportunities. - October 2004. Aging and Disability in Manitoba. Accessed from: <http://smd.mb.ca/uploads/DoublelensreportFinal.pdf>.
- Stafford, P. B. (2010). Supporting community inclusion of aging adults with developmental disabilities, *Impact*, 23(1), 6-7.
- Stax, T. E., Luciano, L., Dunn, A. M. and Quevedo, J. P. (2009). Aging and developmental disability, *Physical Medicine and Rehabilitation Clinics in North America*, 21, 419-427.
- Strydom, A., Hassiots, A. and Livingston, G. (2005). Mental health and social care needs of older people with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 18, 229-235.
- Sullivan, W. F., Berg, J. M., Bradlet, E., Cheetham, T., Denton, R., Heng, J., Hennen, B., Joyce, D., Kelly, M., Korossy, M., Lunskey, Y. and McMillian, S. (2011). Primary care of adults with developmental disabilities Canadian consensus guidelines, *Canadian Family Physician*, 57(May-June), 541-553.
- Thorpe, L., Davidson, P., & Janicki, M.P. (2000). Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues. Geneva, Switzerland: World Health Organization.

- Torr, J., Strydom, A., Patti, P. and Jokinen, N. (2010). Aging in Down syndrome: Morbidity and mortality, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 70-81.
- Trotter, J. L. and Allen, N. E. (2009). The good, the bad, and the ugly: Domestic violence survivors' experiences with their informal social networks. *American Journal of Community Psychology*, (43), 221–231.
- United Nations (2006). The convention on the Rights of Persons with Disability. Accessed from <http://www.un.org/disabilities/convention/convention.shtml>
- United Nations (nd). The Elderly. Accessed from: <http://www.humanrights.is/the-human-rights-project/humanrightscasesandmaterials/humanrightsconceptsideasandfora/Undirflokkur/elderlypersons/>
- USA today (nd). Nana technology: tools help older adults be independent. Accessed from http://www.usatoday.com/tech/graphics/nana_tech/flash.htm
- Vinton, L. (2010). Caregivers' perception of a consumer-directed care program for adults with developmental disabilities, *Journal of Family Social Work*, 13, 208-226.
- Webber, R., Bowers, B. and McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes, *Disability and Society*, 25(6), 657-671.
- Wiebe, R. (2008). Manitoba forum on aging and disabilities report. Unpublished report prepared for The Province of Manitoba's Older adults and Healthy Aging Secretariat and Disabilities Issues Office. Accessed from http://www.gov.mb.ca/dio/pdf/forum_report2008.pdf
- Wilkinson, H. and Janicki, M. (2002). The Edinburgh Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- Wong, Y. I., Nath, S., and Solomon, P. (2007). Group Organizational Involvement Among Persons with Psychiatric Disabilities in Supported Housing. *The Journal of Behavioral Health Services & Research*, 34(2), 151-167.
- World Health Organization (2000). Ageing and intellectual disabilities - Improving longevity

ENDNOTES

- ⁱ Bittles, A.H., Petterson, B.A., Sullivan, S.G., Hussain, R., Glasson, E. J., & Montgomery, P.D. (2002). The influence of intellectual disability on life expectancy. *Journal Gerontology A Biological Science Medicine Science*, 57, M470-M472.
- influence of intellectual disability on life expectancy. *Journal Gerontology A Biological Science Medicine Science*, 57, M470-M472.
- ⁱⁱ Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- ⁱⁱⁱ Janicki, M. P., McCallion, P. and Dalton, A. J. (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities, *Journal of Gerontological Social Work*, 38(1-2), 179-195.
- ^{iv} Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- ^v McCallion, P. and Janicki, M. P. (1997). Area agencies on aging: Meeting the needs of persons with developmental disabilities and their aging families, *Journal of Applied Gerontology*, 16, 270-284
- ^{vi} Janick, M. P. (2011). personal conversation in Calgary Alberta, May
- ^{vii} Trotter, J. L. and Allen, N. E. (2009). The good, the bad, and the ugly: Domestic violence survivors' experiences with their informal social networks. *American Journal of Community Psychology*, (43), 221–231.
- ^{viii} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{ix} Hahn, J. E. and Cadogan, M. P. (2011). Development and evaluation of a staff training program on palliative care for persons with intellectual and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 42-52.
- ^x Webber, R., Bowers, B. and McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes, *Disability and Society*, 25(6), 657-671.
- ^{xi} Bigby, C. (2002). Aging with a lifelong disability: Challenges for the aged care and disability sectors, *Journal of Intellectual and Developmental Disabilities*, 27(4), 231-241.
- ^{xii} McCallion, P. and Janicki, M. P. (1997). Area agencies on aging: Meeting the needs of persons with developmental disabilities and their aging families, *Journal of Applied Gerontology*, 16, 270-284.
- ^{xiii} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 3-15.
- ^{xiv} McCarron, M. and Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland, *Aging and Mental Health*, 7(6), 413-417.
- ^{xv} Chicoine, B., McGuire, D., Herbein, S. and Gilly, D. (1995). Use of the community-oriented primary care model for a special-needs population: a clinic for adults with Down syndrome, *American Journal of Public Health*, 8, 869-870.

