

Framework for Quality Community Supports for People Living with an Intellectual Disability and Dementia

Foundational Values and Beliefs

The grounding of this framework comes from The Edinburgh Principles (Wilkinson & Janicki, 2002). In 2001 a working group developed these internationally recognized principles, guided by a series of meetings that involved researchers and service providers, in the field of aging and people with an intellectual disability (ID), from around the world. The aim was to promote continued community care and supports. The Manitoba Advisory Committee for Quality Community Supports for People with an Intellectual Disability and Dementia (MAC) embraces the following principles:

The Edinburgh Principles

1. Adopt an operational philosophy that promotes the utmost quality of life of persons with intellectual disabilities affected by dementia and, whenever possible, base services and support practices on a person-centered approach.
2. Affirm that individual strengths, capabilities, skills, and wishes should be the overriding consideration in any decision-making for and by persons with intellectual disabilities 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 an intellectual disabilities affected with dementia.
4. Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs, and support healthy ageing, of persons with intellectual disabilities affected by dementia.
5. Plan and provide supports and services that optimize remaining in the chosen home and community of adults with intellectual disabilities affected by dementia.
6. Ensure that persons with intellectual disabilities affected by dementia have the same access to appropriate services and supports as afforded to other persons 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 intellectual disabilities affected by dementia. (Wilkinson & Janicki, 2002, p. 280)

Introduction:

Manitoba's Framework for Alzheimer's Disease and Other Dementias is an important roadmap for guiding care and support for all Manitobans with dementia and the people who provide that care and support. The document references the need to "Develop and implement a plan for

diverse needs groups” and this Framework is a response to that goal. Also noted in the Manitoba Framework, is a need to facilitate coordination and integration amongst all the health and social sectors in order to avoid duplication of effort. A common thread of this document is collaboration across sectors.

MAC began in 2014, out of an informal inter-agency group and in response to the Coming of Age –*the dialogue continues* national conference. The group currently consists of representatives from the Alzheimer Society, Community Living Disability Services (CLDS) and Community Living Psychiatry, psychogeriatric program specialist and agencies that support people with an ID. The desired outcome for this document is to provide best practice guidance and direction to funders, service providers and community groups in order to inform decisions related to policy, resources and service planning. It is a focusing mechanism for future work and advocacy in this area. As efforts have progressed it has become clear that strategic themes mirror those found within the existing Manitoba Framework.

International research on the incidence of dementia, amongst people with ID, focuses primarily on those with Down syndrome (DS) due to the increased risk of dementia of the Alzheimer type within this group (Strydom et al., 2010). Prevalence rates vary across studies but all demonstrate that “dementia is common in older adults with DS, and that the prevalence increases sharply from the age of 40 until the age of 60” (Strydom et al., 2010, p.103). Some research shows prevalence rates for people who have DS, over the age of 60, to be as high as 50% (Strydom et al., 2010). Everyone with DS has some of the neuropathological symptoms of Alzheimer disease, post mortem, by the age of 40 although not everyone will demonstrate the clinical features (Moran, Rafii, Keller, Baldev, & Janicki, 2013). Studies exploring prevalence of dementia amongst the larger group of people with ID are much smaller and do not consistently demonstrate an increase amongst this group (Strydom et al., 2010).

In 2015, Shooshtari and colleagues conducted a study of dementia prevalence in Manitobans with ID, based on linked data from several administrative databases. They found “that of the 8,655 adults with ID who lived in Manitoba in 2012, 704 (i.e., 8.1%) had a diagnosis of dementia” (Shooshtari et al., 2015, p. 2). Among Manitobans with ID, who were at least 55 years of age, 17.7% had a diagnostic code for dementia. In 2012, the age of Manitobans with ID and dementia was 57, as compared to 69 years of age for those without ID but with dementia. This study also found that of the 704 Manitobans with ID and dementia, 34.7% were living in a long-term care facility. The age of persons with ID and dementia, in long term-care facilities, ranged between 32 and 99 years of age.

These statistics, in combination with international findings, point to the fact that although people with ID and dementia represent a small percentage of the overall group of people with dementia, the impact of the diagnosis is significant within this population. Unfortunately, to date, there has been little recognition of the specific impact of dementia on this population of people and there have been unique challenges in trying to access supports and services available to the rest of

Manitobans with dementia. This Framework outlines goals and opportunities to address this concern and make efficient use of existing resources.

Contextual Considerations:

Just as the distinct needs of all Manitobans with dementia need to be recognized and tailored, regardless of where individuals reside in the province, so do the distinct needs of people who live with ID and dementia. There are legislative and policy initiatives that look at the requirements and rights of people with ID both within our province and internationally and speak to how we should consider the provision of dementia supports.

