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

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Part A – Research context.

1. Background.

People aging with neurodiversity (ND)[1] and their family caregivers represent communities that have faced significant social exclusion over the life course. Interlocking oppressions including but not limited to, ableism, sanism[2], and ageism, are implicated in creating unequal social conditions that limit people's opportunities for inclusion and belonging. The theoretical framework informing this study integrates the mutually reinforcing concepts of **social exclusion** (Billette et al., 2012; Grenier & Guberman, 2009) and the **intersectional life course** (Ferrer et al., 2017; Brotman et al., 2019)[3]. The explicit integration of these theoretical concepts facilitates an understanding of the complex ways in which relational, communal, institutional, and governmental forces shape experiences over the lifetime, and sheds light on the resulting precarious living conditions among those subject to social exclusion.

Presenting an accurate picture of the number of people with disabilities in Canada is challenging. The Canadian Survey on Disability (CSD), undertaken by Statistics Canada every 5 years, is currently the standard national source of population data available to researchers and policymakers. Unfortunately, the CSD dataset includes only those identified as having a developmental disability and so these data do not capture the full diversity of people living with ND. Nonetheless, they can provide some insight into overall prevalence rates for the purposes of planning. According to the most recent CSD 2022 (Statistics Canada, 2023), 27% of people aged 15 and over reported having a disability, with 41% of this group reporting a severe or very severe disability. By comparison approximately 1.5% identified a

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[1] 'Neurodiversity' (ND) is a term developed by disability rights communities that has started to gain recognition in sites and sectors of health and social care, and within the wider public discourse. Neurodiverse people include those living with intellectual disability, developmental disability, autism, cerebral palsy, fetal alcohol spectrum, Down syndrome, among other conditions. We sometimes use terms such as neurodisability, neurodivergence, neurodevelopmental, developmental or intellectual disability, or autism spectrum disorder in this section to respect the categories used in the documents sourced.

[2] 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.

[3] For a more detailed description of the interconnection between Social Exclusion and the Intersectional Life Course Perspective (ILCP), see Appendix 1.

developmental disability, an increase of 4% from 2017[4]. While the 2022 data reporting severity by disability type was not publicly available at the time of writing this report, previous research estimated that almost 73% of people with a developmental disability reported having a severe or very severe disability (Canada Mortgage and Housing Corporation [CMHC], 2010). Advances in medical care and public health practices have led to an increase in life expectancy among neurodiverse people (Janicki et al., 2008). As a result, it is expected that the rate of ND within the older population will continue to rise over the next decade (Dolan et al., 2021). Since reaching old age is a relatively recent reality in the lives of some neurodiverse people, we still know little about the impact of social exclusion and other health challenges on the aging experiences of both people living with ND and their families, many of whom are also aging (Brotman, 2021b; Milot, 2024).

While living with any disability creates challenges across the life course, aging with ND typically results in unique experiences of exclusion and precarity when compared to those with a physical disability alone, or those without any disability. For example, in 2018[5], it was reported that a staggering 90% of people living with developmental disability across a range of severity, lived below the poverty line (as compared to 28.3% of all people with severe disability) (Morris et al., 2018). This can be linked to low levels of educational attainment and significant un(der)-employment within the ND population (Canadian Association for Community Living [CACL], 2018). Further, people with a developmental disability were more likely than those without any disability to rely on government transfers as their major source of income (71.9% versus 18.7%) (Morris et al., 2018). Finally, it has been reported that people living with ND require the most hours of care when compared to those living with other forms of disability (Statistics Canada, General Social Survey, 2012). Much of this care is provided by close family

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[4] This figure should be read with caution and is likely an underestimate of the population given the limitations of the CSD data parameters since people under 15 years of age, residing on a First Nation reserve or in 'collective dwellings' such as institutional residences are not included in the sample.

[5] Some of the statistics reported here are based on information from the CSD 2017 because detailed figures by disability type collected in the CSD 2022 were not generally made available by Statistics Canada at the time of writing.

members (notably parents and siblings) regardless of living arrangement (Janicki et al, 2010). 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 (Hole et al., 2013; Mailik-Seltzer et al., 2011, Milot, 2024).

Literature has demonstrated that housing and social support are important areas of concern. This has also been raised by disability rights activists themselves. Limited housing options and a lack of opportunities to engage socially have been identified as major sites of social exclusion, and as a significant obstacle to the health and well-being of neurodiverse older adults (NDOA) and their aging family caregivers (Bigby et al., 2011; Hole et al., 2013; Walker & Hutchinson, 2018). Decades-long wait lists for adapted housing has left NDOA, and their family members, in a state of crisis, with placement often being undertaken in a context of trauma (i.e. after the death or incapacity of a caregiver, or in the context of an emergency), so that the transition to housing takes place in a manner which incurs physical and mental health consequences among them (ASC et al., 2017). Given the fact that many people with ND also experience persistent mental health challenges (Einfeld et al., 2006; Brotman et al., 2021a), the impact of transition and relocation can be a significant challenge for individuals and their families, as well as for the service providers supporting them. Several factors increase the risk of housing instability, including a lack of appropriate housing stock, limitations in the capacity of health and social services to provide adequate support to people living independently, and lifelong experiences of poverty, underemployment, social inequality, and social isolation (Dickson, 2016; ASC et al., 2017). Residential resources have only recently begun to grapple with the intersections of aging and ND among their clientele and have cited a lack of integrated knowledge, intersectoral dialogue and exchange, and limited resources to provide specialized services as contributing to significant gaps in knowledge and service delivery options (Brotman et al., 2021b). Still, NDOA, their families, and advocates in both neurodiversity and broader disability-rights networks have time-and-again called for more attention to be placed on the considerable lack of financial and other resources, the lack of relevant, appropriate, affordable, and sustainable housing and support options, and the need for better policy and service integration across regional jurisdictions and sectors.

2. Objectives.

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.

3. Principal research questions.

Our principal research questions centred on the following:

- What are the life course experiences of people aging with neurodiversity and the family caregivers who support them? How do participants make meaning of these experiences? What strengths and challenges are made visible through their stories?
- What are service providers' perspectives on the realities and challenges facing people aging with neurodiversity and their family caregivers?
- What recommendations for change emerge from the stories and perspectives of people aging with neurodiversity, their family caregivers, and the service providers who support them?

Part B – Methodology.

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[6] to enhance opportunities for shared meaning-making and accessibility in the research process and outcomes. Life/care lines complemented the conversational interviews and were drawn by participants themselves or were co-drawn with researchers. Each line showcases the people, places, and events that are meaningful to participants. Care lines were used with caregiver participants and visually represented the relational nature of care. Finally, the research team created an intersectional life/care line as a visual-analytic representation of the life course that combined components from the drawings (when available) with both an indication of the institutions/organizations encountered, and adjectives highlighting identity strengths. All these lines were edited and validated by participants.

Recruitment and sample: In total, 63 participants were interviewed in Montréal and Québec City. This included 21 people aging with ND 45+ years of age[7], 15 family caregivers (parents and siblings), and 27 service providers from both the community and public sectors (see Appendix 2). We deliberately

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

[7] We have chosen 45+ years in recognition of "early aging" amongst NDOA, largely due to the combined impacts of biomedical complications of aging more common to some forms of ND and life course experiences of social exclusion.

chose a small sample size to prioritize in-depth insights and to derive unique portraits of the participants' lives. Interviews took place between 2021-2024, with a delay occurring in the early years of the project because of restrictions imposed by the COVID-19 pandemic. Advisory group members representing organizations across sectors were actively engaged in outreach and recruitment (see Appendix 3).

Interview process: We undertook 4 meetings with older adult and caregiver participants. Each participant engaged in an introductory conversation in which we discussed the consent and assent process (see Appendix 4)[8]. We undertook two conversational interviews with each participant, spaced at least one month apart. The analysis process consisted of re-storying the interview conversations and life/care lines into an individual 'portrait' (storybook). Every participant's portrait tells the story of the person from their perspective and using their own words (represented by substantive quotes from their interviews). Portraits were validated with each participant in a final conversation with them.

We simultaneously undertook semi-structured interviews with service providers to gain their perspectives on the realities facing older adults living with ND and their family caregivers, challenges in service provision, and policy and practice recommendations. Final thematic analysis consisted of working iteratively across the three participant cohorts to establish common themes emerging.

Textual analysis of policy: Finally, a textual analysis of policy-level data (Halperin and Heath, 2020), exploring the inclusion of NDOA in select policies using the Rights of Persons with Disabilities (UN-CRPD) document (United Nations, 2006) as an analytic tool, and an analysis of the MSSS "Rapports AS-485" (DI-TSA) longitudinal data set, were undertaken in year 3. The interpretation of policy-level data offered a bridge between personal accounts of aging with ND and policy discourses and practices.

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[8] Ethical approval was received by the CIUSSS-ODIM, (for recruitment via public sector services across regions (CIUSSS-ODIM and CIUSSS-CN) and by community organizations based in Montréal) and by the CERUL (for recruitment via community organizations in the Québec City region).

Part C – Findings.

Our findings are divided into 3 distinct overlapping areas: 1) co-creation of individual life story portraits; 2) thematic analysis of interviews, and 3) analysis of policy-level data.

1. Individual life story portraits.

Individual life story portraits of all 21 people aging with neurodiversity and all 15 family caregivers interviewed were developed. Each portrait attests to the unique realities, challenges, and strengths of our participants from their own perspectives and in their own words. While the space allotted for this report does not leave room to present all of these stories (4-7 pages each), 3 portraits have been included in Appendix 5 as an illustrative example of their power, richness, and depth.

2. Thematic analysis of interviews.

Our thematic analysis revealed 10 emerging themes that resonate across cohorts and regions. These are: aging, caregiving, housing, mental health and addictions, mistreatment, lack of control over daily life, gaps and challenges in the health and social service system, parenting, the role of community organizations in the lives of people aging with neurodiversity and their families, and identity, agency, activities, and pride. In this final report we will report on 7 of the themes that were considered most urgent by our participants and our Advisory Group members. Due to space limitations, we will only briefly touch upon the rich and complex findings in each theme area, however a more full accounting of subthemes and participant quotes which are tied directly to recommendations emerging on each theme are detailed in our infographics which can be found at www.creges.ca/en/aging-neurodiversity and which are included in booklet form as a separate file connected to this report.

Aging

Neurodiverse older adults (NDOA) experience aging like those in the general population. However, they can often face unique vulnerabilities due to a rapid decline in their social networks and barriers to accessing appropriate and integrated health and social services because of existing silos and a lack of specialized knowledge about the intersection of age and neurodiversity. Aging can bring about sudden changes or early onset medical issues that have an impact upon NDOA's well-being, their living situation or other life circumstances. NDOA interviewed in our study spoke about these unique challenges and transitions, including experiencing new limitations in what they can do, reduced opportunities for work, social, or recreational activities, facing the death of their parents and/or other loved ones, and feelings of uncertainty about the future and who will provide care. Aging and end of life were raised by NDOA as important topics for discussion in which they reflected upon what it was like to age in parallel with their parents. Even though many faced aging with uncertainty, they also shared stories of hope, with some participants proudly speaking about feeling young at heart.

In the back of my mind, I am worried about my health, in the back of my mind I am afraid of dying and you know it's not something I want to deal with right now... [with] aging comes depression, anxiety. Not to mention, fear... (Elisa, NDOA)

My mom died and I have no one to take care of me... well I do have someone to take care of me, but it's not the same. (Rosemary, NDOA)

I take care of my maman a lot. I do the housework, I do a bit of shopping because my maman ended up at the hospital, she has Alzheimer's. She is 93 years old. (Annie, NDOA)

Caregiving

Family caregivers play an extremely important role in the care of people living with neurodiversity (ND) throughout their lives. In our study we interviewed both parents and siblings. Whether the person they are caring for lives with them or somewhere else (like in a residential or long-term care resource), family caregivers are a vital link to well-being, inclusion, and system navigation. Family caregivers devote all their time and energy to ensure that their neurodiverse older relative to whom they provide support can live a life with meaning, contribute to making their own daily choices, and realize their goals and dreams. The commitment, dedication, and emotional connection demonstrated by family caregivers is reflected in the everyday care they provide in the face of life's ups and downs. Despite the many positive aspects of care, there are also many challenges experienced by caregivers that can lead to strain and significantly limit the time they have available to pursue activities, relationships, and goals of their own. Although challenges are well documented, they are nonetheless, not always well recognized in the health and social service system. This results in caregivers having to remain vigilant and advocate for their own - and their neurodiverse relative's - needs to be met. System-wide service gaps and a lack of communication with service providers are among the most common concerns of caregivers. Parallel aging, the phenomenon whereby people with neurodiversity and their family caregivers, particularly parents, are aging at the same time, was the central finding of our theme on caregiving. As people age, challenges shift and can become amplified. The consequences of parallel aging can put stress on care capacities, care arrangements, and caregiver health and well-being.

When we were young like you, we needed our weekends to rest. After, when my son was hospitalized, I said "look, I will no longer exist, but I will bring my son back home". And our life became monotonous. At a certain point you habituate yourself. And you lose contact with everyone, whether you like it or not. (Alessia, mom)

We are worried because if ever we leave this world, we will leave one day, we are getting older every day, will they be able to manage? We have no family here, no-one. (Blanche, mom)

My husband and I were looking forward to being able to travel, we wanted to go do things that other retirees do, but we can't. So, we're not exactly the happy retirees that we would like to be. (Clara, sister)

Housing

Social inclusion in housing for NDOA and their family caregivers is crucial for promoting overall well-being and quality of life. However, many still face obstacles. Research and advocacy groups have pointed time and again to the crisis in housing for people aging with neurodiversity. Recent policy initiatives at federal, provincial, and municipal levels have not improved the situation. These obstacles include; inaccessible housing options, limited support services, and discriminatory practices at all levels. All of our participants spoke about the many untimely and unwanted transitions NDOA experience, the long wait lists, concerns about the quality, accessibility, and affordability of housing options in the context of privatization, a lack of control over daily life in collective settings, a lack of specialized housing and services for people with co-occurring mental health and behavioural challenges resulting in inappropriate and often long-term psychiatric hospitalization, unclear strategies of policy implementation, early entry into long-term care, unclear use of restraints, and persistent navigation challenges. There is an urgent need for collaboration to achieve housing justice so that people's inclusion, dignity, and self-determination are guaranteed.

We have parents who are in their 80s and they put their adult child on a waitlist 10 years ago for residential services and they're still not called off the waitlist. But if an emergency happens, they will be prioritized at that time (Lily, service provider)

It hurts so much that I'm here [CHSLD], you know I like to do some things on my own… I don't know why I'm here. (Rosemary, NDOA)

This place gives me a roof over my head [but]…getting older living in a group home... it's harder because you have to have the food that they want. (Johanne, NDOA)

Mental health and addictions

Many people aging with neurodiversity (ND) experience mental health challenges. Some have faced challenges for most of their lives (persistent), while others only experience these challenges from time to time (episodic). Aging can sometimes worsen existing challenges or contribute to the development of new challenges. The issue of addictions among people living with ND is not well documented. Both issues: mental health and addictions, are *interconnected*, and the lack of recognition and inclusive supports are shared and common problems. The impact of life-long social isolation and stigma can result in significant mental health challenges as people age. Such issues as over/under prescribing of medications, mis/under/over diagnosing of mental illness, a lack of specialized knowledge among both rehabilitation and mental health providers, restrictive eligibility criteria, inappropriate or extended psychiatric hospitalization due to limits in specialized services, and increased risk of interactions with the criminal justice system, were all issues brought up in conversations with all 3 cohorts. NDOA are even more likely to have experienced early life psychiatric hospitalization (before the movement for de-institutionalization came into effect) and so they face unique mental health challenges stemming from that experience. Unfortunately, the long-lasting mental health impacts faced by people with ND as they age are largely ignored because there is very little support mobilized to help people process this early life trauma. Despite all these challenges, NDOA demonstrate courage and resilience when facing mental health and addiction challenges, especially considering the significant silos and barriers that exist within mental health and addictions services. Community organizations offering social and recreational programs are an important resource for supporting the mental well-being of NDOA.

You know, I think people have been consistently socially excluded, are living in difficult financial conditions, often living in really inappropriate housing conditions and so, unfortunately if you have that pattern for a long time, at some point that might lead to anxiety and depression. (Stephanie, Service provider)

I don't like the hospital… reminds me of a prison (Lisa, NDOA)

There are fewer and fewer resources, it costs more and more, more and more the state shrinks, and so our small world of neurodivergence with mental health issues, will they get more resources? Sadly, the prognosis is not good. (Thomas, Service provider)

Mistreatment

Mistreatment is a complex issue that can take many forms. Mistreatment can be physical, psychological, emotional, financial, sexual, and systemic/institutional. It includes more subtle everyday gestures like ignoring someone, laughing at them, or denying their rights to make choices and participate equally in activities they enjoy. Mistreatment can also be more direct, as in all forms of violence and intimidation. Neglect is a form of mistreatment that often goes unrecognized. Many NDOA have experienced mistreatment throughout their lives. Mistreatment has long-lasting effects on physical and mental well-being, self-esteem, and relationships. It can make it harder for neurodiverse older people to trust others. Older adults and their caregivers with whom we spoke shared experiences of mistreatment in childhood homes, in schools, in intimate partner relationships, in care residences, in workplaces, in services, in the justice system, and in the broader community. Although participant stories highlight the frequency of experiences of mistreatment in the lives of NDOA, they also demonstrate how people resist, challenge stereotypes, and use their experiences to help others.

Intimidation is very heavy amongst our people, I don't know anyone who hasn't been intimidated because of their disability, their slower pace, their physical appearance. They have all experienced bullying at every age. As a result, they can be more submissive, less assertive. They won't say, "Well, that hurts me what you say or what you do." They will just swallow it. And they can end up with behavioral problems, manifesting through signs of anger, physical violence towards others, as if reproducing what they experience. (Iceberg, Service provider)

He [dad] used to call me a ghost, "go put the ghost in the backyard". I don't know, he was mean, that's pretty mean, eh? my mom wished he was dead because he was beating us. (Batman, NDOA)

He was so thin. He weighed… I think he weighed 85 pounds. It made no sense. He ended up... there, in the hospital because he had pneumonia. It doesn't make sense to be so thin. It was like they didn't give him much of anything. (Marie-Thérèse, caregiver)

Lack of control over daily life

People living with ND struggle with being able to assert control over daily life. This situation persists, and often intensifies, as people get older. Agency (self-determination) can be restricted in many ways. NDOA in our study described experiences of controls and restrictions put in place by both service providers and family caregivers. Lack of control over daily life was especially salient among people living in congregate settings. Sometimes control measures were used to ensure cooperation, maintain order, or produce desired behaviour. At other times, they were put in place out of concern, with the goal of protection from harm. Unfortunately, controls can go against the wishes and choices of NDOA who expressed feeling frustrated, sad, angry, or resigned because of restrictions placed upon their finances, food, housing, activities, and relationships.

