Coalition of Civil Societies for Dementia

Coalition of Civil Societies for Dementia Parallel Report

for the

UN Committee on the Rights of Persons with Disabilities’

2nd and 3rd Review of Canada’s Implementation of the

Convention on the Rights of Persons with Disabilities

Contributing Organizations of Persons with Dementia and Civil Society Organizations:

Alzheimer Society of Ontario

Alzheimer Society of Montreal

Brainwell Institute

Canadian Centre for Caregiving Excellence

Canadian Coalition for Seniors’ Mental Health

Canadian Network for Prevention of Elder Abuse

Canadian Down Syndrome Society

McGill University

National Task Group on Intellectual Disabilities and Dementia

New Society Institute

Parkinson Canada

University of Waterloo

Reena

List of Abbreviations

■ CRPD – Convention on the Rights of Persons with Disabilities

■ DASD – Division of Aging, Seniors and Dementia

■ FPT – Federal-Provincial-Territorial (e.g., governments)

■ GDP – Gross Domestic Product

ID- Intellectual Disabilities

■ LTC – Long-term care

■ MAiD – Medical Assistance in Dying

- MAB – Ministerial Advisory Board
- OECD – Organisation for Economic Co-operation and Development
- OPD – Organization of Persons with Disabilities
- PHAC – Public Health Agency of Canada
- PTs – Provinces and territories

WHO – World Health Organization

INTRODUCTION

People living with dementia are the fastest growing population with disability in Canadian society. Canada's National Dementia Strategy, released in 2019, was an important milestone in recognizing the needs of people living with dementia and their caregivers, however, there continue to be fundamental human rights issues that remain unaddressed.

The Strategy states that actions taken within the Strategy should respect the human rights of those living with dementia and reflect and reinforce Canada's domestic and international commitments to human rights. Yet, without appropriate implementation, specific targets, measures, benchmarks, and timelines and a more explicit consideration of human rights, people living with dementia as a disability continue to experience significant discrimination and barriers to accessing and fully engaging in their communities while also reaching their fullest health potential.

Indeed, recent studies indicate rates of gender-based violence and elder abuse have increased dramatically since the start of the pandemic, as has an increasing trend in stigma and discrimination against people living with dementia. We reiterate the Civil Society Parallel Report for Canada to implement a rights-based approach to dementia, which includes a consistent framework for recognizing legal capacity, supports to receive an accurate and complete disclosure of their diagnosis and to receive the most autonomy-enhancing and rehabilitative options available to support equal access and participation.

We recommend that CRPD monitoring is directly linked to monitoring of Canada's Dementia Strategy, including benchmarking and indicators for reporting on progress in fulfilling the human rights-oriented objectives of the strategy.

ARTICLES 1 - 4: General principles and obligations

Dementia issues need inter-jurisdictional coordination: Responsibility for dementia implementation is divided among Federal-Provincial-Territorial (FPT) governments. The federal government has a role in developing the framework and coordinating national implementation, while the provincial and territorial governments are responsible for implementation within their jurisdictions.

Canada does have an FPT Coordinating Committee on Dementia, Interdepartmental Committee on Dementia and committee of people with lived experience of dementia and researchers Ministerial Advisory Board (MAB), referred to on occasion in the National Dementia Annual reports to Parliament and Evaluation Report of the Public Health Agency of Canada (PHAC)'s Division of Aging, Seniors and Dementia (DASD) Activity. However, the extent to which these forums meet, have the ability and mandate for implementation of the National Dementia Strategy is unclear. As noted in the Civil Societies Parallel Report, they do not generate concrete measures, benchmarks, or timelines for implementation. PHAC's own audit of dementia activities notes "Governance tables were established by DASD to help with the development and implementation of the national strategy. These tables were essential to the development and launch of the National Dementia Strategy and must now be used to support the implementation of the objectives set out in the Strategy. There are opportunities for these tables…to support PHAC in developing a plan and identifying priorities for its future role in implementing the strategy".