- The Accessibility for Manitobans Act (n.d.) became effective on December 5, 2013, with the stated purpose to “achieve accessibility by preventing and removing barriers that disable people with respect to ... b) accommodation: d) the delivery and receipt of goods, services and information: ... e) a prescribed activity or undertaking”. There are barriers, within these areas, for people with ID and dementia that hinder equitable access. They are linked to a lack of access to information, policy and practice barriers and attitudinal barriers.
- The Human Rights Code of Manitoba (n.d.) prohibits unreasonable discrimination based on mental disability and speaks to the need to make reasonable accommodation for the special needs of a group. The code also contains reference to people having the equality of opportunity. This reflects the need for people with ID to have access to appropriate and equitable treatment for age related health issues, just as is offered to the rest of the population.
- *Opening Doors: Manitoba’s Commitment to Persons with Disabilities*, released in 2009, made a commitment to better inter-departmental cooperation in promoting inclusion and access for all people living with a disability (Ouellette-Kuntz et al., 2012).
- Building on Abilities – Community Living Disability Services has launched a new initiative to ensure that “People with intellectual & developmental disabilities who are eligible for services get the services and supports they need to live, love, work and play, just as others do in their community” (Province of Manitoba, n.d.).
- The U.N. Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) was ratified by Canada in 2010. This document describes disability as a social construct where attitudinal and environmental barriers prevent full inclusion. Countries who have ratified this agreement have committed to equal access, for people with a disability to services, health care and health programs. There is also a commitment, when developing legislation and policies, to active involvement of people with a

disability. Article 25 of the CRPD reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination.

- The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) is a group in the United States that ensures that people with ID and dementia are an integral part of the U.S. National Plan to Address Alzheimer’s Disease. The work of this group has led to the development of a screening tool, the NTG-EDSD (Esralew et al., 2013) and the following practice guidelines: Guidelines for Structuring Community Care and Supports for People with Intellectual Disabilities Affected by Dementia (Jokinen et al., 2013), Consensus Recommendations for the Evaluation & Management of Dementia in Adults with an Intellectual Disability (Moran et al., 2013), and Guidelines for Dementia-Related Health Advocacy for Adults with Intellectual Disabilities and Dementia (Bishop et al., 2015). Although there are aspects unique to the U.S. perspective, many of these resources are directly applicable to Manitoba and Canada.

Responses to Dementia and Corresponding Themes:

**RAISING AWARENESS
AND UNDERSTANDING**

Achieving old age is a relatively new phenomenon for individuals who have ID, with significant life expectancy increases over the past 50 years (Bigby & Haveman, 2010; Strydom et al., 2010). Overall this population now has a life expectancy equal to that of the general population (Ouellette-Kuntz et al., 2005). Longevity has also increased for individuals who have DS, whose life expectancy increased from 35 years of age in 1982 (Thase, 1982) to 53 years of age in 2007 (Presson et al., 2013) and are now living to be 55+ (Watchman, 2016). This has meant a shift in focus for families, support services and care providers, many of whom are unprepared for this cohort.

Within the general population, the promotion of risk reduction strategies, such as exercise, good nutrition and brain engagement activities, is becoming more prominent but this is not the case in the field of intellectual disability. Research indicates that, in general, there are disparities between the general population and people with ID when it comes to preventative care and engagement in health promotion activities (Krahn & Fox, 2014). Additionally, families of younger people with ID and their support systems are often not even thinking of aging or aware of the risk factors for dementia so such strategies are not a focus.

The overall provision of good health care and health care information, a key element in both risk reduction and diagnosis of dementia, are often issues for individuals with ID. People with disabilities are more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care (World Health Organization, 2011). Health care professionals and the health care system in general, know very little about people who have ID and even less about the dual diagnosis of ID and dementia. In an informal survey conducted in 2016, through Abilities Manitoba, service providers identified challenges such as diagnostic overshadowing and barriers to accessing specialists, health and social service supports and programs developed for the general population (Abilities Manitoba, 2016).

People with an ID, their families and/or caregivers and friends, often know very little about the symptoms and early interventions for Alzheimer disease, Vascular Dementia, Lewy Body, Frontal temporal and other less common forms of dementia. This lack of information extends to what supports and services are needed for people with this dual diagnosis (Bishop et al., 2015). Although there has been an increase in awareness around the risks of Alzheimer disease for people who have DS, there is still much misinformation and minimal information is available on other types of I.D. and dementia.