No drink, no drink, [they tell me]. I keep the drink [in my room], I've saved them up. Don't tell on me, eh?... [I'm] hungry in the night. They locked the room [kitchen] and I'm so mad. (Batman, NDOA)

When my brother was moved suddenly, when he arrived there, [RTF] he was in 1000% crisis. He did not want to be there… [and] if my brother wants to go out they don't let him, [but] a lot of the time his behaviour stems from him seeking his freedom. (Adora, Caregiver)

Gaps and challenges in the health and social service system

Neurodiverse older adults (NDOA) and their family caregivers (parents and siblings) face significant challenges when trying to access services across the life course. These challenges often intensify as people get older because of the many silos within the health and social service system that make it difficult for NDOA and their family caregivers to navigate complex sectors of care that are disconnected from each other (aging, disability, mental health, and physical health services) and in which professionals do not always communicate with each other. This leaves NDOA and their family caregivers feeling overwhelmed, isolated, misunderstood, and underserved. Service providers confirmed what NDOA and their family caregivers told us, highlighting how systemic challenges such as those related to limited intersectoral collaboration, long wait-lists, high staff turnover, and bureaucratic burdens contribute to the fragmentation of care. Family caregivers spoke repeatedly about being ill-informed and under included in care decisions because of the crisis nature of transitions that occur, particularly as people age and new health situations emerge. Service restrictions and inadequate funding means that there is a limited supply of integrated and specialized services tailored to the unique realities and needs of NDOA and their family caregivers. All participants agreed that though many NDOA have received good quality care from people they trust, the gaps and challenges in the health and social service system often overshadow all the good work that is being done by dedicated professionals on the ground. Our participants shared that something must be done at the policy level to rectify the many problems in the system.

> *What happens is, whether you like it or not, when we work with someone, we attach... we talk to them, we confide certain things... when there is a change, it's like you lose a friend. At one point in time, you continue to confide, but you lose that inclination to develop a friendship. I lost a lot of service providers who I was close to, and it hurts. They continue on with their lives, but it has a huge impact on me. (Audrey, NDOA)*

> *I think it is really at the intersection of "they are lacking in supports for people living with ND" and "they are lacking in supports for the aging population". It is a certainty that when you put these two issues together, the situation does not look good. They are at the intersection of two extremely vulnerable populations and for whom there is not necessarily a service offer that meets their needs.*
> *(Mélissa, Service provider)*

> *The system is not set up for older adults. They're very, very low priority, especially now that there is the mandate of 'one goal-one episode of service', versus like when it used to be more long term follow up. (Stephanie, Service provider)*

4. Policy findings.

In addition to the interviews conducted, our research team evaluated several recent Québec policy initiatives and extracted data from the MSSS "Rapports AS-485" completed by the "Services DI-TSA" of the CIUSSS/CISSS provincial network. Analyzing policy-level data can help us to better understand some of the current ground-level practices of public sector institutions, as well as shine a light on what is missing in the way governments understand a situation or act on a "problem". Similarly, exploring this data enabled us to confirm, at a high-level, some of the issues participants raised during their interviews. This section summarizes our policy-level findings (see Appendices 6 and 7).

Lack of Intersectionality in Public Policy Responses

An analysis of Québec's policies using the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) as an analytical lens demonstrated that the province tends to ignore intersectionality in its laws, policies ("politique"), and action plans. This was especially evident in the lack of explicit attention to neurodiversity within aging policies, and aging within neurodiversity policies. Unfortunately, these silos often end up creating policies that **do not account for the specific realities and challenges faced by NDOA**. This in turn creates significant challenges related to policy implementation and service delivery. Indeed, without specific policies geared towards NDOA, Québec's health and social services network, as well as other ministries, often do not adequately meet their needs. In addition, because no specific consideration is granted to this population, service providers are expected to meet their service users' needs without proper institutional support or resources, or even clear guidance on necessary adaptations. This situation is unfair to both individuals and workers and needs to change.

You know the thing with policy is, it is so far removed from the ground level that there are quite a few steps of management that exist between the policy, and you, and the actual client you never see [who is] receiving the services, meaning that some institutions will just keep their own culture, you know, and do whatever they're used to doing. (Marco, service provider)

Finally, Québec is lagging on the realization of its obligations under the UN-CRPD. The absence of reference to the UN-CRPD in policies is blatant, despite some of these documents using some of the Convention wording or ideas. While imperfect, the UN-CRPD is a useful tool for policy formulation and implementation. Québec needs to fulfil its commitment to the UN-CRPD more comprehensively.

Health and Social Services Ministry Datasets

An analysis of the MSSS "Rapports AS-485 - Services DI-TSA" of the CIUSSS/CISSS provincial network completed our policy analysis. While these datasets have limitations, as they only account for *individuals actively receiving services* in the network in any given year, they are still helpful to understand policy priorities and policy implementation.

In 2021-2022, **older adults with ID/ASD[9] 45+yrs represented 18,54%** (6609 people) of all adults with ID/ASD receiving specialized services in the MSSS (most were individuals with ID (90.7%)). This proportion is significantly lower than the proportion of individuals aged 45+ in the overall population (46,6%)[10]. This situation was made worse by the fact that over a 10-year period, there was **a significant decrease** in the number of NDOA receiving services in proportion to the total population receiving services. This **decrease is especially significant for individuals with ID**. There were 8962 individuals with ID in 2011-2012, whereas the number was 5995 in 2021-2022 (-33.11%). The bulk of the decrease is in the 45-64 category (-38.91%). Regarding **individuals with autism, there was a significant increase,** with the number served going from 371 in 11-12 to 614 in 21-22 (+65.60%). It is nonetheless concerning that the overall number of individuals aged 45+ being served has drastically decreased, with no information as to why, nor any indication of what followed.

With regard to housing and community living, in 2021-2022, most individuals with ID/ASD of all ages (60,69%) lived with their family (parents, siblings). However, **only 10.79% of adults 45+, lived with their family**. **33,31% lived in an "intermediate resource (IR)"**and **31,16% lived in a "family-type resource (RTF)".** The rest lived in other community or public sector resources, with a small number living independently with support.

Finally, an important datapoint identified was the global problem with waiting lists in the network, for which NDOA are at a **much bigger disadvantage.** In 2021-2022 there were **more cases closed than opened** for this group. For aging individuals with ID/ASD, the **wait time is longer** than for the entire group of those receiving services. For example, for **"services d'intégration residentielle" the wait time was 43,04% longer for those 45+.** In all service categories (work, housing, direct support), aging

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[9] Intellectualy disability/autism spectrum disorder

[10] Source: https://statistique.quebec.ca/vitrine/egalite/dimensions-egalite/demographie/population-quebec-selon-age-et-sexe?onglet=ensemble-de-la-population

individuals with ID received services more slowly than the average for the entire population. The situation is very similar for individuals with ASD, with a slightly faster access to direct services.

Both the policy analysis and dataset exploration reveal a patchwork approach to the situation of NDOA and to the services they might, or might not, receive. This approach is creating problems that need to be considered seriously, as it has an impact on the health and well-being of NDOA, and their families. It also can have an impact on the ability of service providers to do their work and to offer quality services in a consistent and satisfactory way.

1. Conclusion: Project relevance, contributions, and potential impact

Our work contributes to the growing body of knowledge on aging with neurodiversity. The innovative and participatory nature of our research provided an opportunity to develop a holistic lens, including the voices of people in their own words and paying homage to their unique and textured stories of survival and agency in the face of significant exclusion experienced over the life course. This approach created possibilities for a deeper understanding between researchers and research participants, and enabled participants to take pride in their participation, as well as in the sharing of their stories. This in turn highlighted the success of our work and our approach to knowledge creation and mobilization. We believe the use of the ILCP offered the possibility of finding balance between the presentation of the harsh realities of social exclusion and precarity while at the same time centring strengths and agency among participants. Finally, given our approach to accessibility and engagement with a wide array of audiences and in a manner that fostered intersectoral collaboration, we believe the trustworthiness and relevance of our findings have the potential to be far-reaching and impactful. The alliances developed with groups already engaged in advocacy will continue, as will our work with partners to ensure that the products emerging from our study (See Appendix 8) support their tireless efforts to safeguard the rights and dignity of NDOA and their families.

Part D – Recommendations.

Our interviews with participants and our policy analysis provided important insights on ways in which to improve the experiences of people aging with neurodiversity and their families. The following recommendations are grounded in the lived experience of participants, including NDOA, family caregivers, and service providers from both community and public sectors. These recommendations have been reviewed, revised, and confirmed by members of our Advisory Groups and represent the aspirations and wishes of the community and of our research partners.

Two main categories of change have been identified: those related to policy and those related to practice. While policy and practice have an intrinsically dialectic relationship, we have separated them so that the different actors in the field can quickly identify who is responsible for creating change, what they could do, and what changes might be needed. In some cases, recommendations englobe both policy and practice. The following table lists some of the most important recommendations identified during the research. For each theme that emerged, the table lists the related recommendations, whether they are tied to policy or practice (or both) and identifies the ministry or organization responsible for implementing change. This table is not meant to be exhaustive. Additional theme-specific recommendations are available in the thematic infographics published on the CREGES website and attached as a companion document to this report. We believe these recommendations are at the core of improving the experiences of aging and social inclusion of NDOA.

Limitations.

The most important limitation of our study relates to the context of our work during the COVID-19 pandemic. Undertaking research with marginalized and underserved communities was rendered more complex and challenging during the early years of the pandemic when the nature and extent of sanitary measures were at their peak. Our Advisory Group members were fully occupied with managing lockdowns while trying to remain in contact with their membership and had limited time to engage in project planning. The sites and sectors of care on which we had hoped to rely for recruitment were also struggling with significantly changed circumstances including the redeployment of staff to other sites. Sanitary measures in place also required our careful reconsideration of interviewing protocols, especially given the importance of meeting in person and unmasked with participants whose communication needs differ. In the end, we were required to make several amendments to our ethics protocol throughout this time period as we adapted to changes in pandemic conditions or extended our recruitment via new networks with organizations and/or professionals. Notably, it took us almost 2 years to identify a key person at the CIUSSS-CN willing to support a convenance approval process given the impact of the pandemic on their staffing and workload. Unfortunately, we only managed to identify 5/10 caregivers willing to be interviewed in Quebec City, despite recruitment efforts there. Feedback indicated that the reasons had to do with limited time and energy, particularly during the pandemic, when many respite and socio-recreational activities were temporarily shut down, requiring caregivers to be “on duty” 24/7. Finally, our recruitment strategy, though successful overall, did not reach NDOA with no connection to services or organizations (although some participants described having accessed services quite late in their life journeys). We conclude by noting that one of our ongoing preoccupations is how best to engage NDOA with limited or no capacity to communicate verbally or to read. We met with a few participants in this situation in our project. We adapted our strategies including; the hiring of research professionals who had experience working with the population, extending the number of interviews or contact hours with participants to adapt to their communication needs and/or to read their portrait to them, and/or putting more emphasis on the artistic component of data collection in order to enhance accessibility. We continue to think creatively about how to adapt our strategies to reach a greater diversity of NDOA in future projects.

Recommendation	Policy	Practice	Actor(s) responsible for change
Priority Cross-cutting Recommendations			
Place people aging with neurodiversity, their families and allies within community organizations at the centre of practice and policy-level decision-making processes.	X	X	All ministries and organizations
Conduct an impact analysis focussed on neurodiverse individuals, specifically accounting for the realities of NDOA, in all budgetary decisions and public policies in Quebec.	X		Québec government
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, and (3) comprehensive supports for social inclusion, that centre on people's rights and dignity.	X		Québec government Disability organizations
Address the issue of parallel aging among NDOA and their parents within public policies and front-line services (notably in housing, home care, respite, and mental health).	X	X	All ministries and organizations Disability organizations
Improve training initiatives on the intersection of aging and neurodiversity targeting service providers at all levels and across all sectors.		X	All ministries and organizations Ordres professionnels (e.g., TS, Barreau, Notaires)
Reduce silos in the provision of services in favour of intersectoral and interdisciplinary transfer of knowledge and put in place specialized multidisciplinary and inter-professional teams in all regions of Québec.		X	Front line workers in health and social services All ministries and organizations
Create an independent inter-ministerial structure to collaboratively address all issues relating to disability, neurodiversity and aging in Québec.	X		Premier of Québec
Aging			
Provide adapted and individualized care and support to NDOA considering their strengths, their changing realities and needs related to aging, and including their unique experiences of loss and bereavement.	X	X	All ministries and organizations
Develop new palliative and end of life care models that centre on making it possible for NDOA to receive services in the comfort of their own home/resource and provide training to support workers.	X	X	MSSS / Santé Québec
Ensure collaborative transition plans (short, mid, and long-term) with NDOA which respects their rights, thoughts, and wishes, and which includes the people that are important to them.	X	X	MSSS / Santé Québec
Caregiving			
Promote the recognition of caregivers as equal members of the ecosystem around NDOA and ensure that they benefit from resources that are specifically designed for them, including emotional, psychological, and financial support.	X	X	MSSS / Santé Québec Front line workers

Recommendation	Policy	Practice	Actor(s) responsible for change
Integrate prevention strategies into service delivery to move beyond a singular focus on crisis management (notably through the use of tools for advance care planning).	X	X	MSSS / CIUSSS|CISSS[11] | Santé Québec
Raise awareness about the unique challenges facing life-long caregivers of neurodiverse people, including the reality of parallel aging, and ensure the creation of specialized policies and services, including specialized respite services, that are tailored specifically to address needs in every region of the province.	X		MSSS / Santé Québec Disability organizations OPHQ
Ensure that measures in the Québec government action plan on caregiving (2021-2026) that specifically address caregivers to neurodiverse individuals (promising practices in caregiver assessment and diversified respite options) are inclusive of the realities and concerns of caregivers to NDOA.	X		MSSS / Santé Québec OPHQ
Housing			
Develop public housing models that enable NDOA to age in place, including those with complex and co-occurring conditions, and provide specialized training for individuals with complex needs.	X		Ministère des affaires municipales et de l'Habitation (MAHM) MSSS / Santé Québec
Guarantee a minimum number of housing units reserved for NDOA in all new social and affordable housing projects.	X		Federal government MAHM
Enhance oversight to ensure quality standards are met in all health and social services housing resources (i.e. re-implement random visits, impose sanctions and reinforce surveillance when problems occur or are reported).	X	X	MSSS / Santé Québec
Support the creation of alternative housing resources developed by individuals with ND and their caregivers by (1) centring housing policy decisions on their needs and wishes; (2) guaranteeing recurrent funding for organizations providing housing or accommodation; (3) redirecting funding from private housing resources to publicly or community-owned housing resources.	X		MSSS / Santé Québec OPHQ MAMH
Incorporate CHSLD in the MSSS reporting via the "Rapports AS-485 for Services DI-TSA", CIUSSS/CISSS provincial network.	X		MSSS / Santé Québec
Mental health and addictions			
Reduce diagnostic-based exclusion criteria to ease access barriers to mental health and addictions programs and services.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Train staff to counter misinformation, bias, and discomfort among mental health professionals.		X	MSSS / CIUSSS|CISSS | Santé Québec
Avoid automatic psychiatric labelling of people presenting with complex behavioural challenges.	X	X	MSSS / CIUSSS|CISSS | Santé Québec

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[11] When referring to CISSS and CIUSSS, we intend to include all relevant directorates: e.g., Déficience intellectuelle, Trouble du spectre de l'autisme (DI-TSA) et Déficience physique (DP); Soutien à l'autonomie des personnes âgées (SAPA); Santé mentale (SM).

Recommendation	Policy	Practice	Actor(s) responsible for change
Create specialized interdisciplinary teams in every CIUSSS/CISSS and develop specialized and trauma-informed support teams for people who have experienced psychiatric hospitalization.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Break the silos between services, ministries, and public and community-based actors by improving communication and collaboration, and by favouring an integrated and holistic approach to the life course of NDOA.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Increase funding for specialized community mental health and addictions services.	X		MSSS / Santé Québec
Mistreatment			
Ensure that mistreatment laws and policies are known to all actors in the health and social services sector, as well as with NDOA and their caregivers, including the right to make a formal complaint, and the obligation to report a situation of mistreatment.	X	X	MSSS / CIUSSS|CISSS | Santé Québec Ordres professionnels
Simplify and accelerate the complaints process and make it more accessible to service providers across the network of public and community sector services.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Prioritize interdisciplinary and collaborative interventions in situations of mistreatment (involving public sector service providers including educators and social workers, the Public Curator's office or other people acting as a curator/tutor, community sector service providers, families, housing resource managers, police, ethicists, etc.).	X	X	MSSS / CIUSSS|CISSS | Santé Québec Ordres professionnels Curateur public Police services
Ensure better monitoring of quality of life of NDOA who are represented by the Public Curator.	X	X	Curateur public
Lack of control over daily life			
Advocate to improve the social conditions that would support the full agency of neurodiverse older people.	X		Disability organizations OPHQ
Develop processes and practices that centre relational autonomy in public sector services, including in the Public Curator's Office.	X	X	MSSS / CIUSSS|CISSS | Santé Québec Curateur public
Gaps and challenges in health and social services			
Integrate a life course approach in all facets of service provision, ensuring long-term and continuous interventions and follow-up (i.e. through creating provisions to ensure 'intervenants pivot' maintain clientele across transitions in age, housing, needs, or service directorate); focus on a continuum of services and collaboration within and between public and community sector services.	X	X	MSSS / CIUSSS|CISSS | Santé Québec Quebec government and ministries
Remove barriers to access based upon strict diagnostic criteria.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Create integrated, intersectoral, and specialized services for NDOA and their aging family caregivers and include them in all aspects of decision-making and advance care planning.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Provide ongoing training on the unique realities and needs of NDOA and their family caregivers; reduce bureaucratic systems that impinge upon the best-practice goals of service providers (i.e. reducing caseloads,	X	X	MSSS / CIUSSS|CISSS | Santé Québec Disability organizations OPHQ

Recommendation	Policy	Practice	Actor(s) responsible for change
increasing face-time, ending the standardization of "one episode-one service" in order to avoid the revolving door of file closures).			
Extend the hours of care, and time for completion of ADL/IADL tasks to NDOA clients and their aging parents.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Promote fair and equitable caseload distribution based on the needs of NDOA and their family caregivers.	X	X	MSSS / CIUSSS|CISSS | Santé Québec
Community Organizations			
Better recognize and fund community organizations working with NDOA and their families, particularly those that offer housing or respite services, and those providing general support and services geared to NDOA and their family caregivers.	X	X	MSSS / Ministère de l'Emploi et de la Solidarité sociale (MESS)
Introduce future health and social service professionals to the importance of community interventions with NDOA.	X	X	Universities, CEGEPS Ordres professionnels
Agency			
Respect NDOA's inherent dignity and right to self-determination; empower NDOA to realize their dreams and reach their full potential by offering encouragement, support, and opportunities for participation in activities aligned with their interests and goals.	X	X	Everyone
Ensure the use of accessible language and adapted approaches; consider the unique situations, needs, wishes, and realities of NDOA. Take the time to understand, including learning about NDOA's backgrounds, identities, relationships, interests, and sources of happiness.	X	X	Québec government
Create opportunities to celebrate and honour NDOA through the development of ongoing and sustained relationships of care using a relational autonomy approach.		X	MSSS / CIUSSS|CISSS | Santé Québec Front line workers Disability organizations
Make room at the decision-making table for NDOA and their allies as equal partners in the development of programs and policies.		X	MSSS / CIUSSS|CISSS | Santé Québec Front line workers Disability organizations

Part E – Future directions.