While PHAC does participate in reporting on the WHO Global Dementia Observatory, there is a lack of coordinated data and implementation, particularly on the crucial pillar of care in the Dementia Strategy. General lack of coordination causes gaps in legislation, policies, and practices, resulting in people living with dementia experiencing different legal protection, access to services and social inclusion depending on where they live in Canada.

Recommendations to Canada:

Enact a comprehensive national action plan to implement the National Dementia Strategy in coordination with PTs and with involvement of diverse dementia communities. The plan must include specific targets, measures, implementation benchmarks, and timelines along with reporting requirements and accountability.

Ensure that CRPD monitoring is directly linked to monitoring of Canada's Dementia Strategy, including benchmarking and indicators for reporting on progress in fulfilling the human rights-oriented objectives of the strategy.

Work with diverse dementia communities to identify and reform laws, policies, programs, and services that do not comply with the CRPD and National Dementia Strategy's human rights approach to dementia.

ARTICLE 5: Equality and non-discrimination

We reiterate the Civil Society Parallel Report - Canada's National Dementia Strategy includes human rights as a primary principle underpinning the strategy, in addition to Canada's Constitution, and FPT human rights laws that prohibit discrimination on the basis of disability. However, this is not implemented or enforced.

People living with dementia regularly experience discrimination, stigma and barriers to participation in all aspects of society with an increasing trend: From public opinion polls, nearly two in three Canadians agree that people living with dementia generally face a lower quality of life than people without dementia (a substantial increase from 2020). They also agree that people have negative assumptions about the abilities of people living with dementia (83%), that people living with dementia are usually perceived as needing others to make most of their decisions (80%). Only 43% feel very comfortable interacting with a person living with dementia (down from 50% in 2020).

In general, only 27% feel people in their community are knowledgeable, respectful, and supportive of people living with dementia, 75% have never heard of dementia-inclusive communities or know of any plans for their community to become one. Only 41% of Canadians agree that people living with dementia are sometimes able to continue working for years after the onset of symptoms, which has worsened since 2020 polls. Canada specific data on the detailed stigma and discrimination experienced by people living with dementia is extremely limited, but recent global reports show that 88% of people living with dementia report experiencing discrimination in 2024, up from 83% in 2019 that is further compounded when there are co-occurring conditions.

Recommendations to Canada:

Implement the principle of participation as outlined in the CRPD, ensuring that people living with dementia are actively involved in developing and implementing policies that affect their lives. This includes their participation in decision-making processes at all levels, from local community initiatives to national strategies.

Take appropriate steps to ensure that reasonable accommodations are provided to people living with dementia, including adaptations in healthcare services, social services, employment, and community facilities to ensure equal access and participation.

Ensure that all laws, policies, and practices in Canada explicitly prohibit discrimination on the basis of disability, including dementia.

ARTICLE 6: Women and disability

Of the 747,000 Canadians living with dementia, approximately 64% are women. Women represent the majority of both those living with dementia and their informal caregivers, bearing a disproportionate caregiving burden and face intersecting challenges that reflect systemic inequities. For older women, structural violence and functional misogyny worsens as they get older, leading to increased vulnerability to violence and abuse. Intersections with race, ethnicity, ability, sexual orientation, status, create additional inequities, though supports and data are lacking. Women living with dementia often experience stigmatization, compounded by their gender, which can result in delays in diagnosis, inadequate support, and exclusion from decision-making processes. Indigenous women living with dementia encounter additional systemic barriers, including limited access to culturally appropriate educational and health resources and a lack of awareness about their rights under the Convention.

The unpaid labor of caregiving is projected to grow significantly: with over one million caregivers expected to provide the equivalent of 690,000 full-time jobs by 2050. The indirect labor market impact of women serving as informal caregivers is projected to lead to a GDP loss of $118.6 billion.9 When combined with costs related to treatment, living arrangements, and other indirect factors, the total annual economic burden on women is expected to reach $274 billion by 2040, a threefold increase compared to 2012. Caregiving for dementia is both emotionally and physically demanding, and caregiver distress has risen sharply in recent years, with nearly two-thirds of caregivers reporting significant distress. Fewer than half feel equipped to provide the necessary care, a decline from 57% in 2020.