-
- ^{xvi} Chicoine, B. McGuire, D. and Rubin, S.r. (1999). Speciality clinic perspectives. In M.P. Janicki and A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities* (PP. 278-291). USA: Taylor and Francis.
- ^{xvii} Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- ^{xviii} Janick, M. P. (2011). personal conversation in Calgary Alberta, May
- ^{xix} Ibid
- ^{xx} Doka, K. J. and Lavin, C. (2003). The paradox of ageing with developmental disabilities: Increasing needs, declining resources, *Ageing International*, 28(2), 135-154.
- ^{xxi} ibid
- ^{xxii} Heller, T, Janicki, M. P., Marks, B. Hammel, J. and Factor, A. (2008). Brief Report State of the Scientific Symposium on Aging and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 5(4), 386-388.
- ^{xxiii} Doka, K. J. and Lavin, C. (2003). The paradox of ageing with developmental disabilities: Increasing needs, declining resources, *Ageing International*, 28(2), 135-154.
- ^{xxiv} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- ^{xxv} Ibid
- ^{xxvi} Long, T., & Kavarian, S. (2008). Aging with developmental disabilities: An overview. *Topics in Geriatric Rehabilitation*, 24(1), 2-11.
- ^{xxvii} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- ^{xxviii} Ibid
- ^{xxix} Ibid
- ^{xxx} McCallion, P. and Nickle, T. (2008). Individuals with developmental disabilities and their caregivers, *Journal of Gerontological Social Work*, 50(Suppl #1), 245-266.
- ^{xxxi} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{xxxii} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- ^{xxxiii} Ibid
- ^{xxxiv} Alberta Health Services interviewee, 2011
- ^{xxxv} Brehmer, B. and Weber, G. (2010). Frailty vs. disability distinctions in people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 49-58.

-
- ^{xxxvi} McCallion, P. and Nickle, T. (2008). Individuals with developmental disabilities and their caregivers, *Journal of Gerontological Social Work*, 50(Suppl #1), 245-266. p. 248
- ^{xxxvii} Janicki, M. P. and Dalton A.J. (1999). Dementia and public policy considerations. In M.P. Janicki and A. J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities* (pp. 388-414). Philadelphia: Brunner-Mazel).
- ^{xxxviii} Janicki, M. P., McCallion, P., and Dalton, A. J., (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities, *Journal of Gerontological Social Work*, 38, 1-2, 179 – 195.
- ^{xxxix} McCarron, M. and Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland, *Aging and Mental Health*, 7(6), 413-417.
- ^{xl} Silverman, W. (2009). Our children's "Golden Years", *EP Magazine*, 82-84.
- ^{xli} Conroy, P. and Mangan, I (2006). Ageing and disability: A discussion paper. Dublin: National Council on Ageing and Older People.
- ^{xlii} *ibid*, p. 36-37.
- ^{xliii} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{xliv} Hellar, T., Caldwell, J. and Factor, A. (2007). Aging family caregivers: Policies and practices, *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 136-142.
- ^{xlv} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of policy and practice in intellectual disabilities*, 7(1), 3-15.
- ^{xlvi} Crews, J. (2011). Aging, disability, and public health. *Public Health Perspectives on Disability: Epidemiology to Ethics and Beyond*, 3, 163-183.
- ^{xlvii} Schalock, R.L., Luckasson, R.A., & Shogren, K.A. (2007). The renaming of mental retardation: Understanding the change to the term developmental disability. *Intellectual and Developmental Disabilities*, 45, 116-124.
- ^{xlviii} Patja, K., Molso, P., & Livanainen, M. (2001). Cause specific mortality of people with intellectual disabilities in a population-based, 35 year follow-up study. *Journal of Developmental Disability Research*, 45, 30-40.
- ^{xlix} Sherman, S.L., Allen, E.G., Bean, L. H., & Freeman, S.B. (2007). Epidemiology of Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 221-227.
- ^l Kapell, D., Nightingale, B., Rodriguez, A., Lee, J.H., Zigman, W. B., & Schupf, N. (1998). Prevalence of chronic medical conditions in adults with mental retardation: Comparison with the general population. *Mental Retardation*, 36, 269-279.
- ^{li} Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N., & Chicoine, B. (2001). Healthy ageing - adults with intellectual disabilities: Physical health issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 175-194.