Our research results represent the beginning of a journey. Our commitment to community-engaged research has opened many new collaborations and avenues of inquiry, particularly considering the emerging nature of the population, and the current gaps in knowledge and service delivery options related to the intersection of aging and neurodiversity in Quebec and beyond. Centring the voices of NDOA and their family caregivers is our primary preoccupation. In this way, we hope to break through the 'problem-focussed' lens of much research, policy, and practice in favour of foregrounding strengths and agency using the ILCP approach.

Regarding the **current project**, our intent is to maximize the accessibility of our findings. As the central feature of our end-of-project celebration which took place in the spring of 2024, we produced a performance of our findings (see Appendix 9). Created by two of our partner organizations and featuring actors who themselves are aging with neurodiversity, *Neurodiversity! Age together, Act together* was presented to resounding applause. The performance was filmed, and we will be creating a companion toolkit for training purposes in the coming year. We also hope to find additional funding to develop animated podcasts of our participants' portraits, and to publish a collective book of their stories for awareness-raising and education within and among community and public sector organizations, health and social service providers, governmental policymakers, and the public.

Finally, we will be working with our Advisory Group over the next 8 months to identify areas for **future research** emerging from the synergy between their ground-level knowledge and our project findings. Areas of potential inquiry already identified include; precarious housing and homelessness, criminal justice system involvement, palliative and end-of-life issues, co-occurrence of ND and serious mental illness, housing innovations focussed on aging in place, rural and remote regions, and further explorations on categories of social difference such as immigrant or ethnocultural communities.

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Appendix 1 - Dimensions of Social Exclusion in the context of aging with neurodiversity and their connection to the Intersectional Life Course Perspective (ILCP) in: *Experiences of social exclusion and inclusion among neurodiverse older adults and their aging family caregivers (2020-2024)*

Understanding the complex and nuanced ways in which social exclusion and inclusion are lived in everyday life across the life course into old age requires an emphasis on both structural factors *and* individual life stories across time. Intersectionality theory asserts that social locations (i.e. gender, race, class, ability) and concomitant experiences of social domination cannot be separated out from one another (Crenshaw, 1991; Brotman & Ryan, 2004; Winker & Degele, 2011). The intersectional life course approach requires an understanding of relations and power differentials as co-constituted and co-constitutive: that is, a person's social position reflects the ways in which she/he reproduces these relations. Such power negotiations occur throughout a person's life course. This perspective challenges assumptions of uni-dimensional, fixed and additive forms of oppressions (McCall, 2005), brings into focus interactions between multiple identities, social locations and structural forms of oppression, and devotes specific attention to unique experiences of diversity in communities. In this study, we employ the practices of anticategorical and intracategorical complexity that question the 'givenness' of categories of difference and focus instead on neglected points of intersection within and across categories.

The Intersectional life course perspective (Brotman et al., 2019; Ferrer et al., 2017) draws attention to: (1) major life events, timing and the structural forces which shape these events, (2) "linked lives" in both a local and transnational context, (3) categories and processes of differentiation (i.e. identity, social location and processes of othering), and (4) oppression, agency and resistance. These 4 key steps are interconnected and highlight the ways in which structural forms of oppression are explicitly and/or implicitly embedded within individuals' life stories and identities (Ferrer et al., 2017). The concept of linked lives is particularly important because it emphasizes the ways in which experiences are seldom lived individually, but rather they invoke relationships between individuals, families, and communities. Thus, the concept of linked lives considers how people organize their lives, and formulate their identities based on relationships that occur, in our particular case, across the seven dimensions of social exclusion. Intersectional life course theory enables a shift from a focus on "vulnerability" (which locates risk within individual or group characteristics and/ or behaviours) to the fluid and shifting *sociopolitical* and *relational* production of "risk." As such, risk based upon fixed identity categories of difference is reformulated as a process of "othering" (relational, social and structural) experienced across the life course (Hulko et al., 2020). **Social exclusion** and the **intersectional life course** can therefore be understood as *mutually constituted and reinforcing* across multiple dimensions. Finally, intersectional life course theory facilitates an accounting of agency (resilience and resistance strategies), thus enabling an explication of the ways in which social inclusion is lived, and/or imagined.

Social exclusion has been defined as both the denial of resources, rights, and entitlements, and the impeding of meaningful participation in relationships (informal and formal), decision-making and other activities, included within economic, social, cultural and/or political domains of public life (Grenier & Guberman, 2009; Grenier & Ferrer, 2010). Social exclusion has been theorized as occurring across seven dimensions. These dimensions are interlocking and reflect symbolic (i.e. socio-political discourses and ideologies), spatial/geographic (i.e. home, school, work, organizations, institutions and built environments, region and neighbourhood) and relational (i.e. informal and formal) forms. An analysis using a social exclusion framework enables an explication of the dominant discourses shaping relations of power *and* the resulting practices and processes which are the explicit and implicit outcome of these discourses. This includes the operationalization of professional discourses and practices of care common to the various sectors in which marginalized people, their families and communities interact. Importantly, a social exclusion framework also facilitates the exploration of counter-discourses and practices of agency (both resilience and resistance) enacted by both those subject to exclusion, and their allies. Our project incorporates an integration of all seven transversal dimensions of social exclusion, which are operationalized in below:

1. Symbolic: Dominant discourses play a major role in the invisibility and marginalization of older people with ND within society, most notable of which is biomedicalization (people viewed *as* their diagnosis); notions of dependence, incapacity, simplicity, asexuality and lacking agency are examples of negative portrayals rooted in biomedicalization; this contributes to paternalism and segregation; intersections of ableism, ageism and sanism lead to unique forms of exclusion.

2. Identity: Internalization of symbolic forms of exclusion results in identity negation and challenges to positive self-concept; many older people feel unworthy and incapable of enacting agency and insecure about making decisions without the help of others; this is exacerbated by a lack of opportunity to voice, define and choose, as well as restricted opportunities, outside of segregated environments, to experience a sense of belonging.

3. Sociopolitical: Challenges with intersectoral collaboration between various ministries, levels of government, and service sectors (i.e. those related to aging, families, housing, health, mental health, rehabilitation, work and income security); leads to barriers to the development of best policies to inform practice; lack of adequate funding; non-involvement of affected communities in decision-making processes; existing forms of consultation are geared more towards caregivers and service providers.

4. Institutional: Due to the lack of alternatives, some older persons with ND grew up in an institutional environment and others were forced to relocate to institutional settings (i.e. CHSLDs) that are not well adapted to their needs; ND settings are also ill-equipped to deal with aging residents; lack of funding within this sector has been identified as akin to a crisis, and results in transitions taking place under conditions of considerable stress; “silos” across sectors result in barriers to the development of intersectoral knowledge and service coordination.

5. Economic: Limited opportunities for education (> 21 years) and employment result in life-long experiences of economic precarity; limited availability and access to specialized services requires families to supplement services out-of-pocket (i.e. physio, speech or occupational therapy, psychological services, home adaptations, respite) to meet care needs; caregivers often must quit or reduce paid employment in order to provide care, resulting in economic precarity.

6. Meaningful relationships: As a result of the combined impact of multiple forms of social exclusion, older people with ND have limited capacity and opportunity to develop and maintain meaningful social relationships; the absence of social networks beyond the immediate family, a lack of access to them as a result of territorial and economic exclusion, and/or rejection from them due to discrimination lead to vulnerability and marginalization.

7. Territorial: Segregation of people with ND across the life course results in limited interaction between older people with ND and their neighbours and communities; regional variation in access and availability to supports; many people with ND feel out of place in their living environments and neighbourhoods; ND settings also ill-equipped to deal with aging residents; economic disadvantage results in unstable housing and homelessness as people age.

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Appendix 2 – Participant demographics

About the research participants

Our participants reflect the diversity of people aging with neurodiversity (NDOA), as well as the family caregivers (FC) and service providers (SP) that support them! The tables below present information on the age and gender of all of our participants, as well as other pertinent information. We also highlight the general work sector (public or community) of service provider participants, and their years of experience working with the population. The legend underneath explains the abbreviations used in the tables. Note that NDOA and FC participants are not related to each other.

Neurodiverse older adults (NDOA)

The 21 participants range in age from 45 to 78. They all have very different experiences of housing and accommodation. This diversity is beneficial for the research, as it allows us to observe the different places in which social inclusion/exclusion occurs.

CHSLD : Residential and long-term care centres
FTR : Family-type resources
NPOH : Non-profit organization-housing
IR : Intermediate resources

Québec			
Pseudo	Age	Gender	Housing
Annie	52	W	NPO-H
Lise	52	W	NPO-H
P'tit loup	69	M	NPO-H
Jean	57	M	Private boarding room
Dédé	74	M	Seniors' residence
Marilou	62	W	Private market apartment with housing support program
Annie-Pier	49	W	Private market house
Wu Fei Chang	49	M	Subsidized housing
Hélène	67	W	Seniors' residence
Frank	45	M	Private market apartment
10			

Montréal			
Pseudo	Age	Gender	Housing
Audrey	56	W	Private market apartment
Elisa	59	W	Social housing
Johanne	48	W	FTR
Tina	61	W	FTR
Suzy Q	78	W	CHSLD
Mr. X	67	M	IR
Christine	52	W	IR
Lisa	48	W	With family
Tim	52	M	Private market apartment with wife
Rosemary	62	W	CHSLD
Batman	65	M	IR
11			

Family caregivers (FC)

The 15 participants (parents, siblings) are between 51 and 87 years old. As NDOAs age, so do their family caregivers. Living arrangements are very diverse and specific to each situation.

Montréal				
Pseudo	Age	Gender	Taking care of...	Living arrangement
John	87	M	3 children (62,61,57)	3 children living together - private market housing
Blanche	85	W		
Alessia	69	W	2 children (56, 42)	Lives with children
Dadou	73	W	2 children (48, 39)	Son (48) in FTR, lives with daughter (39)
Gates	57	W	Sister (55)	Lives with her sister
Luce	61	W	Brother (67)	Brother in IR
Annie	75	W	Daughter (48)	Lives with daugther
Clara	62	W	Sister (72)	Lives with sister
Cassie	70	W	Daughter (48)	Daughter in FTR
Rose	58	W	Sister (62)	Sister in CHSLD
Adora	58	W	Brother (53)	Brother in IR
10				

Québec				
Pseudo	Age	Gender	Taking care of...	Living arrangement
Thérèse	69	W	Son (46)	Son back home
Laurent	75	M	Sister (58)	Sister in CHSLD
Vicky	63	M	Brother-in-law (61)	Brother-in-law in CHSLD
Marie-Thérèse	82	W	Son (59)	Son in CHSLD
Brigitte	72	W	Daughter (52)	Daughter lives independently
5				

Service providers (SP)

We interviewed 27 SPs (psychoeducators, social workers, community workers, educators, managers, administrators, and liaison workers). Some had more than one professional title. The diversity of professionals enables us to understand social inclusion/exclusion from different perspectives (community, mental health, rehabilitation, etc.).

CO: Community organization
HSS : Health and social services
ND : Neurodiversity

Québec				
Pseudo	Age	Gender	Type of organization	Years work with the population
Mélissa	N.D.	W	CO (ND)	5-10 years
Nathalie	N.D.	W	CO (ND)	20+
Judith	N.D.	W	CO (ND)	<5
Pascale	26	W	CO (ND)	5-10
Maude	N.D.	W	CO (ND)	11-20
Marie-Claire	N.D.	W	CHSLD	<5
Juliette	43	W	CHSLD	20+
Claude	N.D.	W	CHSLD	<5
Vanessa	47	W	CHSLD	11-20
Marie	N.D.	W	CO (ND)	<5
10				

Montréal				
Pseudo	Age	Gender	Type of organization	Years of work
Marco	29	M	HSS (mental health)	5-10
Stephanie	31	W	CO (seniors)	<5
Chantale	41	W	CO (ND)	11-20
Martine	32	W	CO (ND)	5-10
Hannah	40	W	HSS (ND)	11-20
Linda	62	W	FTR	11-20
Hugo	60	M	FTR	20+
Rebecca	39	W	SSS (ND)	11-20
Marie	59	W	SSS (ND)	20+
Lily	33	W	SSS (ND)	<5
Iceberg	67	W	CO (ND)	20+
Theresa	52	W	HSS (mental health)	20+
Geneviève	33	W	HSS (ND)	5-10
Mike	59	M	HSS (ND)	20+
Ellis	45	W	IR	20+
Thomas	44	M	HSS (mental health)	5-10
Cory	35	M	HSS (mental health)	5-10
17				

The experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-2024)

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

Appendix 3 –List of research team members

Co-Investigators:

Shari Brotman (chercheure principale et responsable de l'équipe-Montréal),
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Collaborators:

Anna Andrianova, Zelda Freitas, Julien Simard

Assistant.e.s de recherche/ Research Assistants :

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Advisory group:

Sandra Asselin, Service d'autonomisation, d'intégration, et de réadaptation aux adultes ayant un handicap (SAIRAH) **Nancy Chamberland**, Autisme Chaudière-Appalaches
Matthew Charbonneau, CIUSSS de l'ouest de l'île de Montréal
Camille Demers, Sans Oublier le Sourire
Carmela de Lisi, Avatil
Ariane Deveau, Association pour l'intégration sociale de la région de Québec (AISQ)
Leslie Dickie, caregiver
Elaine
Jessica Levine, CIUSSS de l'ouest de l'île de Montréal
Lynn
Susie Navert, Société québécoise de la déficience intellectuelle (SQDI)
Sandy Neim, Centre Cummings
Karyann Pilon, Société québécoise de la déficience intellectuelle (SQDI)
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Michelle Robitaille-Rousseau, Mouvement Personne d'Abord du Québec Métropolitain
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Partners:

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Faculté des sciences sociales
École de travail social et de criminologie

The Experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-2024)

Appendix 4 - Consent and Assent Protocol

Preamble

Disability rights advocates have long championed the phrase 'nothing about us, without us.' Historically, the voices of people with neurodiversity (ND) have often been excluded from research about them, owing in part to paternalistic misconceptions about their capacity for informed consent. While for some within this community, the nature of their precise impairment necessitates a different model of decision-making, this difference should be accommodated rather than used to justify their exclusion. Given that the primary objective of this project is to explore the multidimensional concept of social exclusion for this specific population, older adults with neurodiversity (NDOA) are the most important informants. In this way and drawing from an established tradition of research in Canada which employs the 'assent and consent' and 'supported decision-making' and 'relational autonomy' models (Bach & Rock 1996; Cleaver et al., 2010; Kelly, 2010; Martino & Schormans, 2018), this project prominently positions the voices of people with ND, such that it will not be written about them, without them.

In adherence to the supported decision-making model, the assent and consent process involves acquiring both assent from the participant with ND and consent from their supported decision-maker (i.e. tutor, curator or mandatory). Even though many adults with ND are able to make significant decisions independently, there are some who, due to the nature of their disability, engage in processes of supported decision-making by involving close family members and/or support staff in significant decisions. In order to move away from categorizing participants as more or less capable we will use the same consenting process for everyone. As such, we will not ask respondents to indicate what decision-making process they use, and instead will ask every participant with ND that we interview if they wish to engage in supported decision-making. This means that assent to participate will be required from the participant themselves, alongside consent from at least one advocate chosen by the participant themselves, when necessary. Both assent and consent will be indicated on an assent and consent form that will be signed by participants and their supported decision-makers where indicated. Moreover, supported decision-makers can be present throughout the interview process. If possible, we will distribute the recruitment letters to participants with ND and their families or other support persons at an introductory meeting, where we can effectively answer questions and concerns about the nature of the research.

The participants in this study belong to, or are related to, a group that faces stigmatization both for being older in age and living with ND. Given the small percentage of the population comprised by NDOA, even general demographic information such as diagnosis or ethno-cultural identity, when taken together, can be used to determine an individual's identity and will be omitted from published reports. To provide an additional measure of confidence in protecting the confidentiality of respondents, we will not reveal the names of the cooperating agencies from which the participant was recruited. Information on confidentiality measures is provided in all recruitment materials and the assent and consent forms for NDOA.

Owing to confidentiality measures, the only possible risk pertains to psychological discomfort stemming from the discussion of sensitive topics. We have designed the interviews to avoid this possibility, so that the nature of the conversation is designed to be similar to other conversations that participants are likely to engage in during their normal daily routine. However, there are measures in place to manage this risk. The potential presence of a support person during the interviews means that someone with a close personal relationship may be present. In the event of psychological discomfort, participants are free at any time to discontinue participation. We are prepared to provide a list of resources for follow-up where necessary. The specific assent and consent process is outlined below:

1. Referral source identifies potential participants and reaches out to the participant for consent to share contact information with the researcher.
2. Researcher receives name and number of the potential participant from the referral source. If relevant the researcher also receives information regarding if the potential participant has a substitute decision-maker (SDM)and what type (curator, tutor or mandatory) from the referring source;
3. In conversation with the potential participant explain the project and discuss the following using plain language questions:
    a. Ask, "Can you tell me in your own words what the project is about?"
    b. If the response is unclear, discuss further. If the potential participant is able to explain the project in their own words (for example that they will have an opportunity to tell their story, share their ideas about where they live or what services they get, what problems they experience, etc.), proceed to the following questions. Otherwise thank them and end call. Follow up with Referral source.
    c. Respond with "Thank you. Would you like to participate in one preliminary meeting to sign the consent (and assent) form and go over any questions you may have, and 2 interviews (conversations) by Zoom, by telephone or in person?"
    d. If yes keep going otherwise if no say "thank you" and leave them your number in case they change their mind or want to think about it.
    e. Ask, "Is there someone who helps you make decisions that we should speak with as well?" If yes, get their name and number OR ask, "I will also speak to your SDM (use name) to confirm your participation with them, is that ok with you?"
    f. Ask, "Would you like someone to be with you during the interview to support you? Who would that be?"
    g. Set up appointment for meeting 1 to explain and sign the consent form.

h. During the meeting to sign the consent (and assent) form, ask clarifying questions to make sure all is understood. Discuss rights of participant (as outlined on form as well as right of non-impact on services received and rights to be accompanied by a support person chosen by the participant, right to receive a referral in case of triggering event).
i. Set meeting for first interview by Zoom, by telephone, or in person as preferred by the participant.