Recommendations to Canada:

Implement measures to ensure that women living with dementia have the full and equal enjoyment of all human rights and fundamental freedoms. This includes addressing the systemic inequities and intersecting forms of discrimination they face, such as gender-based stigma and lack of access to culturally appropriate resources.

Develop dedicated measures and training to support older victims and survivors of violence including expanding access to shelters specifically for older victims of family violence, gender-based violence and elder abuse

Develop targeted policies to support informal caregivers. This could include expanding access to respite care services, providing financial support for unpaid caregiving roles, and creating more flexible workplace policies for female caregivers as well as considering the unique challenges of young caregivers.

Address the significant economic burden on women resulting from caregiving and the indirect costs associated with dementia care. This can be achieved through policies that support caregivers, such as tax credits, subsidies for care services, and initiatives to reduce the GDP loss projected due to caregiving responsibilities

ARTICLE 10: Right to life

Despite clear evidence that palliative care is beneficial in improved quality of life at the end stages, better symptom management, support and reduced hospitalizations, patients living with dementia are the least likely to receive it (39%), compared to patients with cancer (77%). In general people living with dementia are also less likely to be referred to palliative care teams, prescribed fewer palliative care medications or denied access to hospice care. With adoption of Track 2 for Medical Assistance in Dying (MAiD), and recommendations for access to MAiD through advance directives, the right to life on an equal basis with others may be further undermined for the growing population of Canadians living with dementia.

Stigma about living with dementia is increasing: As the recent PHAC survey shows, in just 3 years there has been a significant increase (63% compared to 49% in 2020) among Canadians of those worried about developing dementia. A majority of Canadians indicate they support advance directives for MAiD, which could provide for a person make a directive that on certain conditions, and when they are no longer able to consent to MAiD, a substitute decision could be made by a physician to administer a substance to terminate the person's life. In the absence of broader public dialogue, the growing support for MAiD advance directives for persons diagnosed with dementia could be reflective of the growing stigma about living with dementia and cognitive disabilities.

Recommendations to Canada:

Prior to any further expansion of MAiD eligibility criteria, there must be an extensive public and policy dialogue in Canada about how to respond to the growing need in Canadian society that is coming with the aging of the population and the continued and deepening social and economic marginalization of many groups.

Investigate and fully address the suffering that is causing persons with dementia to seek MAiD including consideration of the social determinants of suffering, access to alternative options and care such as palliative care and what the range of responses should be consistent with the recognition of the right to life on an equal basis.

Establish an effective and independent monitoring mechanism to track use of MAiD by people living with dementia.

ARTICLE 12: Equal recognition before the law

We emphasize and reiterate the conclusion of the Civil Society Parallel Report that Canada has not complied with the 2017 Concluding Observations calling upon it to create a consistent framework for recognizing legal capacity and the supports needed to exercise legal capacity. It is vitally important that Canada take steps to create this framework and ensure strong engagement and participation of persons living with dementia and the broader dementia community in its development.

The lived experience of individuals with dementia indicates that, with appropriate supports, they can make and guide decisions. However, many have been denied the necessary supports and legal recognition to maintain, develop, and demonstrate their decision-making capabilities. The predominantly cognitive test for determining legal capacity continues to discriminate against persons living with dementia, undermining their right to decide on an equal basis. While safeguards are necessary, they should be designed to prioritize decision-making supports as the first response to ensure that the least intrusive and most autonomy-enhancing options are available for people.

People with Intellectual Disabilities (ID) have had longstanding issues related to their legal capacity. While in some jurisdictions a framework for supported decision-making is recognized, the diagnosis of dementia has served to further restrict any recognition of legal capacity.

Canada's legal, policy, and practice framework for legal capacity must deliver on a foundational principle of Canada's Dementia Strategy: the rights of people living with dementia to make their own decisions.

Recommendations to Canada:

Deliver on the recommendation to develop a consistent FPT framework for protecting and promoting the right to equality in legal capacity without discrimination based on disability. Fully engage people living with dementia and the broader dementia community in the development of this framework.