-
- ^{lii} Oliver, C., & Holland, A. J. (1986). Down's syndrome and Alzheimer's disease: A review. *Psychological Medicine*, 16, 307-222.
- ^{liii} Thomas, E., Strax, T.E., Luciano, L., Dunn, A.M., & Quevedo, J.P. (2010). Aging and developmental disability. *Physical Medicine and Rehabilitation Clinics of North America*, 21, 419-427.
- ^{liv} Janicki, M. P. (2011). Personal conversation, Calgary, May.
- ^{lv} Janicki, M. P., McCallion, P., and Dalton, A. J., (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities, *Journal of Gerontological Social Work*, 38, 1-2, 179 – 195.
- ^{lvi} McCarron, M. and Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland, *Aging and Mental Health*, 7(6), 413-417.
- ^{lvii} Cook, D. (2011). Projections of the Population of Older Persons with Developmental Disabilities in the Calgary Region, 2010 – 2020. Prepared for Possberg and Associates Ltd. Calgary, Alberta.
- ^{lviii} Janicki, M. P., McCallion, P., and Dalton, A. J., (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities, *Journal of Gerontological Social Work*, 38, 1-2, 179 – 195.
- ^{lix} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{lx} Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- ^{lxi} Heller T., Caldwell J., and Factor A.(2007). Aging family caregivers: policies and practices, *Mental Retardation Developmental Disabilities Research Review*,13(2), 136-42.
- ^{lxii} Bowey, L. and McGlaughlin (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning, *British Journal of Social Work*, 37, 39-54.
- ^{lxiii} Parker, G. and Clarke, H. (2002) 'Making the ends meet: do carers and disabled people have a common agenda?' *Policy and Politics* 30, 3, 347-359
- ^{lxiv} Marks, B. A. and Heller, T. (2003). Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities, *Nursing Clinics of North America*, 38, 205-228.
- ^{lxv} Haveman, M., Heller, T., Lee, L., Maaskant, M. Shooshtari, S. and Strydom (2010), A. Major health risks in aging persons with intellectual disabilities: An overview of recent studies, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 59-69.
- ^{lxvi} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{lxvii} Hahn, J. E. and Cadogan, M. P. (2011). Development and evaluation of a staff training program on palliative care for persons with intellectual and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 42-52.
- ^{lxviii} Webber, R., Bowers, B. and McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes, *Disability and Society*, 25(6), 657-671.

-
- ^{lxi} Bigby, C. (2002). Aging with a lifelong disability: Challenges for the aged care and disability sectors, *Journal of Intellectual and Developmental Disabilities*, 27(4), 231-241.
- ^{lxx} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{lxxi} Janicki, M. P., Dalton, A. J., McCallion, P., Davies Baxley, D. and Zendell, A. (2005). Group home care for adults with intellectual disabilities and Alzheimer's disease, *Dementia*, 4, 361-384.
- ^{lxxii} Trotter, J. L. and Allen, N. E. (2009). The good, the bad, and the ugly: Domestic violence survivors' experiences with their informal social networks. *American Journal of Community Psychology*, (43), 221–231.
- ^{lxxiii} Wong, Y. I., Nath, S., and Solomon, P. (2007). Group Organizational Involvement Among Persons with Psychiatric Disabilities in Supported Housing. *The Journal of Behavioral Health Services & Research*, 34(2), 151-167.
- ^{lxxiv} Ibid, p. 151-152.
- ^{lxxv} Clement T. and Christine Bigby, C. (2009). Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 22, 264–275.
- ^{lxxvi} Mert Bal¹, Weiming Shen¹, Qi Hao¹, Henry Xue¹ (2011). Proceedings of the 2011 15th International Conference on Computer Supported Cooperative Work in Design Collaborative Smart Home Technologies for Senior Independent Living: A Review
- ^{lxxvii} Sander Bakkes, Richard Morsch, and Ben Kröse (2011). 2011 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops Telemonitoring for Independently Living Elderly: Inventory of Needs & Requirements
- ^{lxxviii} Aanesen, M. Lotherington, A. T., Olsen, F.(2011). Smarter elder care? A cost-effectiveness analysis of implementing technology in elder care, *Health Informatics Journal*, 17, 161-172.
- ^{lxxix} Cheek, P., Nikpour, L., R., Nowlin, H. D. (2005). Aging well with smart technology, *Nursing Administration Quarterly*, 29(4), p. 329-338.
- ^{lxxx} Hutchings, B. L., Olsen, R. V. and Moulton, H. J. (2008). Environmental evaluations and modifications to support aging at home with a developmental disability, *Journal of Housing for the Elderly*, 22(4), 286-310.
- ^{lxxxi} Ibid, p. 13.
- ^{lxxxii} Conroy, P. and Mangan, I (2006). Ageing and disability: A discussion paper. Dublin: National Council on Ageing and Older People, p. 14.
- ^{lxxxiii} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{lxxxiv} Hahn, J. E. and Cadogan, M. P. (2011). Development and evaluation of a staff training program on palliative care for persons with intellectual and developmental disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 8(1), 42-52.