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Annexe 5 - Appendix 5
Les histoires de : Audrey et Tina, PVSND
The stories of: Audrey and Tina NDOA
et/and
L’histoire de Luce, proche aidante
The story of Luce, caregiver

Les expériences d'exclusion et d'inclusion sociales chez les personnes vieillissant en situation de neurodiversité et leurs proches
The experiences of social exclusion and inclusion among people aging with neurodiversity and their families

Audrey's Story

June 30, 2022

UNIVERSITÉ
LAVAL
Faculté des sciences sociales
École de travail social et de criminologie

Audrey’s Portrait

Audrey is a 56-year-old woman, born in France. When she was 1 year old, her family immigrated to Quebec. She lived in the West Island of Montreal where she completed her studies in adapted classes and has forged friendships that have persisted over time.

Audrey has lived a life of successes, challenges, and transitions. She has experienced multiple and sometimes complex disabilities, some of which are congenital and others which appeared in adolescence. “Vision and hearing yes, alopecia is not too bad because it doesn’t prevent you from working, it doesn’t prevent you from doing these things, but vision and hearing when it is there, you don't have a job, you don't have anything”. As an adult, as her hearing continued to deteriorate, she agreed (over time) to wear a device for the first time, and she heard the sounds of nature for the first time. It was a defining moment for her: "...I could really hear the ocean; it was the first time I really heard the wind in the trees and all that...".

Audrey also experienced changes in her environment at different times in her life. Notably, living with other people (roommates and parents), in a semi-supervised apartment, in a group home, and living alone. She considers that living alone and being independent is the most satisfying situation because she can make her own decisions on a daily basis: "You can do whatever you want, you can fall asleep in front of the TV and nobody can say anything". Audrey exclaimed, "to be in your own apartment... that’s freedom".

Over the years, Audrey has experienced various social relationships within and outside school and socio-professional environments, from formal and informal networks. Throughout the interviews, she described the difficulties she faced during her schooling, as she was often bullied at school and constantly reminded that she was different. “Yeah, it was tough, that’s for sure. It was like, not obvious... you're there, you're different, you're trying to fit in. But there are some who make your life more miserable than it has to be, for real. It's not obvious, but there are children who are in schools, and they don't need to be disabled to be punching bags (laughs) for other bullies”. Despite the denigration she suffered from her peers, Audrey showed empathy towards them: "...I don't know what these people have had, maybe they have had a different life afterwards, I think maybe those people who hurt others in their youth, maybe they lived after that...oh, their children were different, and we know that, we don't know anyone's future”.

Audrey also participated in different professional and recreational activities and talked about places where she felt excluded due to her disability and others where she felt a sense of belonging. "Yeah, yeah, yeah... but it was very funny... it's like, it's a place where I really, really liked... I was comfortable, I was like... I felt like I belonged there. Although I also have... reduced mobility but differently... but for example, I felt good in that environment, we made friends, we made friends... and then we also learned things about them that you can't imagine...”. Audrey said that what is most important to her is that her daily activities, whether professional or recreational, provide her with meaning and fulfilment. "For me, it's keeping myself busy, but not really with work, but keeping busy...especially having fun in what I do, even if it's just activities to get me out of my house. Having like other things to talk about, other than only from home”.

Audrey benefited from the support of many workers from government and community organizations. Referring to a community organization where she has been a client since the age of 18, she described: “it’s like my second family”. For Audrey, the change of worker is experienced as a significant loss. "What happens is that you want, you don't want, when you have worker, you get attached...we talk to them, we entrust them with things...when there is a change, it's as if you’ve lost a friend. At some point, over time, you continue to confide in yourself, but you no longer have this tendency to develop a friendship. I lost a lot of them that I was close to, so it hurts, some even invited me to go to their house and everything, I met their children...it hurts, as if you were losing a friend, it's simple...”. Despite her independent nature, she recognizes the importance of the support she receives to achieve her goals, “having help helps me to have a fulfilling life”.

Audrey’s friendships are very important to her and the loss of her friend when he was 59 years of age was also a difficult reminder of her own aging. She tries not to think about aging, but seeing her parents grow old reminds her that she's getting older too. "Well my parents are getting older...yes we try to avoid thinking about it uh...we try not to...ok of course I see them their hair going white there, you know it's like try not to think about that there... you go there and you say it's, you say good very nice...otherwise if you start thinking about them like they're going to leave, you're going to be...you I know it's going to be unfortunate... of course they're getting old, you're getting old so they can't help but grow old...”. Despite some of her difficult experiences, Audrey considers that these moments have shaped her personality and that ultimately life "...is fun".

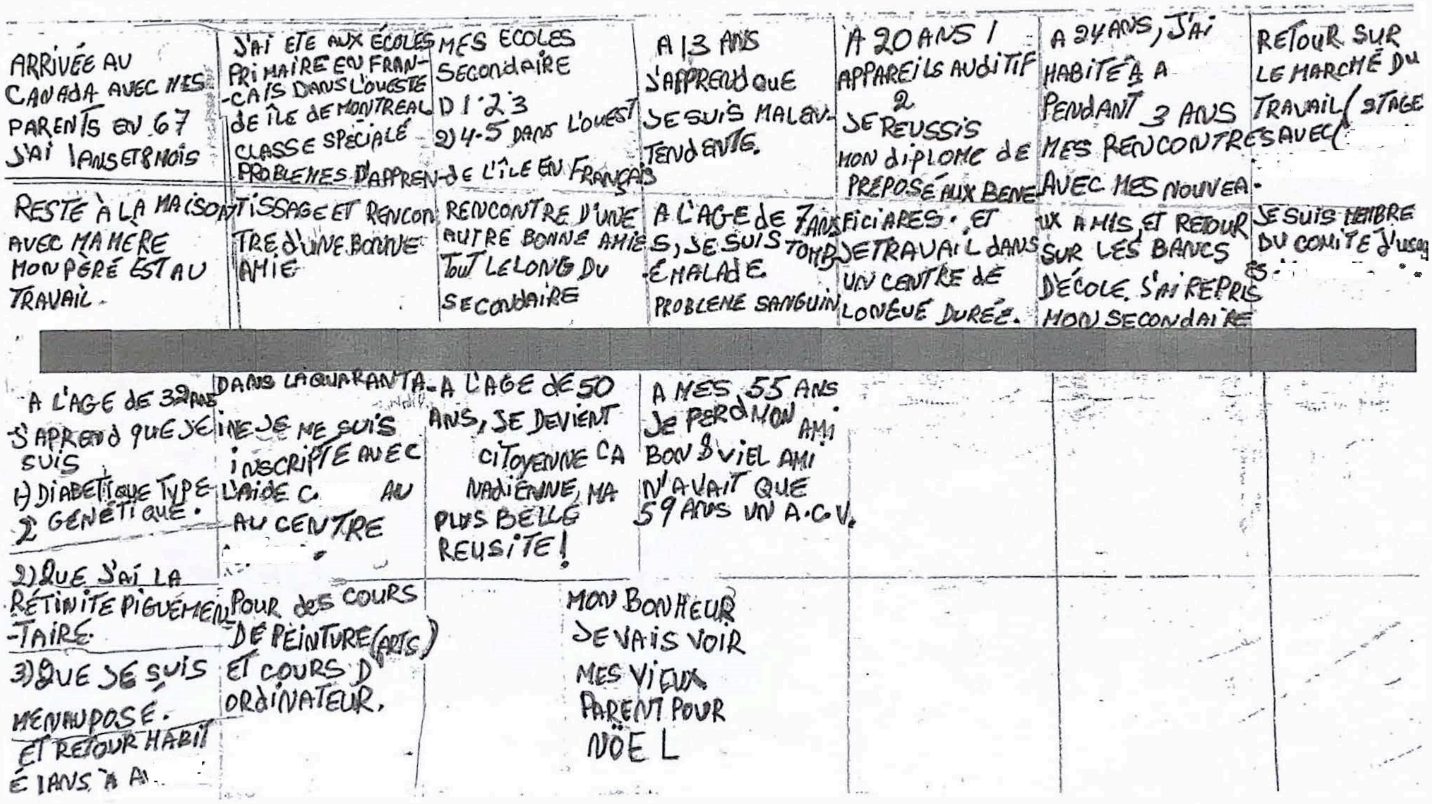
In her thirties, despite the announcement of new physical health conditions, Audrey learned to manage in order to remain active. In particular, she is involved in the users' committee of a health establishment in order to defend rights and propose changes to improve services for people with neurodiversity. Audrey affirmed, "Yes, I think we should be looked at as people...well, I don't like that word...'normal' people, I would like them to look at us like, we are given the same services, that don't use big words so that we don't understand. So, I would say that to the people who are going to take care of us. It's a great effort on their part, but for us too, because it would be easier for us to explain and afterwards, to feel understood. It's important that we feel understood, when we talk to a doctor or a nurse, to say that "I have an injury there" or "it's the little blue pill". It's fair to say, to show us well, like with the things they have at the pharmacy...”.

Through her involvement in various community organizations, she discovered many passions, including painting, and forged meaningful relationships with peers. It is at 50years old that Audrey lived one of the most beautiful moments of her life; she became a Canadian citizen. “Yes, it was a big step, then I really felt...even if I have been here for a long time, almost born here, for me it was home. I think that's what helped me a lot, I was at home, went to school here, spoke the language of Quebec, and also of Canada, which is English. Look there, it's our home, it was just to have it on paper (laughs). I could have done it at 18, but I was like, "oh no, I want to keep my French nationality". I didn't have the same ambitions, because I was young, and I was from Quebec, and after that, as you get older, you realize that many things change...". She learned and developed wisdom through the friendly relationships she maintains with people older than herself. During the last meeting, Audrey announced to us that she had just moved to a new apartment in a social housing unit. For her, it's a dream come true. She will finally be able to be independent in a larger apartment in which it will be possible to grow old comfortably and prepare for retirement. Despite her apprehensions about aging, she maintains a peaceful and positive attitude about what the future holds for her.

Audrey

Ma Ligne de Vie

Les évènements importants qui m'ont marquée



ARRIVÉE AU CANADA AVEC MES PARENTS EN 67 J'AI 1ANS ET 8 MOIS

J'AI ETE AUX ÉCOLES PRIMAIRE EN FRANÇAIS DANS L'OUESTE DE ÎLE DE MONTREAL CLASSE SPECIALE PROBLEMES D'APPRENTISSAGE ET RENCONTRE D'UNE BONNE AMIE

MES ECOLES SECONDAIRE D 1 2 3 2) 4-5 DANS L'OUEST DE L'ÎLE EN FRANÇAIS

A 13 ANS J'APPREND QUE JE SUIS MALENTENDANTE.

A 20 ANS / APPAREILS AUDITIF 2 JE REUSSIS MON DIPLOME DE PREPOSÉ AUX BENEFICIARES. ET JE TRAVAIL DANS UN CENTRE DE LONGUE DURÉE.

A 24 ANS, J'AI HABITÉ À A [redacted] PENDANT 3 ANS MES RENCONTRES AVEC MES NOUVEAUX AMIS, ET RETOUR SUR LES BANCS D'ÉCOLE. J'AI REPRIS MON SECONDAIRE

RETOUR SUR LE MARCHÉ DU TRAVAIL (STAGES AVEC ([redacted]

RESTE À LA MAISON AVEC MA MERE MON PÈRE EST AU TRAVAIL.

RENCONTRE D'UNE AUTRE BONNE AMIES TOUT LE LONG DU SECONDAIRE

A L'AGE DE 7 ANS, JE SUIS TOMBÉ MALADE. PROBLENE SANGUIN

JE SUIS MEMBRE DU COMITE JUSQU'ES [redacted]

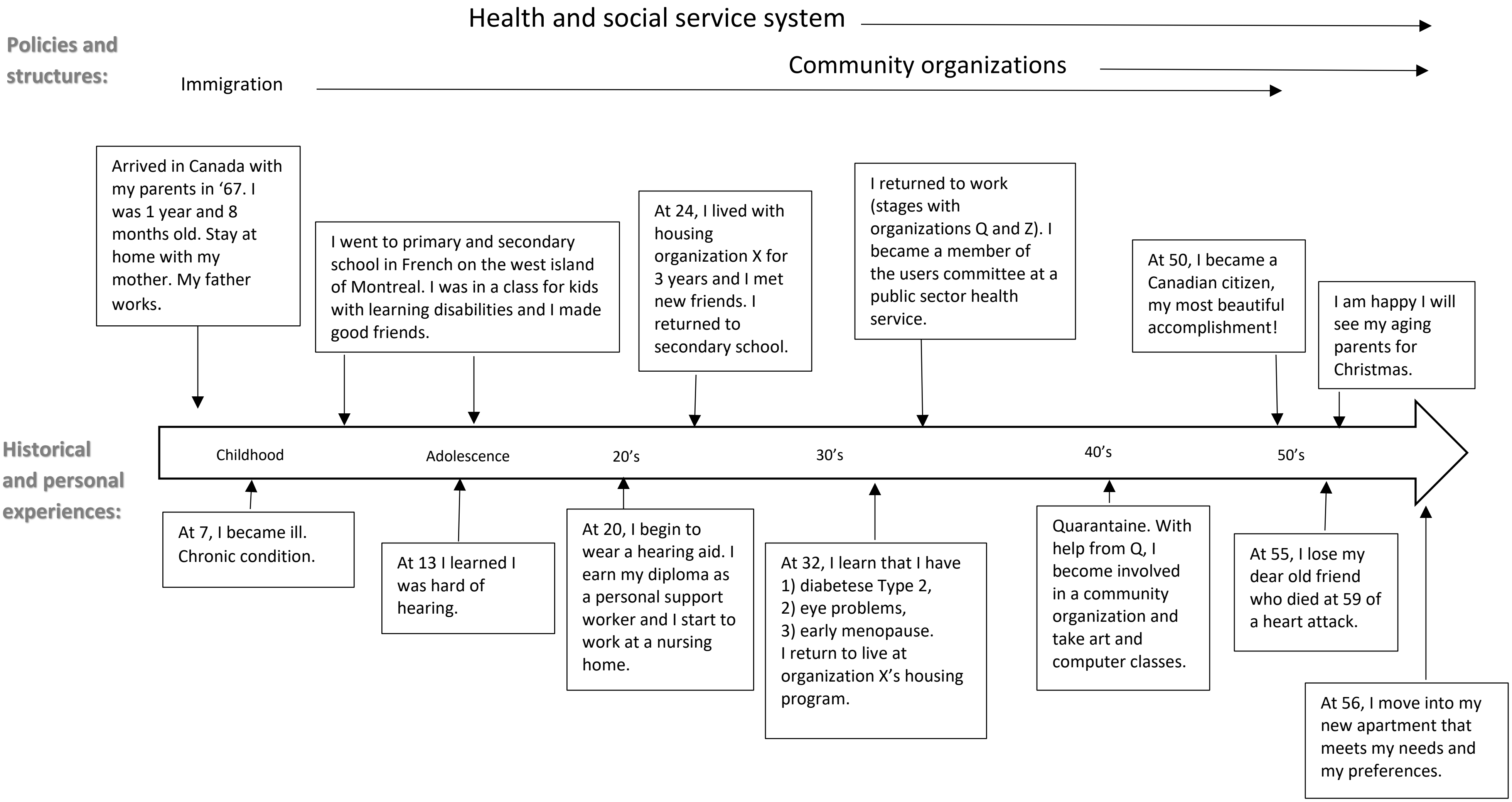
A L'AGE DE 32 ANS J'APPREND QUE JE SUIS
1) DIABETIQUE TYPE 2 GENETIQUE.
2) QUE J'AI LA RÉTINITE PIGUÉMENTAIRE
3) QUE JE SUIS MENAUPOSÉ.
ET RETOUR HABITÉ 1ANS À A [redacted]

DANS LA QUARANTAINE JE ME SUIS INSCRIPTE AVEC L'AIDE C. [redacted] AU AU CENTRE [redacted] POUR DES COURS DE PEINTURE (ARTS) ET COURS D'ORDINATEUR.

A L'AGE DE 50 ANS, JE DEVIENT CITOYENNE CANADIENNE, MA PLUS BELLE REUSITE!

A MES 55 ANS JE PERD MON AMI BON & VIEL AMI N'AVAIT QUE 59 ANS UN A.C.V.

MON BONHEUR JE VAIS VOIR MES VIEUX PARENT POUR NÖEL



Policies and structures:

Health and social service system

Community organizations

Immigration

Historical and personal experiences:

Childhood

Adolescence

20's

30's

40's

50's

Arrived in Canada with my parents in '67. I was 1 year and 8 months old. Stay at home with my mother. My father works.

At 7, I became ill. Chronic condition.

I went to primary and secondary school in French on the west island of Montreal. I was in a class for kids with learning disabilities and I made good friends.

At 13 I learned I was hard of hearing.

At 20, I begin to wear a hearing aid. I earn my diploma as a personal support worker and I start to work at a nursing home.

At 24, I lived with housing organization X for 3 years and I met new friends. I returned to secondary school.

At 32, I learn that I have
1) diabetese Type 2,
2) eye problems,
3) early menopause.
I return to live at organization X's housing program.

I returned to work (stages with organizations Q and Z). I became a member of the users committee at a public sector health service.

Quarantaine. With help from Q, I become involved in a community organization and take art and computer classes.

At 50, I became a Canadian citizen, my most beautiful accomplishment!

At 55, I lose my dear old friend who died at 59 of a heart attack.

I am happy I will see my aging parents for Christmas.

At 56, I move into my new apartment that meets my needs and my preferences.

