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The Experiences of social exclusion and inclusion among people aging with neurodiversity and their families

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Context and background of the research project

People aging with neurodiversity (NDOA) and their family caregivers (parents and siblings) often face significant forms of social exclusion, including ableism, sanism[1] and ageism. These interrelated oppressions create unequal conditions that limit people's opportunities for inclusion and belonging. Among the challenges faced by NDOA, previous research has highlighted that NDOA and their caregivers often live below the poverty line, largely the result of low levels of education and high unemployment, and rely heavily on government transfers. Other studies have highlighted the fact that NDOA require more care than other groups of disabled people, and that this care is mainly provided by the immediate family. While aging is a concern for people with ND, it also represents a significant challenge with respect to the presence and availability of family caregivers whose own aging places care arrangements and social connection at risk. Furthermore, limited housing options for NDOA and the lack of social opportunities are major obstacles to the social inclusion and well-being of these people and their aging caregivers.

It is difficult to estimate the number of people with neurodiversity in Canada, since the only statistical tool available on the subject (the Canadian Disability Survey) collects data related solely to developmental conditions (such as intellectual disability). However, the aging of the population and the medical advances of recent decades have led to an increase in the number of NDOA overall.

The aging of people with neurodiversity is therefore a contemporary public policy issue that deserves to be studied. Our research has highlighted significant challenges faced by NDOA and their family caregivers, while at the same time proposing solutions that can be implemented rapidly. Our project calls upon decision-makers to take immediate action on this important issue. Our core message is that governments should aim to better safeguard the rights and dignity of NDOA and their family caregivers.

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[1] While ableism and ageism are more broadly understood in the wider population, sanism has not yet received full recognition. Sanism refers to the systemic discrimination against individuals perceived as having a mental illness or cognitive impairment. This discrimination is based on several factors including stereotypes about neurodiversity.

This could be done by more closely following the principles of the international conventions to which the province has already signed on.

Research objectives and methodology

Our project sought to deepen our understanding of the experiences of aging with neurodiversity (ND) from the perspectives of neurodiverse older people themselves, their families, and the service providers who support them. We placed specific attention on the realities and challenges associated with accessing *housing* and *social supports (both formal and informal)* within the wider range of health and social services available to NDOA and their caregivers. Our objective was to document experiences in negotiating and challenging social exclusion and to make recommendations for change. In so doing, we hope to contribute to the development of inclusive policy and practice across sectors that foregrounds the experiences of, and agency enacted by, NDOA and their family caregivers.

We used the *intersectional life story narrative approach* (Brotman et al., 2019) first introduced as part of the *Intersectional Life Course Perspective (ILCP)* (Ferrer et al., 2017) as our research methodology.

This approach focuses on the contexts in which people live and incorporates complexity and diversity into data collection and analysis. The approach integrates 4 interrelated 'steps': 1) key life events and their meaning, 2) linked lives (informal and formal relationships), 3) identity, social location and processes of othering, and 4) oppression and agency (the ability to act and to decide), including attention to both resilience and resistance strategies used to push back against oppression. Our narrative approach emphasized 'co-creation' as a central component of research design. We included both conversational interviewing and life/care line drawings[2] to enhance opportunities for shared meaning-making and accessibility in the research process and outcomes.

63 participants from Montreal and Quebec City, including PHAs aged 45 and over (n=21), family caregivers (n=15), and public and community service providers (n=27) were interviewed. The interviews

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[2] Engaging in the life/care line drawing was a choice. Not all participants chose to engage in the co-creation of a drawing.

took place between 2021 and 2024. Each PVSND and family caregiver participated in four meetings, including conversational interviews and the creation of individual portraits validated by the participants. Semi-structured interviews with service providers were also conducted to obtain their perspective on the challenges facing PVSND and their public policy recommendations. A thematic analysis was conducted with all three groups of participants to identify common themes. Finally, an analysis of public policy and MSSS data was carried out to link PVSNDs' personal narratives to policy discourses and practices.