Even when people with ID receive a diagnosis of possible dementia, frequently they are not given information about their diagnosis or involved in future planning for their supports (Watchman, 2016). This can sometimes be a result of receiving a diagnosis later in the progression of the disease, when there is a significant impairment in the ability to understand and/or communicate information but is also a result of caregivers not knowing how to disclose this information (Tuffrey-Wijne & Watchman, 2014). Caregivers, the individuals with the diagnosis and often their friends and housemates, with ID, are in need of free, user-friendly plain language information about the disease and its impact on people. Some of these resources are available but there is no good mechanism to raise awareness of such tools and materials.

Strategic Issues and Direction:

Strategic Issues	Action Required
Lack of awareness of aging/health issues for people with ID	<ul style="list-style-type: none"> ➤ Promote knowledge about people with ID and ID and dementia, amongst health care professionals and the health care system in general. ➤ Provide public messaging by developing and disseminating informational materials. ➤ Partner with a variety of existing community based organizations to raise awareness and disseminate information. ➤ Provide dementia information and training to staff within organizations who support individuals with ID and their families so they can in turn share that knowledge. ➤ Foster a dialogue with the Office of the Public Trustee about care, support and

	end-of-life to assist them in their role as substitute decision maker.
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**EARLY RECOGNITION
AND INITIAL
ASSESSMENT AND
DIAGNOSIS**

People who have ID often experience a lower quality of health care and health outcomes (Haveman et al., 2009; Moran et al., 2013). Reasons behind these disparities are varied “but poor training and preparedness among health care providers nationwide ranks among the key contributing factors” (Moran et al., 2013, p. 4). There is also a lack of comprehensive, systemic health assessment within this population and there is less access to health care services (Haveman et al., 2009; World Health Organization, 2011). Research conducted by Shooshtari and Temple (2014), in Manitoba indicated only 10% of community agencies, who support individuals, complete such assessments. This becomes a challenge in tackling prevention, risk reduction and early recognition of dementia. In this instance, as in other areas, health promotion and prevention activities seldom target people with disabilities (World Health Organization, 2011). It can also contribute to changes in a person’s function/behavior/personality being misdiagnosed as dementia when in fact there’s a treatable condition causing the change (Bishop et al., 2015; Moran et al., 2013). Additionally, diagnostic overshadowing can lead to health care practitioners assuming that changes to an individual are due to their disability (Bishop et al., 2015; Moran et al., 2013). The Comprehensive Health Assessment Program (CHAP), developed by Dr. Nick Lennox, and utilized in Australia, is one potential tool that can offer a solution to some of these issues. Its’ design eliminates some of the barriers to health care for people with ID (Endeavour Foundation, n.d.). The tool consists of two parts, one to be completed by the individual and/or their caregivers and the other to be filled out by the G.P. The G.P. section provides prompts regarding health issues commonly missed for people with ID as well as conditions that may be specific to certain conditions affiliated with ID (Endeavour Foundation, n.d.).

One of the key elements to a good diagnosis of dementia is the demonstration of changes to baseline functioning, over time (Moran et al., 2013). A lack of baseline assessment makes accurate assessment for dementia challenging, particularly for individuals who have no consistent family member or staff person who has known them over a long period of time (Moran et al., 2013). The NTG Screening Workgroup has developed an easy to use screening

and detection tool called the NTG-EDSD (Esralew et al., 2013). It can be accessed free of cost, together with a manual, on the NTG website, and is to be used by front line staff and family caregivers.

Most of the neuropsychological screening and assessment tools that are used to detect dementia within the general population are not effective for people with ID, due to communication challenges and pre-existing cognitive deficits (Nieuwenhuis-Mark, 2009; Prasher, Farooq & Holder, 2004; Sinai, Chan, & Strydom, 2014; Strydom et al., 2009). There are tools developed specifically for use within this population but they have not been adopted/utilized in Manitoba (Abilities Manitoba, 2016). Over and above the challenges of raising awareness of and utilizing available tools amongst health care professionals is the fact that family members and support staff must also understand the importance of early screening and recognition of dementia.

Currently, when a suspicion of possible dementia has been raised, the early onset of Alzheimer disease for people with D.S, means an inability to meet the age criteria for accessing some specialist services within various health care regions, such as psychogeriatric outreach teams. Although some community geriatric teams have demonstrated a willingness to offer services to people with ID, this is not a consistent response across the province.

