



Office of the
SENIORS' ADVOCATE
Newfoundland and Labrador

Submission on the Development of NL's Decision-Making Framework

November 27, 2024

In response to the Provincial Government's public call for feedback on the planned development of a Decision-Making Framework, the Office of the Seniors Advocate (OSA) is pleased to offer this submission to inform the work.

Introduction

Beginning in 1946, Canada was one country where the number of births increased significantly. This growth continued every year through 1964 when the number of births began to decrease and the so-called "baby boom" ended. With the baby boomer generation, Canada's population has been shifting dramatically every year with a rapidly growing proportion of seniors.

Medical advancements, economic changes, and strikingly low birth rates have all contributed to Canada's aging population where it is most pronounced in the Atlantic provinces, with Newfoundland and Labrador having not only has one of the largest proportion of seniors, but also has the fastest growing population of seniors in Canada. The province's current demographics show 47.4 per cent of the province are 50 years and older and 24.4 per cent of the province are age 65 years and older.

The OSA identifies seniors as people aged 65 and older but know that people self-identify at varying ages after 50 years. Whether a person identifies as a senior at age 50, 65 or 90, as a population group, there is no other cohort with as large an age span.

As our population ages and people live longer, there will be more people living with age-related illness which will include cognitive conditions including dementias. While dementia is not considered to be a normal part of the aging process, the risk of developing dementia increases with age. According to the Alzheimer Society of Newfoundland and Labrador, there are more than 10,000 people living with dementia in the province, and this number is expected to grow to 14,000 by 2035, as our population ages. Dementias are progressive and people generally require significant assistance and support.

People living with lifelong cognitive concerns may have depended on help from parents or siblings. As they age, so too will the people around them which means new support for decision-making is needed. Support systems are rarely static.

Given the demographic profile of this province, it is therefore not unreasonable to assume that many people will require some level of decision-making assistance at some point in their lives.

What We Hear and What is Known

In addition to regular ongoing contact with seniors via mail, email or telephone, the Office of the Seniors' Advocate has met with well over 1,000 seniors throughout Newfoundland and Labrador during community consultation sessions. The seniors we have been listening to come from all socio-economic backgrounds, from wealthy,

independent seniors to the most vulnerable people in our society living in extreme poverty and wholly dependent on external assistance.

Many seniors in this province are concerned about being marginalized through ageist thinking, policies and programs. Seniors feel that too often negative stereotypes about aging taint perceptions. And while this is not unique to seniors, too often seniors are subjected to ageist attitudes and actions. While most negative “isms” like sexism and racism are globally denounced, ageism is too often regarded as less serious and, therefore, less important.

Seniors who are isolated, dependent on others, institutionalized, or have an impairment or disability live with greater risk of abuse, violence or disregard. Poor health and age-related conditions, such as dementia, can place a person at higher risk of abuse. Diminished cognitive capacity heightens susceptibility to being taken advantage of and maliciously manipulated.

Decision-Making as a Right

We all have times in our lives when we look for help to make decisions. Some people may want or need support in making certain types of decisions - supported decision-making. In other instances, if a person absolutely cannot make a particular type of decision, another person may do so for them - substitute decision-making.

Making decisions about our own lives, and having these choices respected, has been recognized as a human right.¹ Every adult has the right to make decisions about their life, the care and services they receive and the risks they are willing to take including people living with dementia or other cognitive conditions.

Supported decision-making aims to provide help and assistance for people with disabilities, in making decisions about their lives. The United Nations Convention on the Rights of Persons with Disabilities promotes supported decision-making as a way of respecting a person’s dignity and autonomy and protecting that person’s right to have assistance in making decisions if needed. Dementia is a major cause of disability and the World Health Organization has clearly identified that people living with dementia come within this Convention.²

A person is assumed capable unless proven otherwise through an assessment by a trained assessor. Assessing a person’s capacity should not be an all-or-nothing concept. That is, while a person may not have the capacity to understand how to manage their finances, for example, they may have capacity to make decisions about where they want to live. And a person’s capacity may change over time.

¹ United Nations. Convention on the Rights of Persons with Disabilities (CRPD). New York: United Nations, 2006. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

² World Health Organization. Global Action Against Dementia: Meeting Report. Geneva, 2015. http://www.who.int/mental_health/neurology/dementia/ministerial_conference_2015_report/en/

If a person's capacity to make decisions is limited, he or she should be supported with help to make their own choices wherever possible; they should be provided with all necessary information to do so.