Principal findings

The research results are divided generally into three distinct categories:

1. Cocreation of life story protraits

Life portraits of 21 people aging with neurodiversity (NDOA) and 15 caregivers were developed, illustrating the unique challenges and strengths of the participants. Three portraits included in the appendices of the research report illustrate the richness and depth of the testimonials.

2. Thematic analysis

Ten main themes emerged from the thematic analysis: aging, caregiving, housing, mental health and addictions, abuse, lack of control over daily life, gaps and challenges in the health and social services system, parenting, the role of community organizations, and finally identity, agentivity, activities and pride. These themes are all addressed in detail in the thematic infographics available on the research project website.

Among the most significant findings were issues related to aging, family caregiving, housing and health and social services. With regard to aging, participants reported encountering significant obstacles related to the rapid decline of their social networks and access to health and social services appropriate to their realities. For example, many transitions are made without prior planning, in a context of urgency, often resulting in new traumas and challenges for individuals and those around them. These factors are amplified by the parallel aging of parents, who may themselves have health problems and access to few services adapted to their realities.

As for housing, participants deplored the lack of services to meet their needs. The use of inappropriate resources (intermediate and family-type resources, CHSLDs) rather than forms of support that encourage people to stay at home or develop their residential autonomy in the community is often synonymous with deprivation of freedom, loss of choice, and social isolation for PLWHA. In this sense, it is imperative to improve the supply of housing and services supporting the achievement of residential autonomy. We also need to enhance the quality of existing housing resources.

Finally, a recurring aspect of the discourse of all participants (PVSND, service providers and caregivers) is the difficulty of navigating services. For example, the fact that the health and social services network operates in silos came up in all our interviews. This affects the ability of PVSND to receive the services they need (for example, mental health and ID-TSA services don't talk to each other, and receiving services from one means being excluded from the other). Operating in silos also means that individuals' complex problems are often dealt with "piecemeal", without taking into account the need for comprehensive intervention. These silos are particularly important as people age, since autonomy and aging support services are not adapted to PLWHA, and ID-ASD service workers (for example) are not always trained to meet the needs of aging adults. It is imperative that government and community services be better linked, so that people can benefit from a comprehensive approach to meeting their needs.

3. Analysis of public policies and Quebec datasets on MSSS service use

Analysis of public policies and data sets reveals a fragmented approach to PVSND, creating significant barriers to their health and well-being, as well as to the quality and consistency of services provided by providers. A serious review of this approach is needed to improve the situation of PVSND and adequately support service providers.

Principal actions and solutions emerging from the study findings

Our final report presents some fifty recommendations that can be implemented by Quebec government ministries and agencies, as well as by community organizations and individuals working in the health and social services network. For the sake of clarity and brevity, here are a few key cross-cutting recommendations:

- **Place** people aging with **neurodiversity**, their families, and their allies working within community-based organizations at the **centre of practice and policy level decision-making processes**.
- **Conduct** an impact analysis focused on neurodiverse individuals, specifically accounting for the realities of NDOA, in all budgetary decisions and public policies in Quebec.
- Urgently **advocate** to guarantee universal access to (1) high-quality programs and services, (2) inclusive housing that responds to the needs and wishes of people aging with neurodiversity, and (3) comprehensive supports for social inclusion.
- **Ensure** that these programs and initiatives prioritize people's rights and dignity.
- **Address** the issue of parallel aging within public policies and front-line practice (notably in housing, home care, respite, and mental health).
- **Improve** training initiatives targeting service providers across sites and sectors of care that focuses on the intersection of aging and neurodiversity.
- **Reduce** silos in the provision of services in favour of intersectoral and interdisciplinary knowledge-exchange and put specialized multidisciplinary and inter-professional teams in place in every region of Québec.
- **Create** an independent inter-ministerial structure in order to collaboratively address all issues relating to disability, neurodiversity, and aging in Québec.