Strategic Issue	Action Required
Early & Ongoing Screening	<ul style="list-style-type: none"> ➤ Implementation of the CHAP ➤ Raise awareness with families, community agencies & health care providers about the NTG-EDSD. ➤ Develop & implement a position statement and guideline for early screening.
Access to diagnostic tools specifically designed for use with people with ID	<ul style="list-style-type: none"> ➤ Partner with St. Amant Comprehensive Health Services to establish the use of diagnostic tools. ➤ Provide evidence-based guidelines for assessment and treatment.
Equal access to Medical Specialist Resources	<ul style="list-style-type: none"> ➤ Develop linkages to Seniors Mental Health teams across the province. ➤ Improve rural support and access to specialists.

**MANAGEMENT, CARE
AND SUPPORT**

The workforce engaged in supporting individuals with ID have minimal requirements for education and training and are compensated at a much lower rate than those providing similar care in the health care field. In Manitoba, there is currently no formally organized, ongoing opportunities for staff training around the provision of dementia care for people with ID. The training offered to health care staff in long-term care facilities is not available to staff who support individuals with ID in the community.

The NTG in the U.S. has developed a training curriculum that includes two-day training for staff as well as a third day component for people interested in being certified to then offer information and support, on an ongoing basis, within their agency and their region. The introduction of this curriculum can lead to the development of regional experts and will ensure the sustainability of ongoing training and support for front line support staff.

In terms of training for health care providers, any curricula offered through formal education programs includes little or no information about people with an ID and even less about people who have both ID and dementia. A pilot of the use of the CHAP could provide a key avenue for educating health care practitioners on health care issues for people with ID.

Jurisdictional issues emerge with the ID population as most individuals already have case managers, who may not have intimate knowledge of dementia related services and supports. Conversely, the generic service system does not feel equipped to address the specialized needs of people with ID or feels that such supports should be the sole responsibility of the disability system. This has frequently led to a gap in collaborative care practices, with neither system having the full skill set required to provide good quality care. There is often a lack of coordination and integration between health and social services sectors and programs and exclusion from mainstream dementia services that are usually accessed by people in the general population who have dementia and who are 65+ (Watchman, 2016).

Service silo issues of particular note are the previously mentioned barriers to accessing psychogeriatric services, unequal access to Home Care and Palliative Care. Rather than focusing on the integration of Home Care supports and disability services, people supported by agencies experience denial of service due to the perception of “double dipping”. The reality is that people supported in an agency need access to Home Care services tailored to that unique context. In some cases, people with dementia and ID are discharged out of community housing prematurely due to lack of guaranteed health supports. Better system coordination and a clearer understanding of the roles of community based agencies, CLDS and health care services could significantly reduce the reliance on our already overburdened hospital and long-term care services.

Family members are not reaching out and may not know where to go for information, support and resources. As noted by research in Australia, “the path to diagnosis and support for people with Down

syndrome and dementia who live with their family can be convoluted and unnecessarily complex” (Carling-Jenkins, Bigby, & Iacono, 2014, p. 145). The health care system is difficult to navigate and there is the additional layer of disability services. A comprehensive, up to date listing of available resources and services to people with ID and dementia is not available. This leaves families, service providers and case managers unsure of next steps, expending valuable time and resources looking for information on a case- by-case basis.

Support networks may be unaware of the First Link program through the Alzheimer Society and even if they are aware, they may not feel it is a resource available for people with ID. Opportunities for family and/or caregiver supports exist through First Link, existing family support organizations such as Continuity Care and Inclusion Winnipeg and case managers through Community Living Disability Services. Family support groups can also provide valuable resources and information regarding dementia.

Service providers in the disability field need assistance and guidance to determine care pathways for the people they support who have dementia. According to the informal survey distributed through Abilities Manitoba, in 2016, agencies often do not have clear policies or positions on aging in place and end-of-life care and do not fully understand all the implications of these approaches (Abilities Manitoba, 2016). This gap leads to crises management as opposed to good person-centered planning and people then end up in hospital awaiting long-term care placement. Families indicate that agencies currently wait far too long before identifying that they can no longer support someone with dementia. Shooshtari et al.’s (2015) research showed that 34.7% of people with both ID and dementia were living in long-term care facilities. “Almost two-thirds (64.1%) of all adults with ID in long-term care facilities were diagnosed with dementia, whereas only 5.5% of adults who lived in the community had a diagnosis of dementia” (Shooshtari et al., 2015, p. 3). The average age of those with this dual diagnosis in long-term care was 71 whereas those living in community was 49.

According to survey results and focus group findings, a lack of accessible housing is often the tipping point for referrals from family homes and community based group living situations to long-term care facilities. In addition, within some regions of the province, agency requests for additional funding to support a person with dementia has led to directives, from CLDS, to panel the individual for a personal care home.