Agency and Identity:

independent - friend – active - client – artist - hockey fan - optimist - humble

Les expériences d'exclusion et d'inclusion sociales chez les personnes vieillissant en situation de neurodiversité et leurs proches
The experiences of social exclusion and inclusion among people aging with neurodiversity and their families

Tina's Story

June 30, 2022

UNIVERSITÉ LAVAL
Faculté des sciences sociales
École de travail social et de criminologie

Tina's Portrait

Tina is a 61-year-old woman who currently lives in a group home (family type resource) in a supported housing community not far from Montreal. Her group home is one of several in the supported housing community that has access to many activities and programs and is close to nature. Tina moved to her current group home in her late 40s after many years of struggle and uncertainty with both her own health and her housing situation, which she attributes to decades of alcohol use. "When I came here after I was hospitalized. I was hospitalized, that's why I came here. Because of alcohol, alcohol. Too much… and my liver was damaged. I had an intravenous in my arm. I had to walk, and I couldn't smoke and nothing... and really badly".

Tina openly shared her life story with us, beginning when she was in her early 20s. She began her story here because of the many important events that happened to her during this time in her life, both good and bad. Tina began drinking when she was around 21 years old. She told us "[I started drinking] when I was maybe 21. Yeah, going on 22. I started with a bunch of people. No, just not friends, just a bunch of enemies. Yeah, they were with my friend, I think I started drinking with them. Yeah… too bad". Tina's alcohol use and the impact this has had on her life and relationships is central to her story. She remembers how her brother would "take my alcohol, my beer, and put it down the sink when he came into my… my mother's house". Tina said she would just go drink elsewhere. Sometimes, she would ask for money on the street to buy alcohol. In her late 40s, Tina was found collapsed and very sick on the floor of her apartment by her fiancé. He quickly called 911 and she was rushed to the hospital only to find out that she had liver damage. "The doctor wondered why I was still living with all the alcohol I had in my system".

Tina was mandated by the court to live in her group home "The court put me here for the rest of my life, until I die. Yeah, and I put myself here" and a social worker helped her to make the transition to living in her current home and community. She described her positive feelings towards this worker "And [worker] helped me a lot. Like when I was hospitalized, put me here, and took care of me when I was sick in my room, and like when I was throwing up. She helped me out a lot, [worker]. She's like my mother. Yeah, mother, I don't have anymore". Before this point in her life Tina was not helped by any services or workers.

The impact of decades of alcohol use were major for Tina. She lost contact with her siblings and their families who she feels "They don't know where I am and I don't think they wanted to know where I am". She proclaims "I have no family right now. My mother passed away. My brothers, and I got three brothers and a sister, I don't see any more either. [Worker] doesn't know where they are. I don't know where they are, who knows". Tina described her mother, with whom she lived until the age of 21 or 22, and then afterwards lived next door for some time, as someone who "helped out a lot".

Tina spoke only briefly about her childhood and her experience of school, as she did not remember these early years very well and chose not to speak about it. In reflecting back on her story during the final conversation she had with us, Tina mentioned that her father had been an alcoholic. Regarding her early schooling, she said simply that she had been a shy person who did not talk much to her peers and had few friends. School was difficult for her because she had challenges with reading and writing, which is still true to this day. She mentioned that she needs help to read documents. Because of these challenges, Tina stated that she was always unable to work and relied on welfare payments to survive.

At the centre of Tina's story is the love she has for her three children all of whom are now adults. Her eldest daughter is D., and she has twins, a boy and a girl, named P and L. They are all now in their 30s. When D. was born, Tina lived with her mother for a short time and described her mom as a source of hands-on help and support. When D was still a toddler, Tina took her and moved in with "a guy I met". Because of her alcohol use, the man called youth protection services and as a result, D. was placed in foster care. When her twins were born, they too were placed in care, at birth. Losing her children is the hardest thing that Tina has had to live with all of her adult life. She experiences the fact that they were taken from her and lived elsewhere (in foster care and group homes), and that she has had very little contact with them, as heartbreaking. Tina speaks about this great loss with regret and remorse. She frequently described herself as a "bad mother" during the interviews because she was unable to care for them when they were growing up. Still, she recognizes that she was not in a good place to take care of them "Yeah, I did bad, I was a bad mother… it was sad for me. Happened 'cause I didn't take care. They were better off where they were, too". Tina longs to be in contact with them again "I wish I could see my kids now. I wanna see them. I really miss them".

Tina returns time and again to the love she has for her children and to the great loss of losing them to child protective services. Even as she describes other meaningful moments, ideas, or people in her life, she returns to the subject of wanting to see them. For example, when asked about her feelings about aging, Tina told us "I feel that I'm getting older because it's part of life. And it's part of reality, and part of life. Like, I'm gonna be 60, I'm already 60 - I'll be 61. I was born [date], so I'll be 61 this year, in [month]. Yeah, I don't look it, eh? No, I feel like old lady. …just physically… I just feel like old lady 'cause I'm getting older now. And I can't see my kids".

Tina recounts the time, in June of 2019 when she traveled to another province to be reunited with her son and meet his partner. It was an important moment for her, and not only did she get to see her son again, but he also told her that she was a grandmother. Her eldest daughter D. had a boy, and though she has not met him, she speaks with pride about having become a grandmother. Unfortunately, both Tina and her workers have not been able to contact him again. Tina mentioned that she tried to call him several times but could not reach him.

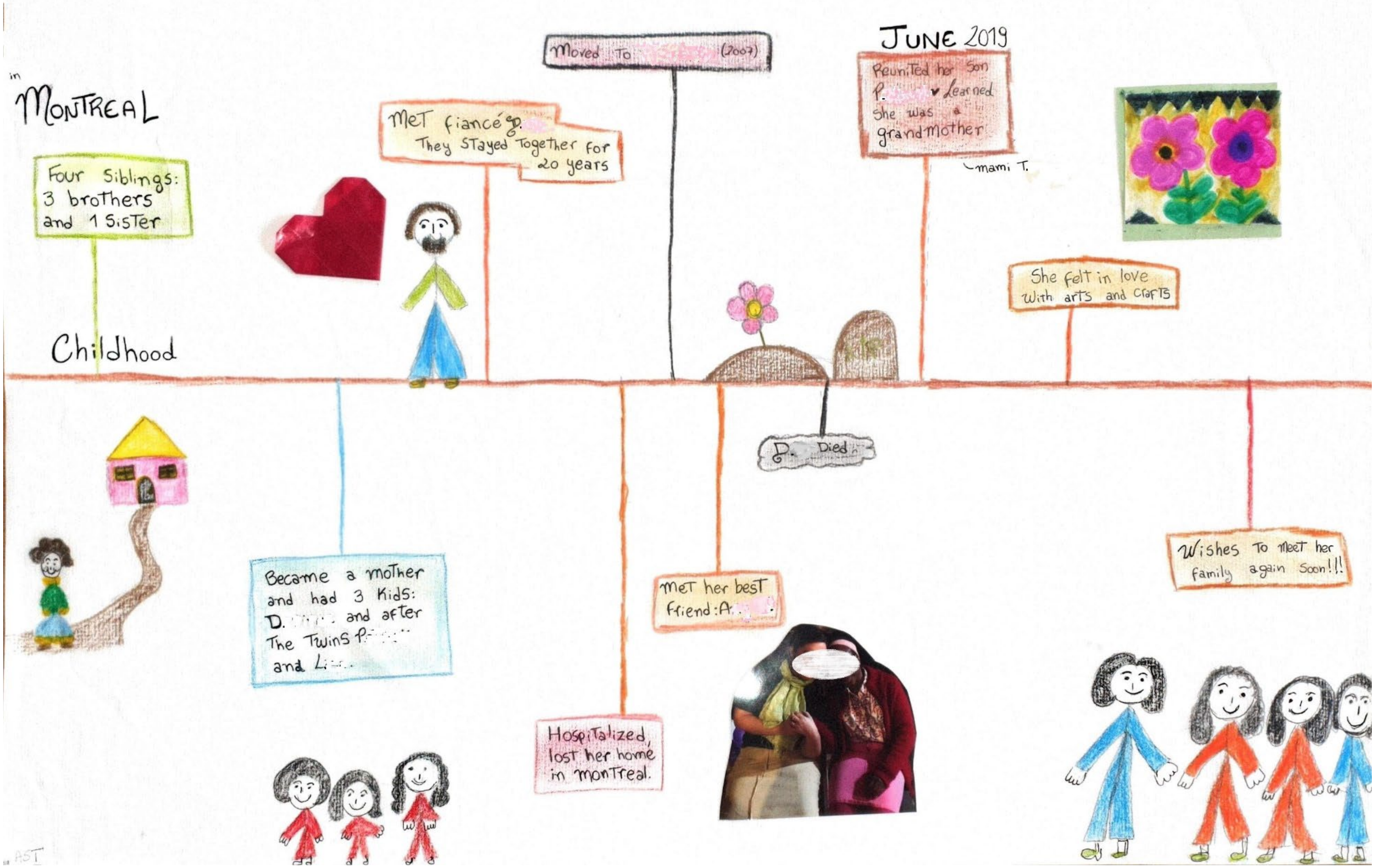
Aside from her children, the other love of her life was her fiancé D. who she was with for over 20 years. She identified how "… he helped me a lot with some guys that just weren't healthy. They just, they wouldn't care so much as he cared about me. Now I wish he was still here. He was the best for me…". She met D. when she moved into a low-income apartment building in her 30s and he lived in the same building, working as the janitor. They spent many years together, always supporting and loving each other. After she had collapsed and he found her on the floor of her apartment, D. called 911. When the social worker at the hospital told her about moving into a group home, D. encouraged her to make the move, so she could get the support she needed to quit drinking and take better care of herself. He visited her there several times. Sadly, D. passed away not long after she moved. Tina did not find out about it right away but had a feeling something was wrong when she could not reach him. In speaking with her support worker during the interview she said “I really like it here and it’s a good place for me to be here and it's okay. The first few years, I was not so good to me 'cause I missed my fiancé and I wanted to be with him, instead of living here. But I realized when, when, when I came here, ‘cause you told me after a while after that he passed away and then I didn't want to eat or nothing and be by myself in my room. That's the way I felt inside, to myself”. Thinking back, she regrets that they never got married.

Tina told us that her mother passed away before Tina moved into the supported housing community. She regrets not having been able to see her when she died. “I just realized when I came here that she had [already passed away]. Then after I, I felt real bad. That I didn’t get to say nothing to her before she passed away, but it is part of life, and I have to accept it that’s she's not here anymore”. Although Tina is, at times, uncertain about the dates of these important and sometimes tragic moments, the feelings of loss, and of gratitude, particularly for the over 20 years she shared with her fiancé, run deep inside. She speaks of her continued relationship with her fiancé despite his passing as she shared that she still talks to him every day, like she always did. She misses him but is reminded about how special their relationship was. “And I really miss him. Yeah, he was the only one who cared about me. Nobody else in [my province]... I had a long life with him when he was still here, though, ‘til his time came, that was the best. The every little day things that mattered”.

Despite all the challenges Tina has faced in her life, she still has a bright smile and a positive attitude. She loves doing arts and crafts projects and enjoys baking. At her group home and in her community, she actively participates in activities. Her room is filled with photos. From the walls, pictures of her young children and her fiancé smile back at her. Tina has an art display wall where she hangs her art projects and she shares this with great pride. She loves music and has many CDs of her favourite singers and bands. She loves shopping and says “And [my worker] said not to go shopping too much. I love to shop and I don't know why! Lot of stuff, lot of clothes and that in my room and I still want to go shopping”.

Tina shared her daily routine with us, describing when she gets up, has her cigarette and then her shower, and stays quietly in her room until breakfast as is required so as not to disturb others too early in the morning. She spoke of the workshops in which she is currently involved and shared a story of previous visits from the dog that lives close by. She also describes the contributions that she makes within her community “Sometimes I knead bread dough and that. I make granola for the houses and that. And bring out the recycling, the garbage, the compost, the chicken bucket. I bring all that, away. Yeah, I'm going to clean up after that. That's what I do too ... I have cooking too. Where I help out set the table, doing dishes and cleaning the floor and cleaning the counters, and I clean the table, and that too”. Although Tina shared some ambivalence about some aspects of her current living situation, overall, she states that she wants to stay where she is, that it is the best place for her so that she can get the help and stability she needs. On her own, she says she “would not make it”. But she has a difficult relationship with one resident who she does not like which causes her stress and tells us that she must go to church every Sunday, which is “Too bad 'cause I'm not into church. I have to go every Sunday. But I don't like it, but I have to go. That's life, yeah. Yeah, [everyone] goes. Dress in nice clothes, and nice skirt, nice top, and nice tights, nice shoes. And because it's a service, dress in all nice clothes. Yeah, that's what I did. That's what we did. Oh, it's okay. It's okay, I got it. I'm used to it now since I'm staying now. I'm living there now. Yeah, I don't … wanna live nowhere else. I like it here at [residence]". Tina's attitude is one of acceptance and she tries her best to do what is expected of her and to ignore the difficult resident with whom she does not get along. Happily, Tina tells us that she has made a best friend in the community who lives in one of the group homes nearby and they talk frequently and listen to music together. Each week, they walk together to attend church. This good friendship is something she cherishes. Tina dreams of meeting someone, though she says it is likely impossible given her living situation. She also wishes that a dog or cat could live at the home because of her love for these animals. But most importantly, Tina hopes and waits for the day that she can be reunited with her children, especially as she grows older. "What I want in life? Well, I want my kids again, that's all I want".

Tina [redacted] - Life line



in MONTREAL

Childhood

Four Siblings:
3 brothers
and 1 SisTer

Became a mother
and had 3 Kids:
D.[redacted] and after
The Twins P.[redacted]
and L.[redacted]

MeT fiancé D.[redacted]
They STayed Together for
20 years

Moved To [redacted] (2007)

HospiTalized,
lost her home
in monTreal.

MeT her besT
Friend: A.[redacted]

D. Died

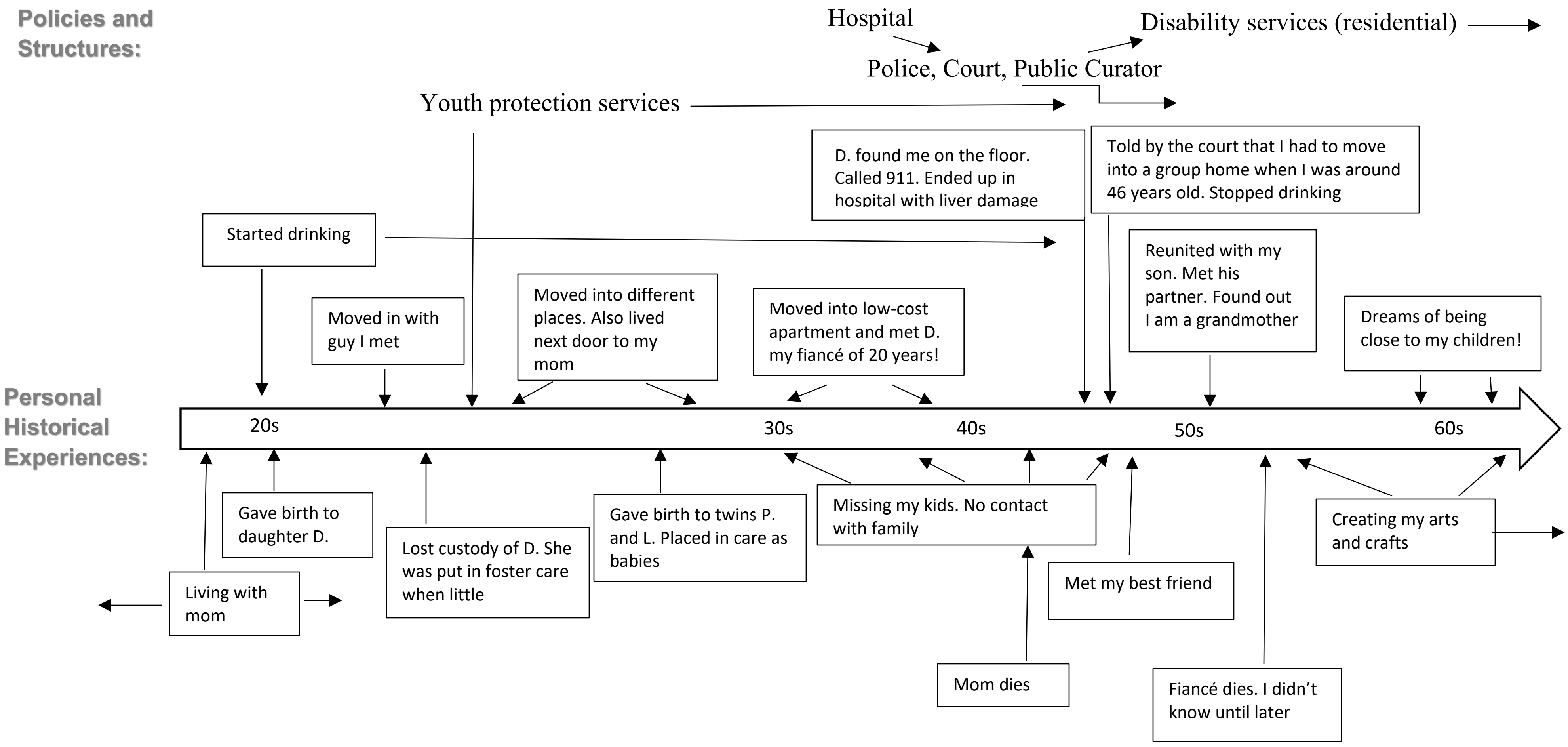
JUNE 2019

Reunited her Son
P.[redacted] ♥ Learned
She was a
grandmother

mami T.

She felT in love
With arTs and CrafTs

Wishes To meeT her
family again Soon!!!



Policies and Structures:

Hospital

Police, Court, Public Curator

Disability services (residential)

Youth protection services

Personal Historical Experiences:

Started drinking

Moved in with guy I met

Moved into different places. Also lived next door to my mom

Moved into low-cost apartment and met D. my fiancé of 20 years!

D. found me on the floor. Called 911. Ended up in hospital with liver damage

Told by the court that I had to move into a group home when I was around 46 years old. Stopped drinking

Reunited with my son. Met his partner. Found out I am a grandmother

Dreams of being close to my children!

20s

30s

40s

50s

60s

Living with mom

Gave birth to daughter D.