Systematically assess the current legal regimes regulating legal capacity to identify systemic cognitive accessibility barriers preventing people living with dementia from maximizing their right to decide all areas of life.

Adopt into legislation a decision-making capabilities approach to legal capacity, to replace the predominant and discriminatory cognitive/functional approach. This alternative must focus on identifying the decision-making supports a person needs to maintain and developing their evolving capabilities in ways that maximize their autonomy.

Work with dementia community support providers local-to-provincial/territorial-to-national/pan-Canadian to develop and demonstrate proactive community-based decision-making support systems that assist people in maintaining and developing their evolving capabilities in ways that maximize their autonomy.

ARTICLE 25 – Health

As reiterated in the Civil Society Parallel Report, Canada's public health system is under strain. The core services required by people living with dementia and their caregivers, from primary care to home care and LTC have been chronically underfunded for years,, or do not exist in an equal access leading to significant consequences for those living with dementia and their caregivers.

The average wait time for a diagnosis of dementia in Canada in 2019 was estimated at 21 to 28 months, compared to a measure of weeks for other life-limiting diseases. This wait time is expected to grow exponentially due to systemic gaps – limiting people's ability to get timely access to early interventions, treatments and community supports that can slow progression of the disease, support planning and improve quality of life.

The attitudinal stigma surrounding dementia in Canada significantly impacts the disclosure of a diagnosis, referral processes, and access to dementia care, exacerbating the already strained public health system. Healthcare providers often hesitate to communicate a dementia diagnosis directly to the individual due to fear of causing distress which can lead to delayed or incomplete disclosure. Some delay disclosure entirely due to stigmatized view of the quality-of-life post-diagnosis., This stigma results in self-stigma, where individuals internalize negative attitudes and may avoid seeking help or hide their symptoms, further complicating the diagnosis process. These are all compounded for those with young onset dementia and those with ID. For people with ID, the lack of awareness/knowledge on diagnosing dementia for

a person with ID leads to diagnostic overshadowing - either attributing changes the person is experiencing to the disability - or in the case of people for Down Syndrome in particular -diagnosing dementia without a full assessment to rule out other causes for change. The lack of awareness and negative attitudes among healthcare professionals create barriers to referral and access to specialized care; for instance, only 35% of family doctors report feeling well prepared to manage dementia in the community.

The underfunding and lack of community-based clinics with interdisciplinary teams mean many people living with dementia do not receive timely access to early interventions, treatments, and community supports, with 43% having a home care assessment completed within six months of diagnosis and only 57% receiving home care overall. For those with ID who experience dementia at a younger age, they

are often excluded from assessment, care and support due to not meeting age eligibility37. This stigma and lack of support after diagnosis can lead to social isolation, depression, and a loss of self-worth.

Recommendations to Canada:

Adopt a rights-based approach to diagnosis and treatment of dementia in which individuals have a right to make an informed decision based on a complete disclosure of the diagnosis and treatment options

Enact a comprehensive national action plan to implement the National Dementia Strategy with targets in coordination with PTs to create pathways of dementia care through the health system that support timely access to the full range of services and supports that promote autonomy

Implement pathways of care for dementia through the health system with coordinated supports from diagnosis to death

Implement national measures to train front-line healthcare professionals in a rights-based approach to care of people living with dementia

ARTICLE 28: Adequate standard of living and social protection

The COVID-19 pandemic, particularly in LTC homes, highlighted the systemic failures that disproportionately affected individuals with dementia, who are especially vulnerable to both the virus and inadequate care. In Canada, LTC homes accounted for 81% of all COVID-19 deaths during the pandemic, with many of these deaths occurring among residents with dementia. Canada experienced one of the highest proportions of COVID-19-related deaths in LTC among OECD countries, exposing critical systemic issues, including chronic underfunding, inadequate staffing, outdated infrastructure, and insufficient infection prevention protocols.