A starting point for the development of care pathways is the NTG document “Guidelines for Structuring Community Care and Supports for People With Intellectual Disabilities Affected by Dementia” (Jokinen et al., 2013). It provides practice guidelines, utilizing the staging model, from pre-diagnosis to end stage care. It consists of stage-based outlines for expected changes in behavior and function, together with potential actions to undertake.

Strategic Issue	Action Required
Education & training of a skilled workforce	➤ Implement the NTG training curriculum across the province including the

	<ul style="list-style-type: none"> development of regional experts. ➤ Utilize the CHAP as an avenue for education of health care professionals.
Care Coordination/System Navigation	<ul style="list-style-type: none"> ➤ Provide and maintain an up to date, comprehensive listing of available resources & services to be accessed by families, agencies and case managers. ➤ Develop & disseminate decision making tools and dementia care pathway documents to assist in the development of Aging in Place plans. ➤ Obtain clarification of CLDS policies around paneling for PCH.
Family/Caregiver Support	<ul style="list-style-type: none"> ➤ Redefine caregiver to include those supports provided by staff within agencies. ➤ Create accessible information and training for families based on NTG guidelines. ➤ Ensure families have access to support groups specific to dementia.
Equal Access to Programs & Services	<ul style="list-style-type: none"> ➤ Collaborate with the Home Care System on how best to share services between the departments of Health and Families. ➤ Clarify roles across CLDS, health services and community agencies. ➤ Review age restrictions for geriatric mental health access. ➤ Develop a team of experts in the area of ID and dementia to provide consultation. Tie into comprehensive health services initiative out of St. Amant.

END-OF-LIFE

There is a lack of knowledge or provision on end-of-life care for people with dementia in general, let alone for those who also have ID (MacCarron, Fahey-McCarthy, Connaire, & McCallion, 2008). A lack of resources extends all across the province of Manitoba and the types of resources available vary from health region to health region. Staff who are involved in supporting people with ID lack in experience and training around end-of-life and have many fears that impact on their ability and willingness to support death at home (Abilities Manitoba, 2016; MacCarron et al., 2008). Palliative Manitoba offers a

course in the provision of palliative care for people with an ID but, due to funding restraints, it's availability is restricted to the Winnipeg region.

There have been some great experiences in Winnipeg with agencies offering end-of-life care in partnership with the Winnipeg Regional Health Authority community palliative care teams. Residential staff and families have indicated a significant increase in confidence in their ability to support people to die at home when the palliative care teams have become involved (Abilities Manitoba, 2016).

According to a recent study completed by Shooshtari et al. (2015), of the people with ID and dementia, 55+, 27% were with the Office of the Public Guardian and Trustee of Manitoba. Anecdotally, agencies that support people with ID and dementia have indicated significant challenges in engaging in advanced health care planning with the Adult Services Administrators that oversee the care of these individuals. In the absence of such planning, palliative care resources are not accessed in a timely manner and people are at risk of undergoing interventions that are not seen as best practice in the end stages of dementia.

Strategic Issue	Action Required
Access to knowledge and resources for the provision of end-of-life care	<ul style="list-style-type: none"> ➤ Develop an end-of-life planning document to guide agencies and family members. ➤ Promote the enhancement/provision of palliative care teams across the province. ➤ Obtain funding for Palliative Manitoba to offer the Compassionate Care Course for Support Workers around the province.

RESEARCH & EVALUATION

There are currently very few students or researchers attracted to this particular area of study. Even when there is an established interest, the relatively smaller numbers of people with both ID and dementia make it very difficult to compete for limited research dollars. In the absence of access to statistical data, several non-profit organizations funded Dr. Shooshtari to conduct the Manitoba study of persons with ID and dementia in 2015. This is the study now used to provide population-based estimates of persons with ID and dementia, their characteristics and related statistics.

The International Association for the Scientific Study of Intellectual Disability and the NTG are the two existing avenues for accessing good quality research and best practice information but that does not reflect the realities that are unique to Canada and Manitoba.

Strategic Issues	Action Required
Consistent, ongoing epidemiological research	<ul style="list-style-type: none"> ➤ Promote the initiation and submission of proposals, in this area, by interested parties. ➤ Develop and maintain connections to researchers and university faculties in order to facilitate interest in this research area.
Capacity for and utilization of knowledge translation activities	<ul style="list-style-type: none"> ➤ Incorporate information on the NTG-EDSD screening tool into knowledge translation activities offered by interested parties.

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