Lost custody of D. She was put in foster care when little

Gave birth to twins P. and L. Placed in care as babies

Missing my kids. No contact with family

Mom dies

Met my best friend

Fiancé dies. I didn't know until later

Creating my arts and crafts

Agency Identity:

mother – grandmother – fiancée – friend – artist – baker – cat & dog lover

Les expériences d'exclusion et d'inclusion sociales chez les personnes vieillissant en situation de neurodiversité et leurs proches

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

Luce's Story

January 25, 2023

Université Laval
Faculté des sciences sociales
École de travail social et de criminologie

Luce's Portrait

Luce is a 61-year-old woman who lives in Montreal with her husband, whom she calls "my kindred spirit". With the support and encouragement of both her husband and sister, Luce has acted as the primary family caregiver to her older brother for almost 14 years. Luce began her story by sharing that she grew up in a loving family. She is the youngest of three siblings. The eldest sibling is her brother O, who was born in 1955 and who lives with disability. Luce's older sister P. was born in 1959 and is the middle child. Luce asserted that she has "always known my brother" and that the family dynamic was "already there" by the time Luce was born.

O was first evaluated for developmental delays in early infancy and was diagnosed with intellectual disability and Cerebral Palsy. Beginning in childhood, O had challenges with fine motor skills, personal hygiene and bathroom function, reasoning, and sometimes experienced tantrums, which made hands-on care and supervision part of the family's daily routine. Luce felt that because O "required a lot of attention", she and her sister "grew up very fast". Luce remembered the time when the professionals involved in his treatment decided, at the age of 16, that O needed to go to a psychiatric hospital after it was determined that he already "took everything he could" from his previous "special school". Luce explained, "…in 1970, they did a 360 where they… wanted to understand how much more he was going to learn, how was his development and what kind of care he would need… to get to the maximum of his potential, so they… confirmed that he had Cerebral Palsy and that he had limitations when it came to intellectual development and that's when they determined that if he stayed at home that he was not going to thrive, because he was overprotected… he was not going to be able to become autonomous". For about 10 years, O spent the week in the hospital and returned to the family home every weekend. This was a challenging time for the whole family, especially for O who, though "resigned to the fact that he had to stay there, was sad to leave the house" when he was taken back in the car by his parents and siblings each Sunday. Luce described these trips to drop him off at the institution as "…hard, heart gutting…" for her parents, her sister and herself. Nevertheless, reflecting back Luce believes that it was the "right thing to do" as "it was understood at that time that he needed to move on for his own good so that he could become autonomous". Becoming more autonomous was a motivating factor for O who was determined to be more independent and to be able to live on his own where he could control his own daily life choices, schedule, and activities. Luce shared that "…he wanted to do his own thing, didn't want to have any kind of restriction as to when he came in, when he left, what he ate, you name it. So, he succeeded in becoming more autonomous, but at the same time we always were involved… he came to my family, to my parents' place… he always stayed connected with us…". O was eventually able to leave the psychiatric hospital and experienced several housing transitions including living in family type resources before finally achieving his goal to live in his own apartment. The apartment he stayed in for many years was situated above a pet store, which was a good location for O because, as a "night owl", he could play his music and walk around his apartment without disturbing neighbours. O had frequent supervision each week from service providers to help support his hygiene, cleanliness and to ensure he did not "keep everything" (Luce, I1, 364) in such a way as to clutter his apartment and for it to become a safety risk, as he was prone to hoarding.

Luce recounted that the most difficult decision her parents had to make was to put O under protective supervision with the Public Curator at the age of 18. At the time, doing so was the only way to ensure his eligibility for services. Luce declared "[It] was the worst, the most difficult decision that they had to make. But if they did not do that, they could not have access to any services for my brother, who [was] getting to be 18 years of age and then there's nothing for them, right?... My parents remained very much involved… my brother would come every weekend to see them, but he would be in an environment that would help continue to support him and provide the services that he could not have had, had he remained within the family unit".

Luce spoke lovingly and respectfully about O's many strengths during the two interviews. For example, Luce stated that O "knows the transit system… more than anyone in the city" and is "so smart in so many ways". Luce said that O's situation was very unique because "he is very witty, so that is actually something that would frustrate my father very much because how can he be so strong in so many ways and then at the same time not have the reasoning… it was always such a contradiction in the way that he was so smart in so many ways and at the same time he had those limits that made it even more of a challenge. There is a limit to his reasoning, and he has his own way of thinking you know, so we have to adapt to that".

Luce described O as very social and friendly, willing to talk to everyone and making lasting connections in the different settings he had been in. For example, he spent a few months in a rehabilitation center where he received support after he broke his hip. Luce declared "at that time he was thriving, he had his meals, he had physical education like he had to, you know he loved it, there were all sorts of activities". This was a place he wished he could have stayed at longer. Despite being discharged, O returned to visit there to keep in touch with people he had met as "he basically connected with them and decided to adopt them and vice versa". Luce also described that O was very skilled in getting his needs met over his entire life, and would often approach family, people in his various networks, and even sometimes strangers, to ask for help. According to Luce, this was both a skill and a challenge, because sometimes it meant that O "…goes to people who will have the humanity, and the 'bienveillance' to take care of it, so he'll go back to them all the time for that". Luce shared an example of a woman who worked at a gas station near where he lived, who had been in foster care as a child and so "could connect with O". O would go to visit her regularly and if he asked her for help, she would try to support him. Speaking about herself and her sister, Luce shared that "…he has a little bit of trembling in his hands, his coordination is affected and anything that needs precision, he has a very hard time doing, so he would need assistance for us to do things for him. And also, because he would, it would be easier for him to ask somebody else to do it, he would not necessarily do it on his own unless somebody instilled him to do it, so for a young daughter to have this kind of pressure already, to always be there for her brother it had an impact. … I never knew anything different you know, my sister either, but we became support systems for my brother very early in our lives. My parents sat us down and explained the situation because it was difficult as a child".

Things were not always easy for Luce growing up. In her early childhood, Luce experienced different illnesses that kept her home from school, and so her mother's attention was divided between her, and O. Luce reflected that this was probably the hardest on her sister, who was "in the middle". Luce shared that she coped by eating. Food became an outlet for her, and it was at its worst when she was a teenager between the ages of 13 and 14 years. Luce's relationship with her sister also suffered, as they coped with the situation at home differently. Although Luce "wanted to have a sister in [her] life" it wasn't always easy. However, since their parents have passed away, Luce said that she and her sister were able to reconnect and now have a closer relationship.

Luce shared that her parents wanted her and her sister to be independent women and cared very much about their education. Although she was initially set back in school because of being sick, Luce described how she "really blossomed by the time I got to CEGEP and university". After that, Luce excelled in her career as divisional director with a national company. In 2015, Luce was diagnosed with breast cancer. After undergoing treatment successfully, Luce decided in 2017 to take time to think about her work-life balance. She told us "…my husband was taking his retirement at the same time, so I took a pause between 2017 and 2020 to reflect and say, OK what am I going to do and take more time to get better. I was cancer free at the time, but it scared me and I took a pause and then decided… I volunteered for a couple of years before going back to work part-time and doing something I enjoy so much [working at a retirement home]".

Luce described her parents as "they worked together, they rolled up their sleeves and they made sure that we stayed a unit that was going to be taking care of each other and they stayed, they stayed together until the very end". She explained that her parents "were very much in love, very united" and although having a child with a disability can be difficult, in their case "it unified them". Luce's mother was "the key touchstone, the caregiver" for O until her death in 2009. She was extraordinarily involved as a caregiver in the early years when there were no services available. Luce's father was a doctor, and worked a lot, so she didn't get to see him much in her childhood. With his knowledge and expertise in medicine, Luce's father helped to ensure O received a proper diagnosis and treatment and was involved in medical and administrative decisions throughout his life. Luce shared that, in her adult years, she met many people who worked with, and knew, her father. Luce feels that she "really got to know him much more" (Luce, I1, 37) because of these encounters and affirmed that "after 11 years of his passing, [I] still hear so many great things about him, it's really great".

Throughout her life story, Luce recounted both the triumphs and struggles of having a sibling with a neurodisability. Luce told us that it was sometimes difficult for her, her sister and her parents and at times, she could be frustrated and impatient with O. Luce described different examples of how her brother's needs became overwhelming and reflected upon one meaningful moment in the 1980s when her parents, sister, and she had a meeting with a service provider during which she was asked how she felt for the very first time. Luce reflected that living at home was sometimes difficult, as she didn't always feel comfortable bringing friends over and that, even within the family unit, it was hard "being subjected to an environment that was stressful because everything was focused on him". Luce decided to move out of the family home after her graduation from university at the age of 24. Luce declared that she really wanted to "have my freedom and to be in my own space, my own apartment".

Luce met her first spouse in 1989 when she was 30 years old. She and her spouse moved to England where he wanted to pursue a job opportunity. Luce spent her time abroad volunteering, taking computer courses, and even applied to university to pursue her MBA. Luce told us "my common-law spouse at the time said 'well I have an opportunity, and why don't we just take advantage of it and go', and before we left, even way before then, he knew that my brother was going to be part of my life and that if I decided to go to Europe, that it was only for a certain period of time, because I would eventually need to go back. So, I said 'let's do three years and we'll take it from there, but for sure I'm coming back to Montreal'". Luce admitted that this was "one of the reasons why it didn't work out". Luce explained that her former spouse didn't accept O. She recounted the time when he first met O and told her that he "can't stand this, this is not something that I'm comfortable with". As a result, when he told her he wanted to end the relationship and move on, she felt relieved and "didn't fight it because I wasn't happy either".

Luce shared that she feels "deeply rooted" to Montreal and finally moved back from England on her own when she was 32 years old. "I met with a psychologist for many years during that period of time and it [was] the support of the psychologist that help[ed] me thrive and find my calling, my personal taste and interests. Because I never really thought of what was interesting for me, I was always thinking either [about] work, or my brother, or this and that… and I changed my career at the same time… but the psychologist support was key for me to find my own path… And after someone that is more objective is able to provide me with [an]other outlook, it helped me thrive, it helped me become who I am. It was key for me to go through the family dynamic… even at one point the psychologist said, 'are you able for a certain period of time to disconnect from your family, your brother, your sister, can you step away from all of them, not be so involved, so that you can focus on yourself for a while?' …it was quite an enlightenment... I realized how much you get into the, the day to day not realizing how you get into a rut… and you don't think anymore... That helped me find my way… that's probably why I'm stronger now and that I was able to be open to find a relationship down the road".

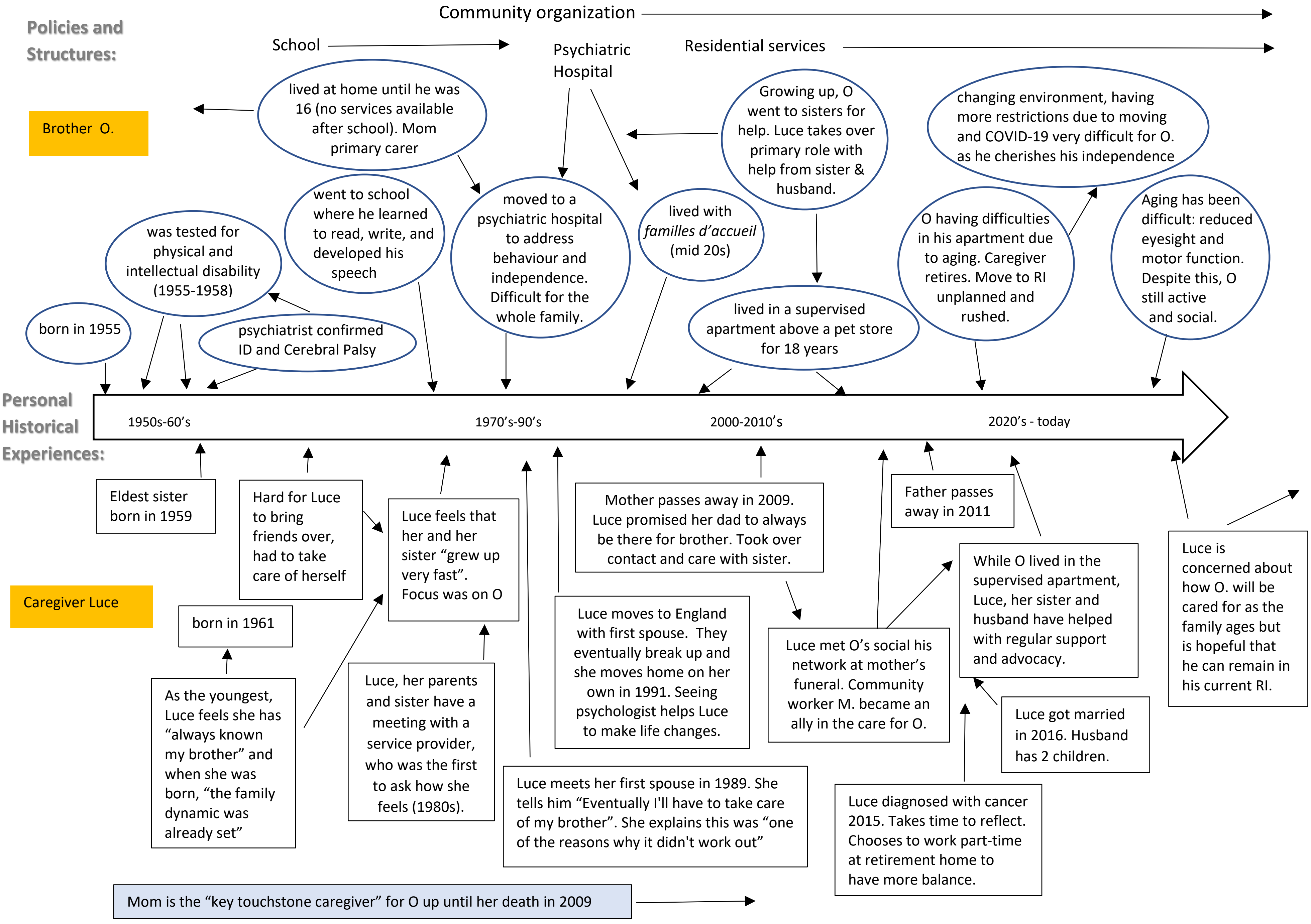
During this time Luce discovered salsa dancing and explained that's where she "blossomed the most". It also became the catalyst for meeting her current husband, whom she married in 2016. In this relationship, it was important to Luce that her significant other had similar values to her and affirmed that he "has to accept my brother, he has to accept my family". Luce felt that the "circumstances with my first relationship [were not] conducive to having children" because "I didn't feel that my relationship was strong enough, [and] I wasn't going to bring in children in that equation unless I knew that they were going to have like a family unit that was strong". Luce shared that she loved and would have welcomed children in her life but that she was already 45 years old when she met her current husband, and so she feels fate decided she wouldn't have children of her own. Still, Luce has "no regrets" and she loves her two adult stepchildren who bring her a lot of joy.

After Luce's mother passed away in 2009, Luce promised her father, then 89 years old and unable to take on O's care, to always be there for her brother. Luce explained that "… in the last few years, especially since my parents have passed, I have my, my husband and I have been really the ones who have been very close to O for his, you know, day-to-day support. He would call us every, almost every other day, you know, to go back to his apartment, the TV didn't work, [or] he needs to change the light bulb, you name it, for any reason. He basically solicited us all the time; we were in his apartment at least 2-3 times a week. And we realized that the apartment was not clean, he was not taking care of it... And he's also a hoarder, which required the support [of the] 'intervenants' who would work with him on a monthly basis, to do a full clean up with him… which was always very difficult for him because he wants to keep everything, it's a safety, he wants to make sure that he's not gonna miss anything. I, we repainted the place, we changed the furniture, we changed everything to make sure that he was in an environment that was, you know, 'salubre', but then you come two weeks later… all the drawers would be completely upside down and then we have to start all over again…".

When speaking about recommendations for health and social care services for people aging with neurodiversity, Luce shared that she feels that no one is looking out for O. Luce worries about O's care, especially without anyone besides herself and her sister to advocate for him. She explained that it’s “unsettling for us as a family, because we're not going to be there forever… Because if something happens to us, I'm very afraid of thinking what would happen to him if we’re not there”. Luce shared that she and her sister created a trust and designated two friends and a cousin to take care of things when they are gone. She also wondered what happens to people who do not have someone looking out for them and stated that “it's as if they are left on their own”. Luce believes that services are lacking in follow-through, and that there is no system to track “the evolution of the needs of a… of the persons who are under their care”. Luce shared that it was scary to think that someone who is in a vulnerable position is at the mercy of the government’s care from people who don’t know them well because of the constant change of employees. Luce wishes there had been “an opportunity for us to have an annual review and support with psychologists that provide us with insight and tools to understand what the next steps are going to be, [what] you can anticipate that your brother is going to go through, and this is how it may impact you or what you have to look out for…. [But also] to know that we're all working in the same direction... that we're all understanding that what we do has an impact on what they're trying to do so that we're all working in tandem”. Luce also shared “if there's one message it is if we are able to have more continuity and more communication between all parties that are involved in the care of a person with mental and physical disabilities combined, that would be such a relief for everyone involved and my brother would be the one who would benefit the first”. Luce also mentioned the importance of community services and that the community worker M., who works at the organization in which O participates in activities, has become “an ally”. Notably, Luce mentioned that she met M. for the first time at her mother’s funeral which M., as well as several of the people in O’s various social networks, attended. Luce shared that O has always kept his social connections separate from the family and explained that at the funeral “I see all these people coming to see my brother. Never met them before and ultimately on the other side the friends never knew he had a family like us. [I heard someone] he said, you have a brother, you have a sister, you have two sisters? You have, you have a father? And the whole family like the cousins and uncles. And so he really made sure that we didn't know each other because it suits him well. He's very smart, he's very, very intelligent and he knows how to play to get what he wants. That's probably a very good, protection mechanism to say, well, I'm going to get what I need and this is the way I'm going to get it and it's through sentiment, then I'll be able to get what I need. It’s survival, it’s survival and it's fine”. In reflecting, Luce stated that she was grateful to have met M. and to be able to speak to her about her concerns and questions regarding O’s situation and care.