It is important to note that just because a person may lack decision-making capacity (even with assistance), this does not automatically justify employing the help of another person or overriding the person's desires and preferences. And if substitute decision-making is employed, it should be "last resort" and monitored carefully to ensure that the person's best interests are honoured and that the process does not open the door to potential abuse.

For Consideration

The OSA has an extensive database of seniors' who wish to be informed and consulted on relevant issues. OSA has endeavored to promote government's work on this Decision-Making Framework and widely circulated the link to the questionnaire for seniors to provide feedback.

The OSA has heard from seniors who felt the explanation and information about the purpose of this Framework were not sufficient. Seniors have commented that they felt ill-informed and therefore their responses were not as knowledgeable as they might have been. Seniors felt that the questionnaire and short timeframe in which to respond was not adequate to truly be considered a thorough consultative process. Further, the OSA is concerned that organizations providing seniors' programs and services may not have been consulted and therefore the development of this Framework is missing their valuable input.

The OSA concurs with the above-mentioned concerns, as it was unaware of the planned development of this Decision-Making Framework until a letter from the Minister of Children, Seniors and Social Development was received on November 6, 2024, inviting the OSA to participate in this consultative process. The OSA ascertained the information provided and the nature of the questions was insufficient to provide a robust, informed response and requested a meeting with departmental representatives before providing this response.

The OSA offers the following for consideration:

- A person's decision-making ability must be presumed until/unless proven otherwise;
- The presence of a dementia or cognitive impairment without further assessment is not a valid reason to exclude someone from decision-making about their own life;
- Undertaking a capacity-assessment, where a person's right to make decisions is being measured, is no small task and must be afforded the highest level of diligence.

- Who will be tasked with conducting capacity-assessments? What will be the requisite skills and training? How will this be monitored? How will the competencies of the assessors be measured?
- Personnel responsible for assessing decision-making capacity must:
 - be thoroughly trained in the specific condition(s) the person being assessed is living with;
 - possess geriatric expertise if the person being assessed is a senior; and,
 - be well-versed in current approaches and processes of capacity assessment techniques;
- How will the assessors and their work be monitored on an ongoing basis?
- In instances where a person conducts capacity assessments infrequently, there is potential risk that the person could become out of practice and their skillset less honed. What plans will be in place to mitigate for this risk?
- Once in place, what will be the relationship between this Framework and existing documentation regarding decisions including, Advance Health Care Directives and Enduring Power of Attorneys? Would the new decision-making framework supersede existing documentation regarding a person's decisions?
- After an assessment of a person's decision-making capacity finds the person is capable of naming who will support their decision-making or become their substitute decision-maker, the person must be apprised of the process and personnel must be well-satisfied that the individual understands the choices and consequences of naming that person; how will they ensure the person is safe? person
- If a person is named to become a substitute decision-maker for another person, this action must be a decision of last-resort;
- Individuals considering taking on the responsibility of making decisions for/with another person must be apprised of accountabilities and guidelines to enable them to involve, listen to, and respect the views of the person, so as to best represent the desires of that person. Like the capacity assessment, this responsibility is extremely important;
- Will a provincial roster/register be in place to ensure individuals do not become decision-makers for a number of people and thereby heightening the potential risk of abuse? How will such a registry be monitored?
- It is important to include the person in all stages of a decision-making process, as much as they wish to be involved; active participation or kept informed of the process.
- A person's decision-making ability must not be considered to be all-encompassing; that is, a person's ability to make decisions in one aspect of life, must not automatically mean that a person lacks capacity to make decisions in all aspects;

- Accountability measures must be implemented to ensure the person's best interests are tantamount and decisions must be free from undue influence. A definition of what is meant by best interests is needed; and
- A person's decision-making capacity can change over time as a cognitive impairment degenerates or improves. A provision should be in place to re-examine and perhaps reassess a person's decision-making capacity as needed or as per a set schedule.
- How will seniors be consulted on this topic? Will there be a continuing education component before finalizing the framework to ensure seniors have the opportunity for informed input?

Decision-making is about the right to make choices for ourselves and that ability is placed in very high-regard by seniors. Considering the number of seniors currently living with a dementia or other cognitive concerns - and with this number anticipated to grow in the future - the OSA supports the development of a Decision-Making Framework. This Framework will ensure mechanisms are in place to protect seniors' rights to make decisions as they are able. However, given the short notice period on the currently proposed framework, and that consultations only consisted of an online survey with little detail, many questions remain for most senior serving organizations and seniors themselves.

The Office of the Seniors' Advocate thanks the Provincial Government for raising this very important issue and looks forward to further opportunities for community education, consultation and dialogue to inform the Decision-Making Framework and process.



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