-
- ^{lxxxv} Webber, R., Bowers, B. and McKenzie-Green, B. (2010). Staff responses to age-related health changes in people with an intellectual disability in group homes, *Disability and Society*, 25(6), 657-671.
- ^{lxxxvi} Bigby, C. (2002). Aging with a lifelong disability: Challenges for the aged care and disability sectors, *Journal of Intellectual and Developmental Disabilities*, 27(4), 231-241.
- ^{lxxxvii} Wilkinson, H. and Janicki, M. (2002). The Edinburg Principles with accompanying guidelines and recommendations, *Journal of Intellectual Disability Research*, 46(3), 279-284.
- ^{lxxxviii} Ibid
- ^{lxxxix} Heller and Factor, as cited by McCallion, P. and Nickle, T. (2008). Individuals with developmental disabilities and their caregivers, *Journal of Gerontological Social Work*, 50(Suppl #1), 245-266.
- ^{xc} Heller, T. and Arnold, C.K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 16-25.
- ^{xc1} ibid
- ^{xcii} As outlined in McCallion, P. and Janicki, M. P. (1997). Area agencies on aging: Meeting the needs of persons with developmental disabilities and their aging families, *Journal of Applied Gerontology*, 16, 270-284.
- ^{xciii} Ibid
- ^{xciv} Hirst, S. P. (2011). Assessment Tools for Older Adults with DD. Prepared for Possberg and Associates Ltd. Calgary, Alberta.
- ^{xcv} Margaret Salmon, Vancouver Island Health Authority, Personal communication, May 2011.
- ^{xcvi} Bigby, C. (2010). A five-country comparison review of accommodation support policies for older people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 3-15.
- ^{xcvii} McCarron, M. and Lawlor, B. A. (2003). Responding to the challenges of ageing and dementia in intellectual disability in Ireland, *Aging and Mental Health*, 7(6), 413-417.
- ^{xcviii} Chicoine, B., McGuire, D., Herbein, S. and Gilly, D. (1995). Use of the community-oriented primary care model for a special-needs population: a clinic for adults with Down syndrome, *American Journal of Public Health*, 8, 869-870.
- ^{xcix} Chicoine, B. McGuire, D. and Rubin, S.r. (1999). Speciality clinic perspectives. In M.P. Janicki and A. J. Dalton (Eds.), *Dementia, aging, and intellectual disabilities* (PP. 278-291). USA: Taylor and Francis.
- ^c Bigby, C. and Ozanne, E. (2004). Comparison of specialist and mainstream programs for older carers of adults with intellectual disabilities: Considerations for service development, *Australian Social Work*, 57(3), 273-287.
- ^{ci} Hostetler, A. J. (2011). Older adult centers in the era of the "Third Age:" Country clubs, community centers, or something else?. *Journal of Aging Studies*, 25(2), 166-176.
- ^{cii} Havar, L. (1991). Older adult centres in rural communities: Potentials for serving, *Journal of Aging Studies*, 5(4), 359-374.

-
- ^{ciii} McCallion, P. and Janicki, M. P. (1997). Area agencies on aging: Meeting the needs of persons with developmental disabilities and their aging families, *Journal of Applied Gerontology*, 16, 270-284.
- ^{civ} Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- ^{cv} Janick, M. P. (2011). personal conversation in Calgary Alberta, May
- ^{cvi} Janicki, M. P., McCallion, P. and Dalton, A. J. (2002). Dementia-related care decision-making in group homes for persons with intellectual disabilities, *Journal of Gerontological Social Work*, 38(1-2), 179-195.
- ^{cvi} Ibid, pp 189-190.
- ^{cvi} Chaput, J. L. (2002). Adults with Down syndrome and Alzheimer's Disease: Comparison of services received in group homes and in special care units, *Journal of Gerontological Social Work*, 38, 1-2, 197-211.
- ^{cix} Janick, M. P. (2011). personal conversation in Calgary Alberta, May