Luce recounted how her brother had to endure many transitions in his lifetime including several changes in housing over the years. Recently, he has had to face new COVID-19 restrictions, and Luce shared that it has been difficult for O to adapt. Luce also described how aging has been challenging for O and reflected on how he “doesn't accept the fact that he's getting older. He finds it very difficult” as he has had to readjust to having reduced eyesight and motor function. Luce told us that “it's just in the last few years, where we realized that he could no longer be in that kind of apartment because he had some issues with… he fell at one point and he broke his hip, so he had to have a surgery. So, it became a little bit more difficult for him to walk… so it was a good time, it was good timing for us to say, you know what, maybe it's time to move on to another type of environment that will be safer for him". The final push came when his formal caregiver of many years, and someone whom O trusted, announced her retirement. According to Luce, “She [caregiver] told the government or the department that she was retiring in May and by July, we didn't know where he was going, and he had to move by August. So that became the emergency where all of a sudden, we had to find something and it was done without any planning, without any thought of the impact it would have on my brother. So that was the mayhem we had to go through at that time. But then we were very lucky finally to find something. But it was all done in an emergency, where it could have been avoided”. Luce exclaimed, “He's 67 and although he did not want to move, he did not want to change, the change had to be made and it was too sudden… I really wonder sometimes had we not been as a family there to help him I'm afraid to think of how it would have happened, you know as far as the transition and to be able to help him move on to a ressource intermédiaire”.

Although the transition was difficult at first, Luce was glad to report that he now seemed to be settling into his new RI that he moved into in 2021, and Luce hopes that he can live the rest of his life there. Still, there have been some new concerns regarding the negative influence of one of the other residents on O that has led to some challenges of which Luce and her sister were only recently informed by the resource. This situation has only reinforced Luce’s concerns about the lack of communication by the Public Curator and lack of care coordination by the system with the family. Luce thoughtfully, and with a touch of sadness, shared that “my hope is that we can take care of him” (Luce, I2, 537), and that she will outlive him so that he won’t have to go through the same loss as when their parents passed away. A big part of Luce’s life story is her brother, his care, and his well-being. She admitted that “my brother is always in my mind” and though she described an unbreakable bond, she and her sister also learned over the years that they needed to set boundaries with their brother in order to maintain a healthy relationship with him, to support their own health and well-being and so that they will have more energy to give in the long run, and as they get older. Luce ended her interviews by emphasizing that she has so much love and admiration for O, “as a person he is honest, he is witty, generous, very soft spoken… he has such a big heart”, and that she is very proud to be his sister.



Policies and Structures:

School

Community organization

Psychiatric Hospital

Residential services

Brother O.

born in 1955

was tested for physical and intellectual disability (1955-1958)

psychiatrist confirmed ID and Cerebral Palsy

lived at home until he was 16 (no services available after school). Mom primary carer

went to school where he learned to read, write, and developed his speech

moved to a psychiatric hospital to address behaviour and independence. Difficult for the whole family.

lived with *familles d'accueil* (mid 20s)

Growing up, O went to sisters for help. Luce takes over primary role with help from sister & husband.

lived in a supervised apartment above a pet store for 18 years

O having difficulties in his apartment due to aging. Caregiver retires. Move to RI unplanned and rushed.

changing environment, having more restrictions due to moving and COVID-19 very difficult for O. as he cherishes his independence

Aging has been difficult: reduced eyesight and motor function. Despite this, O still active and social.

Personal Historical Experiences:

1950s-60's

1970's-90's

2000-2010's

2020's - today

Caregiver Luce

Eldest sister born in 1959

born in 1961

As the youngest, Luce feels she has "always known my brother" and when she was born, "the family dynamic was already set"

Hard for Luce to bring friends over, had to take care of herself

Luce feels that her and her sister "grew up very fast". Focus was on O

Luce, her parents and sister have a meeting with a service provider, who was the first to ask how she feels (1980s).

Luce meets her first spouse in 1989. She tells him "Eventually I'll have to take care of my brother". She explains this was "one of the reasons why it didn't work out"

Luce moves to England with first spouse. They eventually break up and she moves home on her own in 1991. Seeing psychologist helps Luce to make life changes.

Mother passes away in 2009. Luce promised her dad to always be there for brother. Took over contact and care with sister.

Luce met O's social his network at mother's funeral. Community worker M. became an ally in the care for O.

Father passes away in 2011

Luce diagnosed with cancer 2015. Takes time to reflect. Chooses to work part-time at retirement home to have more balance.

While O lived in the supervised apartment, Luce, her sister and husband have helped with regular support and advocacy.

Luce got married in 2016. Husband has 2 children.

Luce is concerned about how O. will be cared for as the family ages but is hopeful that he can remain in his current RI.

Mom is the "key touchstone caregiver" for O up until her death in 2009

Agency Identity:

Sister - Strong - Caring – Independent - Self-reliant - Advocate

Neurodiverse older adults (NDOA) and public sector services: Key information extracted from the Ministry of Health and Social Services datasets.

September 2023 – Samuel Ragot, PhD Student – McGill School of Social Work

The Experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-2024)

This brief covers some of the most important quantitative findings extracted from the Ministry of Health and Social Services statistical reports. All the data presented come from the AS-485 reports filled by “Services DI-TSA” in CIUSSS and CISSS. All the data is publicly available and has been compiled into an Excel spreadsheet. Unless otherwise indicated, all data presented are for the year 2021-2022.

Number of NDOA

In 2021-2022, adults with intellectual disabilities or autism aged 45 and up represented 18,54% of all adults with intellectual disabilities or autism receiving specialized services in the Health and Social Services network. The vast majority of these aging adults were individuals with intellectual disabilities.

Déficience (1)	**45-64**	**65-74**	**75+**	**Total**	**% 45+**
Déficience intellectuelle	4670	1087	238	5995	35,81%
Trouble du spectre de l'autisme	558	55	1	614	3,25%
Total (L.1 + L.2)	5228	1142	239	6609	18,54%

Table 1: demographic data for 2021-2022 - Entirety of Québec

Over a 10-year period, there was **a significant decrease** in the number of NDOA receiving services in proportion over the total population receiving services. This decrease is especially significant for individuals with intellectual disabilities. There were 8 962 individuals with intellectual disabilities in 2011-2012, whereas the number was 5 995 in 2021-2022 (-33.11%). The bulk of the decrease is in the 45-64 category (-38.91%). With regards individuals with autism, the numbers went from 371 in 11-12 to 614 in 21-22 (+65.60%).

It is unclear why there was such a dramatic decrease in the number of aging individuals with intellectual disabilities receiving services in the network.

Different strategies on housing in the province (older adults)

Because all CIUSSS and CISSS have a "populational responsibility" (responsabilité populationnelle), they are free to organize services as they see fit, as long as they respect the overall frameworks and orientations defined by the Health and Social Services ministry.

This has led to differences in the way they serve individuals with intellectual disabilities or autism. In the case of housing, the difference is clear between the CIUSSS de l'Ouest-de-l'Île-de-Montréal and the CIUSSS de la Capitale-Nationale.

All of Québec

Lieu de résidence des usagers DITSA desservis	45-64	65-74	75+	Total 45+	Weight of individuals aged 45+ in this resource type	Repartition of individuals aged 45+ by type of housing
Milieu naturel (parents)	619	30	4	653	3,73%	10,79%
Milieu naturel (autonome)	503	52	6	561	34,33%	9,27%
Ressources non institutionnelle (RNI) gérée par un autre établissement	188	39	1	228	38,64%	3,77%
Autre RNI gérée par le CR	91	26	4	121	53,30%	2,00%
Ressource résidentielle avec assistance continue (RRAC)	179	26	4	209	25,06%	3,45%
Ressource résidentielle avec allocations pour assistance résidentielle continue (RRAAC)	6	0	0	6	30,00%	0,10%
Admis dans un autre établissement	31	13	4	48	46,60%	0,79%
Ressource intermédiaire (RI)	1564	374	78	2016	52,38%	33,31%
Ressource de type familial (RTF)	1441	372	73	1886	52,46%	31,16%
Internat	21	3	3	27	23,89%	0,45%
Foyer de groupe	2	0	0	2	9,09%	0,03%
Autres	74	31	7	112	32,56%	1,85%
Total (L.1 à L.12)	4719	1150	184	6053	21,00%	

Table 2: housing data for 2021-2022 - All of Québec

The data for the entirety of Québec draws an interesting picture: in 2021-2022, most individuals of all ages (60,69%) lived with their natural family (parents, siblings). However, this was not the case for adults over 45, with only 10,79% of them living with their family. Only a small proportion lived independently, while 33,31% lived in a "Ressource intermédiaire" and 31,16% lived in a "ressource de type familiale". The rest of aging individuals lived in other community or health and social services institutions.

CIUSSS de l'Ouest-de-l'Île-de-Montréal

Lieu de résidence des usagers DITSA desservis	45-64	65-74	75+	Total 45+	Weight of individuals aged 45+ in this resource type	Repartition of individuals aged 45+ by type of housing
Milieu naturel (parents)	70	2	1	73	6,67%	16,15%
Milieu naturel (autonome)	56	8	0	64	64,65%	14,16%
Ressources non institutionnelle (RNI) gérée par un autre établissement	1	0	0	1	100,00%	0,22%
Autre RNI gérée par le CR	0	0	0	0	-	0,00%
Ressource résidentielle avec assistance continue (RRAC)	4	1	0	5	38,46%	1,11%
Ressource résidentielle avec allocations pour assistance résidentielle continue (RRAAC)	0	0	0	0	-	0,00%
Admis dans un autre établissement	0	0	1	1	100,00%	0,22%
Ressource intermédiaire (RI)	42	5	0	47	27,33%	10,40%
Ressource de type familial (RTF)	181	37	15	233	57,53%	51,55%
Internat	0	0	0	0	-	0,00%
Foyer de groupe	0	0	0	0	0,00%	0,00%
Autres	6	3	1	10	76,92%	2,21%
Total (L.1 à L.12)	360	74	18	452	25,08%	

Table 3: housing data for 2021-2022 - CIUSSS de l'Ouest-de-l'Ile-de-Montréal

Numbers for the CIUSSS de l'Ouest-de-l'Ile-de-Montréal show a significant difference from the numbers for the entirety of the province, with more than 50% of aging individuals living in RTF and only 10% in RI. The number of individuals living autonomously is also superior to the rest of the province.

CIUSSS de la Capitale-Nationale

Lieu de résidence des usagers DITSA desservis	45-64	65-74	75+	Total 45+	Weight of individuals aged 45+ in this resource type	Percentage of individuals aged 45+ housed in this type of housing
Milieu naturel (parents)	48	5	0	53	9,01%	11,65%
Milieu naturel (autonome)	27	3	2	32	50,00%	7,03%
Ressources non institutionnelle (RNI) gérée par un autre établissement	1	0	0	1	50,00%	0,22%
Autre RNI gérée par le CR	0	0	0	0	-	0,00%
Ressource résidentielle avec assistance continue (RRAC)	45	10	4	59	33,15%	12,97%
Ressource résidentielle avec allocations pour assistance résidentielle continue (RRAAC)	0	0	0	0	-	0,00%
Admis dans un autre établissement	5	0	0	5	62,50%	1,10%
Ressource intermédiaire (RI)	141	24	9	174	56,86%	38,24%
Ressource de type familial (RTF)	76	17	5	98	60,12%	21,54%
Internat	0	0	0	0	-	0,00%
Foyer de groupe	0	0	0	0	0,00%	0,00%
Autres	8	3	1	12	42,86%	2,64%
Total (L.1 à L.12)	351	83	21	455	34,01%	

Table 4: housing data - 2021-2022 - CIUSSS de la Capitale-Nationale

Overall numbers for the CIUSSS de la Capitale-Nationale are interesting because they vary from the rest of the province. In this CIUSSS, more individuals live within “Ressources résidentielles avec assistance continue”, a model that was largely abandoned in the rest of the province. These resources are similar to RI, but have a higher intensity of services.

Contrary to the CIUSSS de l'Ouest-de-l'Ile-de-Montréal who seems to have developed a model based on RTF, the CIUSSS de la Capitale-Nationale has bet on RIs to serve its aging population, with almost 40% of them living in these settings. A significant number of individuals live in RRAC (12,97%), which is more than the average in Québec.

Privatized housing dominates all other forms of housing and is not sustainable.

Importantly, these resources (RI, RTF) are private businesses with varying degrees of quality and conformity to established norms. All these resources are nonetheless subsidized by public funds.

Some organizations, such as the Quebec Intellectual Disability Society, consider these housing resources to be small institutions. Because of the lack of control, the lack of autonomy and the sometimes-extreme privation of liberty, these housing models fit the UN criteria for institutions. This is worrying, as Québec is supposed to have largely gotten rid of institutions. The fact that public funds are used for such housing models is a problem in and of itself. This problem is compounded by the fact that the cost per capita of housing is extremely high. In 2021-2022, the dedicated budget for institutionalized housing (RI, RTF, internat, RRAC) was $686 346 640,40 (six hundred eighty-six million, three hundred forty-six thousand, six hundred forty dollars and forty cents), or 50,94% of the overall DI-TSA budget ($1 347 262 718,26). These numbers have been growing steadily for the last 10 years, from $490M in 2013-2014 to the current $686M in 2021-2022, a 39% increase in less than 10 years. In fact, of the overall increases in DI-TSA budgets since 2013-2014, more than half of the money went to these housing models ($195M of $369M).

Based on the available data from the ministry, there were 8411 individuals living in RI, RTF, internat or RRAC in 2021-2022 (including 4144 NDOAs). This means that the cost per capita was around $81 601. In other words, it costs public funds in average $81K to house an NDI in a privatized housing setting. This high price per capita raises questions about the sustainability of the model. There are currently 2 465 NDOA that apparently are housed elsewhere than in an RI, RTF, internat or RRAC. If all these individuals had to be housed in a privatized setting, this would represent additional costs of around $201M. In addition, it is clear that the waiting lists are already endless. It is therefore very doubtful that the network would even be able to find satisfying housing for all these individuals.

NDOA Are on Endless Waiting Lists

There is a global problem with waiting lists in the health and social services network. However, NDOAs are at a much bigger disadvantage, as in 2021-2022 there were more cases closed than opened for this population.

Par type de déficience	45-64	65-74	75+	Total	% of 45+ over total population
Reçues				Received	
– Déficience intellectuelle (DI)	408	110	22	540	17,15%
– Trouble du spectre de l'autisme (TSA)	70	7	1	78	1,06%

Total (L.1 + L.2)	478	117	23	618	5,89%
Reçues dont les services ont débutés	**Services started**				
– Déficience intellectuelle (DI)	318	94	31	443	18,54%
– Trouble du spectre de l'autisme (TSA)	55	5	0	60	1,03%
Total (L.4 + L.5)	373	99	31	503	6,11%
Fermées	**Closed**				
– Déficience intellectuelle (DI)	683	270	92	1045	31,38%
– Trouble du spectre de l'autisme (TSA)	87	15	0	102	1,68%
Total (L.7 + L.8)	770	285	92	1147	12,18%

Table 5: service requests by diagnostic - all of Québec

It is questioning to see there are several times more service requests closed in a year than service started, especially for individuals with intellectual disabilities. This seems to correlate with the freefall of the numbers individuals with intellectual disabilities receiving services in the network year after year. In addition, it seems aging individuals are usually slower to receive a first service than the average for the total population. For both aging individuals with intellectual disabilities and autism, the waiting time is longer than for the entire group of individuals receiving services.

Déficience intellectuelle (DI)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	182	53	11	246	18,64%
– Délai moyen (days)	391,39	379,92	266,89	346,07	-12,96% faster than average wait times of all individuals waiting for services (all ages)
– Délai median (days)	110,00	110,00	110,00	110,00	0,00% faster than median wait times of all individuals waiting for services (all ages)

Trouble du spectre de l'autisme (TSA)					
– Nombre de personnes	49	3	-	52	1,05%
– Délai moyen (days)	365,51	284,78	-	325,15	-18,94% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	200,00	-	-	200,00	9,60% faster than median wait times of all individuals waiting for services (all ages)
Nombre de personnes Total (L.1 + L.4)	231,00	56,00	11,00	298,00	4,75%
Délai moyen – Total (days)	404,73	465,05	266,89	378,89	-17,72% faster than average wait times of all individuals waiting for services (all ages)
Délai médian – Total (days)	171,00	249,00	175,00	175,00	3,05% faster than median wait times of all individuals waiting for services (all ages)

Table 6: users waiting for a first service – all diagnostics - all of Québec

PAGE 18 – NOMBRE D'USAGERS EN ATTENTE D'UN SERVICE AVEC UNE DI

Services d'adaptation et de réadaptation en contexte d'intégration communautaire (s-c/a 7001)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	82,00	22,00	2,00	106,00	32,92%
– Délai moyen (days)	671,69	804,05	1211,40	895,71	-96,71% faster than average wait times of all individuals waiting for services (all ages)

– Délai médian (days)	346,00	252,50	-	299,25	-172,05% faster than median wait times of all individuals waiting for services (all ages)
Service d'intégration au travail (s-c/a 7011, 7024, 7025 et 7031)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	110,00	12,00	1,00	123,00	19,49%
– Délai moyen (days)	644,99	1360,50	1112,00	1039,16	-103,41% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	298,00	150,00	-	224,00	-130,93% faster than median wait times of all individuals waiting for services (all ages)
Services d'intégration résidentielle (s-c/a 5516, 5526, 5536, 5546, 6945, 6983, 7041 et 7051)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	178	39	6	223,00	31,06%
– Délai moyen (days)	1446,60	1574,59	1067,00	1362,73	-31,47% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	1155,00	874,00	319,50	874,00	-36,67% faster than median wait times of all individuals waiting for services (all ages)
Services d'adaptation et de réadaptation à la personne (s-c/a 8051)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**

– Nombre de personnes	589	193	58	840,00	29,42%
– Délai moyen (days)	429,24	422,36	886,86	579,49	-45,15% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	141,00	235,00	347,00	235,00	-33,52% faster than median wait times of all individuals waiting for services (all ages)
Nombre de personnes Total (L.1 + L.4 + L.7 + L.10)	959	266	67	1292,00	28,55%
Délai moyen – Total (days)	866,11	871,91	1391,82	1043,28	-51,95% faster than average wait times of all individuals waiting for services (all ages)
Délai médian – Total (days)	327,50	296,25	435,50	327,50	-21,46% faster than median wait times of all individuals waiting for services (all ages)

Table 7: users waiting for services - intellectual disabilities - all of Québec

In all service categories (work, housing, direct support), aging individuals with intellectual disabilities receive services much more slowly than the average for the entire population.