In response to these challenges, the Royal Society of Canada has called for a “Safe Long-Term Care Act” to establish federal standards for care quality. This act would aim to ensure long-term investment, workforce stabilization, and better policy alignment between federal and provincial governments. It also calls for significant reforms to address the gaps in care that were exposed during the pandemic, with an emphasis on improving the living conditions and safety of vulnerable populations, including those living with dementia.

Of note, the negative impact of care in large settings for people with ID, has been well documented and resulted in deinstitutionalization across Canada. Similarly, the vast majority of people living with dementia have expressed wanting to remain living in their communities, however, 87%% of people in LTC have a form of cognitive impairment. A focus on community and home care supports as an essential investment are equally paramount to ensure that people living with dementia have access to the adequate care and protections guaranteed under Article 28 of the CRPD.

Recommendations to Canada:

Adopt the Royal Society of Canada's recommendation to introduce a "Safe Long-Term Care Act." This legislation would set national standards for care quality in LTC homes, focusing on workforce stabilization, adequate staffing, and necessary infrastructure upgrades.

Improve policy alignment between federal and provincial governments to ensure that LTC reforms are cohesive and effective across all jurisdictions. This includes establishing clear, enforceable guidelines for infection prevention, upgrading infrastructure, improving living conditions and measurable quality of care.

A focused investment in home and community care supports to provide equitable access to a range of quality care options

ARTICLE 31: Statistics and data collection

Canada is an active participant in high-level data collection on the status of the National Dementia Strategy through the WHO Global Dementia Observatory reflecting a commitment to tracking implementation of the dementia strategy. However, as noted in the Observatory, gaps in disaggregated data collection on key areas such as diagnostic rates, community interventions, treatments, use of MAiD, rehabilitation supports and the barriers faced by individuals with dementia—particularly young-onset dementia—highlight critical deficiencies. Additionally, there is limited data on the employment and health impacts on caregivers, and significant gaps exist in data collection regarding adults with ID across domains such as housing, health, and family caregiving.

This lack of coordinated data collection, particularly on the crucial pillar of care in the Dementia Strategy has significant impact on the ability to inform policies and programme for people living with dementia and establishing targets. This gap is even further exasperated for those living with young onset dementia with little data available on employment impact. Through the National Dementia Strategy, a surveillance unit has been established, however this data is not fully available in an accessible way to persons living with dementia.

Recommendations to Canada:

Establish a centralized, accessible database that provides regular updates on essential dementia-related statistics aligned with key outcomes of the National Dementia strategy implementation, ensuring data is disaggregated by province, age, gender, socioeconomic status, race, ethnicity, and disability.

Mandate the collection and reporting of data that examines the intersection of dementia with gender, abuse, race, ethnicity, disability, and socioeconomic status.

Incorporate healthcare learning systems with research and data collections as core components of pathways of care for dementia

ARTICLE 33: National implementation and monitoring

We strongly affirm the finding of the Civil Society Parallel Report that "There is a stark lack of coordinated implementation and monitoring of the CRPD at the national, provincial, and territorial levels, and with First Nations, Inuit, and Métis peoples."

Moreover, we want to stress that monitoring and implementation of the CRPD must be coordinated with monitoring of Canada's Dementia Strategy, which is a rights-based strategy to be guided by a human rights lens and consistent with Canada's international human rights obligations.

We strongly support all the recommendations of the Civil Society Parallel Report with respect to Article 33 and emphasize the full engagement of persons living with dementia and the broader dementia community.

Recommendations to Canada:

In accordance with article 33(2), diverse communities of persons with disabilities and OPDs, including persons with dementia and the organizations that represent them, must be involved in all aspects of a permanent intergovernmental coordinating and monitoring mechanism.

Ensure that CRPD monitoring is directly linked to monitoring of Canada's Dementia Strategy, including benchmarking and indicators for reporting on progress in fulfilling the human rights-oriented objectives of the strategy.

Provide sufficient, sustained funding to ensure that persons living with dementia can effectively participate, along with their representative organizations.

In its future reporting to the Committee on the Rights of Persons with Disabilities, ensure that data is dis-aggregated to point to progress on achieving the rights of persons living with dementia, one of the fastest growing demographics in Canadian society.