PAGE 19 – NOMBRE D'USAGERS EN ATTENTE D'UN SERVICE AVEC UN TSA

Services d'adaptation et de réadaptation en contexte d'intégration communautaire (s-c/a 7001)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	18	1	0	19,00	13,19%
– Délai moyen (days)	841,5	32,5	-	437,00	-66,60% faster than average wait times of all individuals waiting for services (all ages)

– Délai médian (days)	380	-	-	380,00	-

Service d'intégration au travail (s-c/a 7011, 7024, 7025 et 7031)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	22	1	0	23,00	6,01%
– Délai moyen (days)	447,125	82,75	-	264,94	-37,09% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	277	-	-	277,00	-417,76% faster than median wait times of all individuals waiting for services (all ages)

Services d'intégration résidentielle (s-c/a 5516, 5526, 5536, 5546, 6945, 6983, 7041 et 7051)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	14	1	0	15,00	3,37%
– Délai moyen (days)	1012,44444	612	-	812,22	-43,04% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	1082	-	-	1082,00	-302,98% faster than median wait times of all individuals waiting for services (all ages)

Services d'adaptation et de réadaptation à la personne (s-c/a 8051)	**45-64**	**65-74**	**75+**	**Total / Median / Average**	**% of 45+ over total population / median and average waiting compared to entire group**
– Nombre de personnes	106	7	2	115,00	1,41%

– Délai moyen (days)	386,9475	466,375	203,6	352,31	-4,60% faster than average wait times of all individuals waiting for services (all ages)
– Délai médian (days)	169	206,5	-	187,75	11,54% faster than median wait times of all individuals waiting for services (all ages)
Nombre de personnes Total (L.1 + L.4 + L.7 + L.10)	160	10	2	172,00	1,88%
Délai moyen – Total (days)	734,17875	509,375	169,6666667	471,07	-7,55% faster than average wait times of all individuals waiting for services (all ages)
Délai médian – Total (days)	230	139	-	184,50	15,99% faster than median wait times of all individuals waiting for services (all ages)

Table 8: users waiting for services - ASD - all of Québec

The situation is very similar for individuals with ASD, with a slightly faster access to direct services to individuals.

Conclusion

The MSSS data show that the proportion of people aged 45 and over receiving specialized services from MSSS has decreased significantly in recent years. This decline, although significant, remains unexplained for the moment. It is indeed impossible to know where people went, whether they obtained services from other programs or directorates of the MSSS or whether their files were simply closed. The fact remains that this decline in the number of people aged 45 and over receiving services raises important questions about access to specialized services from the health and social services network (where these services exist) among NDOA.

Furthermore, the data related to housing and accommodation highlight Quebec's ever-increasing dependence on private residential resources (RI-RTF), despite their high cost. The lack of public or community provision is flagrant and raises questions about the models currently in place.

Added to this portrait are the endless waiting lists for NDOA and their families. It is clear that the MSSS and the CISSS/CIUSSS are unable to “provide” in terms of housing resources and that current models do not meet demand. Both the families met during the research and the present data analysis highlight the fact that it is often necessary to wait years before obtaining a place in a residential resource and that the home care offer is very limited for NDOA. This is despite the fact the home care policy in Quebec provides that home care should always be “the first choice”. The little attention given to home care services for those receiving services from the ID-ASD-PD directorate, reflected by the very low proportion of people stating that they live in an autonomous home environment or with family members, casts a shadow over the picture and highlights the lack of consideration of NDOA in home support policies, which are mainly geared towards the general senior population.

Considering all of these elements, it seems clear that a fundamental reflection should be initiated by the Government of Quebec in order to identify innovative and alternative models to those in currently in place. Such a reflection should include people with disabilities, their families, disability rights organizations, as well as all community partners and relevant ministries and agencies

Exploring the inclusion of neurodiverse older people in Quebec's social policies: the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as an analytic tool

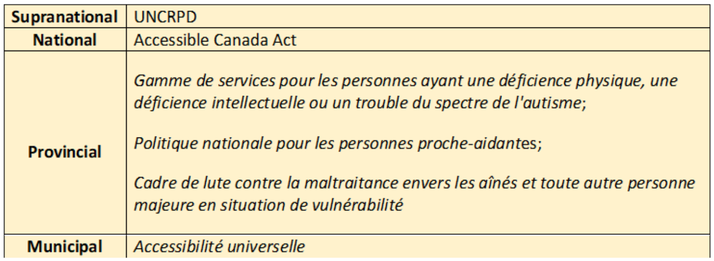
Évelyne Tanguay-Sela, Daniel Dickson, Samuel Ragot, Shari Brotman, Laura Pacheco, Marie-Helene Deshaies, and Camille Demers

Individuals aging with neurodiversity (i.e. intellectual disability (ID) or autism spectrum (ASD)) face unique challenges that inclusive policy design and person-centred care strategies can address (Brotman et al., 2021). We ask:

To what extent do recent Quebec policies on aging and ID/ASD consider aging neurodiverse individuals' realities?

Background

This work is part of the research project ***"The Experiences of Social Exclusion and Inclusion Among People Aging with Neurodiversity and Their Families" (2020-2024),*** which seeks to better understand experiences of social exclusion among neurodiverse older adults (NDOA) and their families. This textual analysis of three Quebec policies aims to provide a policy context to the accounts collected in the study.

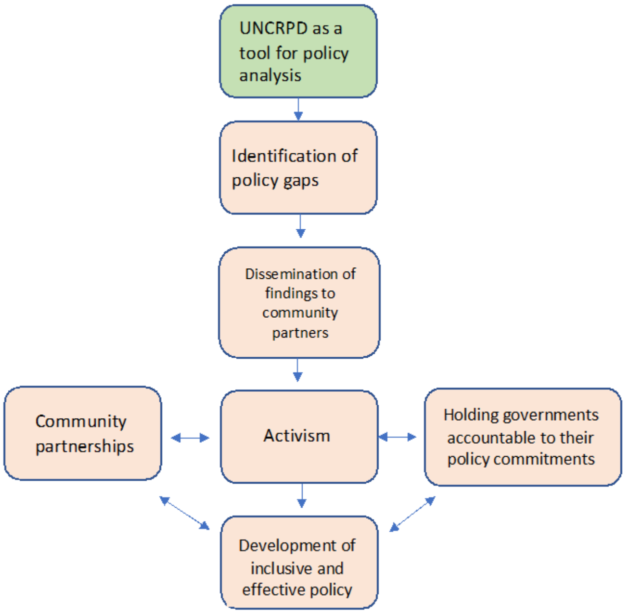


Supranational	UNCRPD
National	Accessible Canada Act
Provincial	*Gamme de services pour les personnes ayant une déficience physique, une déficience intellectuelle ou un trouble du spectre de l'autisme;* *Politique nationale pour les personnes proche-aidantes;* *Cadre de lute contre la maltraitance envers les aînés et toute autre personne majeure en situation de vulnérabilité*
Municipal	*Accessibilité universelle*

Figure 1. Levels of jurisdiction involved in the implementation of policies

Method

- A textual policy analysis was conducted to examine the inclusion of neurodiverse older adults in several recent Quebec policies in relation to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006).
- This analysis uses a selection of measures identified and defined in the UNCRPD as a tool to explore the extent to which the policies consider aging neurodiverse individuals' realities. These **concepts are considered by the UN to have the potential to improve the rights of disabled people if implemented in legal and policy contexts.** The measures used in this analysis include: equality and non-discrimination (article 5), living independently and being included in the community (article 19), accessibility (article 9), access to justice (article 13), participation in political and public life (article 29), awareness raising (article 8), and national implementation and monitoring (article 33). These UNCRPD measures were chosen based on the UN Report on the rights of older persons with disabilities, which highlights key concepts related to the intersection between aging and disability (Devandas-Aguilar, 2019).
- **Quebec policies analyzed**: *Gamme de services pour les personnes ayant une déficience physique, une déficience intellectuelle ou un trouble du spectre de l'autisme* (2021); *Politique nationale pour les personnes proche-aidantes* (2021); *Cadre de lute contre la maltraitance envers les aînés et toute autre personne majeure en situation de vulnérabilité* (2020).



UNCRPD as a tool for policy analysis

Identification of policy gaps

Dissemination of findings to community partners

Community partnerships

Activism

Holding governments accountable to their policy commitments

Development of inclusive and effective policy

Figure 2. UN-CPRD as an analytic tool

Key Findings

- There is a **general lack of explicit mention of neurodiversity and aging** within recent policies. While the "Gamme de services" policy mentions that needs change as one ages, it **does not provide a response for these needs.** On the other hand, the policies related to caregiving and mistreatment focus mainly on aging individuals and do not account for realities that are specific to neurodiverse people.
- The studied policies have **integrated some UN-CRPD measures**. For instance, concepts related to awareness-raising have been identified in all three policies, demonstrating that they has been identified as a priority.
- **Some UNCRPD concepts are often absent or only implicitly referred to.** While implementation strategies (national implementation and monitoring) are included in the caregiver policy, they are underdeveloped in the mistreatment policy and absent from the "Gamme de services" policy. Although implementation is addressed within the 'plans d'action' which were released following, the **scarcity of actionable measures addressing NDOA** is reflected in the experiences of the frontline workers interviewed in this project, who expressed a need to compensate for a lack of service direction and inconsistency in policy implementation.

Conclusions

Lack of intersectionality

Policies are geared either towards older adults or neurodiverse people, with little to no attention to the intersection of both identities. Due to these institutional silos, the policies **do not account for the specific realities and challenges faced by this population**. Without specific policies geared towards aging neurodiverse individuals, Quebec's health and social services system cannot adequately meet their needs.

Inconsistent incorporation of UN-CRPD measures

While the UN-CRPD has been signed by Canada as a means of advancing the rights of individuals with disabilities, the attention provided to its measures in the studied policies is inconsistent. With priority given to some measures over others, **the policies are not comprehensive** according to the standards outlined by the UN-CRPD. The **absence of vital information**, such as implementation strategies targeting NDOA or opportunities for the participation of individuals in their own service provision (national implementation and monitoring and participation in political and public life), represents a significant gap, that could have been avoided by using the UN-CRPD as a tool for the development of the policies.

Challenges to effective policy implementation

The lack of explicit mention of neurodiversity and aging within recent policies represents a significant challenge to the effective implementation of inclusive programs and services in Quebec. As no specific consideration is granted to this population and measures outlined by the UN-CRPD to advance their rights are only sparsely integrated, **service providers are expected to meet their service users' needs without proper institutional support or resources**.

Recommendations

- Promote communication between services for aging adults and disability services to reduce silos;
- Integrate the voices of NDOA and their caregivers as collaborators in developing the policies that affect them;
- Incorporate precise, measurable and actionable implementation strategies related to NDOA and their families in policies;
- Create partnerships between aging and disability community services to improve service provision for NDOA and to fuel advocacy through the dissemination of knowledge and experiences;
- Refer to the UN-CRPD in policy analysis and advocacy efforts as a way of identifying concrete gaps in policy and service delivery and of holding governments accountable to their commitments.

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

Appendix 8 - Knowledge mobilization activities – realized and to come

Knowledge mobilization activities

- Celebration, presentation of the performance *Neurodiversity! Age together, Act together*[1] (drawn from some of the quotes from our NDOA participants), exhibit and reflection held during the CREGES annual conference held on Monday May 27, 2024,
- Celebration and exhibit in Quebec City held on June 10-11, 2024,
- Final report, as well as several publications currently being written,
- Uploading of infographics on the CREGES website,
- Publication of a collective book of the life stories of the participants,
- Creation of animated podcasts of participants' life stories,
- Engagement with organizations defending the rights of people aging with neurodiversity,
- Networking with different projects, including the ReVie project focusing on the evolution of public policies related to people aging with neurodiversity.

Presentations realized:

Pacheco, L., Brotman, S., Deshaies, MH., Mastrostefano, A., Demers, C. (2024). Holding on to the parenting identity throughout the life course: Life story narratives of aging parents with neurodiversity. International association for the scientific study of intellectual and developmental disabilities (IASSIDD). Chicago, August 7, 2024.

Koestner, S., Brotman, S., Pacheco, L., Mastrostefano, A., Deshaies, MH., Demers, C., D., Dickson, Ragot, S. (2024). Food is a footprint of who we are: Exploring the tensions between food as identity metaphor and food as social control mechanism among people aging with neurodiversity (poster). International association for the scientific study of intellectual and developmental disabilities (IASSIDD). Chicago, August 6, 2024.

Brotman, S., Demers, C., Allan-Coté, J., Pacheco, L., Deshaies, MH (2024). Building on the emancipatory potential of community-engaged research through theatre-driven knowledge-sharing: The experiences of people aging with neurodiversity and their families project in 'act'-ion. Canadian Association of Social Work Education (CASWE) annual conference. Montreal, June 18, 2024.

Ragot, S. et Demers, C. (2024) Vieillissement, inclusion et agentivité des personnes vieillissantes en situation de neurodiversité. Réseau d'Études international sur l'âge, la citoyenneté et l'intégration socio-économique (REIACTIS). Montreal, le 5 juin, 2024

Brotman, S. (2024) Opportunities and challenges when operationalizing the Intersectional lifecourse perspective (ILCP) as social justice research praxis: Lessons from the field. Équipe VIES Scientific Student Day: Social justice and empowerment in the aging population. Montreal, QC, March 25, 2024.

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[1] This performance was created in part thanks to the grant « *Support for knowledge mobilization by the voluntary sector* of the Aging Institute of the Canadian Institute of Health Research » received by **Sans Oublier le Sourire.**

Demers, C. and Mastrostefano, A. (2024). Resilience and resistance: Exploring of older neurodiverse adults across the lifecourse. Équipe VIES Journée scientifique étudiante :
La justice sociale et l'empowerment chez la population vieillissante. Montreal, QC, le 25 mars 2024.

Pacheco, L., Brotman, S., Deshaies, M.H., Mastrostefano, A., Mackenzie, R., Tanguay-Sela, E., Sussman, T., Dickson, D., Lach, L., Raymond, E., Milot, E., Freitas, Z. (2024). Caring for people aging with neurodiversity: The intersectional life story narratives of family caregivers in Montreal. Pacific Rim International Conference on Disability and Diversity, Honolulu, Hawai'I, February 28, 2024.

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Tanguay-Sela, E., Dickson, D., Ragot, S., Simard, J., Brotman, S., Pacheco, L., Deshaies, M.H. (2023). Examining the disjuncture between housing policy and the intersectional life course experiences of people aging with neurodiversity in Quebec (poster). Congress of the Canadian Association on Gerontology. Toronto, ON, October 27, 2023.

MacKenzie, R., Brotman, S., Mastrostefano, A., Pacheco, L., Tourangeau, J., Al-Ahmad, W. (2023). Experiences of resilience and resistance across the life course: Stories of Indigenous women aging with neurodiversity and their families in Montreal. Congress of the Canadian Association on Gerontology. Toronto, ON, October 27, 2023.

Tanguay-Sela, E., Dickson, D., Ragot, S., Brotman, S., Pacheco, L., Deshaies, M.H., , C. Demers (2023). Exploring the inclusion of neurodiverse older people in Quebec's social policies: the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as an analytic tool (poster). Congress of the Canadian Association on Gerontology. Toronto, ON, October 27, 2023.

Pacheco, L., Brotman, S., Deshaies, MH., Mastrostefano, A., Tanguay-Sela, E., Mackenzie, R., Sussman, T., Dickson, D., Lach, L., Raymond, E., Milot, E. (2023). Stories of resilience and resistance among older neurodiverse people in Québec. EAMHID, Helsinki Finland, September 21, 2023.

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Brotman, S. & Pacheco, L. (2022). Les expériences d'exclusion et d'inclusion social chez les personnes vieillissantes en situation de neurodiversité et leurs proches. Bien vieillir en situation de handicap et/ou de neurodiversité: Découvrez des initiatives inspirantes. L'Accompagnateur.org. 13 décembre, 2022.

Mastrostefano, A., Pacheco, L., Brotman, S., Lach, L., Dickson, D. (2022). Co-occurrence of intellectual/developmental disability (IDD) and mental illness (MI) among older adults: Exploring opportunities in, and challenges to, the provision of services in Montreal (poster). Canadian Association on Gerontology. Regina, SK, October 21, 2022.

Brotman, S., Mastrostefano, A., Pacheco, L., Deshaies, MH, Elias, B., Sussman, T., Lach, L. Dickson, D. (2022) Exploring agency and voice in qualitative research with neurodiverse older adults. Canadian Association on Gerontology, Regina, SK, October 22, 2022.

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Publications:

Ragot, S., Brotman, S., Deshaies, S., et al. (2024, abstract accepted – in development). Résilience et résistance: exploration des expériences d'exclusion sociale chez les personnes vieillissant en situation de neurodiversité et leurs proches au Québec. Revue Travail Social numéro thématique « Vieillissements, diversités, inégalités » É. Raymond, MH., Deshaies, A. Maindelson Joseph (éditeurs).

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Présentations to come:

Brotman, S. (November 8, 2024). The experiences of aging with co-occurring neurodiversity and mental health challenges: Stories of challenge and resilience. Center for Dreams and Hopes Montreal. McGill University.

Mastrostefano, A. (November 8, 2024). Neurodiversity! Age together, Act together: A video and toolkit to enhance learning and training on aging, neurodiversity and mental health. McGill University.

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Annexe 9 - Événements de célébration
Appendix 9 – Celebration events

Célébration

Perfomance artistique

Exposition

Espace de réflexion

Neurodiversité ! Vieillir ensemble, Agir ensemble

L'équipe du projet « Les expériences d'exclusion et d'inclusion sociale chez les personnes vieillissant en situation de neurodiversité et leurs proches » est fière de vous inviter à son évènement de célébration et de réflexion.

Une performance artistique bilingue présentée par La Gang à Rambrou et Sans Oublier le Sourire présentant les résultats de notre recherche sera suivie d'un espace de réflexion et d'exposition. *Collations fournies. Activités bilingues. Option hybride.*

Lundi 27 mai de 14h00 et 16h00

Les 7 Doigts (studio 2)
2111, Boulevard Saint-Laurent,
Montréal, Québec H2X 2T5

Inscription obligatoire* sur le site du colloque : https://event.fourwaves.com/fr/creges-agir-marginalisation/

*Gratuit pour ceux et celles ayant participé au projet de recherche.

Notre évènement fait partie du colloque Agir sur la marginalisation des personnes âgées : Des savoirs à l'action.

Pour plus de renseignements, contactez Shari Brotman
shari.brotman@mcgill.ca

www.creges.ca/vieillissement-neurodiversite/

EXPOSITION

Projet de recherche

Les expériences d'exclusion et d'inclusion sociale chez les personnes vieillissant en situation de neurodiversité et leurs proches

Lancement : 10 juin, de 16h à 19h
Exposition libre : 11 juin de 10h à 15h

Habitations Marie-Clarisse,
1130, 18e Rue, Québec, QC, G1J 1Z1

marie-helene.deshaies@tsc.ulaval.c

Projet de recherc financé par :