

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



INFOGRAPHICS

Our research project explores experiences of social exclusion and inclusion among **21 neurodiverse older adults (NDOA)** 45-78 years old and **15 family caregivers 51-87 years old** (parents and siblings) in Montreal and Quebec City. Our goal was to collect people's stories about their lives; their experiences of growing older; their strengths, hopes and dreams; their housing realities, needs, and wishes; their experiences with health and social services; and their social networks and supports. We also spoke with 27 service providers from public and community sector programs and services to gain their perspectives on the realities and challenges facing older adults living with neurodiversity and their families.

Our **Research Process** and the **Themes** emerging from our study are presented in the form of **infographics**. Each infographic contains important information on each theme including **QUOTES FROM OUR PARTICIPANTS** as well as **KEY RECOMMENDATIONS** for **service providers and policy-makers** across sectors.

Visit our website to read/download our infographics!

 www.creges.ca/en/aging-neurodiversity 

OUR PROJECT

Our research process

Our project engaged in narrative conversations with people about the meaningful events in their lives and used an arts-based approach (co-created life-line drawings) as a storytelling tool. See this infographic for a description of our project objectives and process!



Drawing by Aglaé,
research assistant

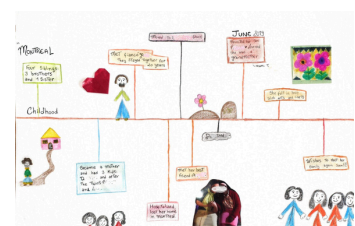
Our team

Consult this infographic to know more about our research team, our advisory group and our organizational partners in Montreal and in Quebec City !



Our participants

This infographic gives some information about our participants (gender, age, living arrangement / housing situation). It also includes the employment context of the service providers we interviewed.



Drawing by Tina, NDOA

OUR INFOGRAPHICS ON EMERGING THEMES

Aging

This infographic illustrates how people aging with neurodiversity experience aging and how they navigate changes like **new limitations**, loss, and uncertainty. They often share stories of **hope** and proudly speak about feeling **young at heart**. Family caregivers and service providers also share their perspectives on such issues as parallel aging and barriers to care. Check out this infographic to **find out what needs to be done to improve and enhance integrated policies and services**.



Monstres, 2018
Collective work of art by older artist members of Sans Oublier le Sourire and students from Élan, an alternative school

Caregiving

Explore this infographic to learn more about the **central role of family caregivers** (parents and siblings) and to have a better understanding of the **challenges** caregivers face in the **context of life-long caregiving** and **parallel aging**. Find out what **services and support systems** need to be put in place to better support family caregivers as they age.



Amour, NDOA

Housing

Housing that **promotes social inclusion** helps everyone live better and feel happier. Our infographic highlights some of the **housing challenges** faced by neurodiverse older adults, such as: untimely transitions, unwanted surveillance, long waitlists, lack of control over daily life, and other threats to self-determination and pride. Consult this infographic for **tips on how to work toward housing justice**.



New house (2016), NDOA living in a CHSLD

Mental Health and addictions

Many people aging with neurodiversity face **mental health challenges** and some experience **substance misuse**. Some challenges are lifelong and others emerge later in life, influenced by factors like **institutionalization** and early trauma. Despite these obstacles, they demonstrate courage and resilience. Explore this infographic to learn more about the **barriers** they encounter and what **inclusive services and support systems** could look like.



Drawing by Shari, researcher

Mistreatment

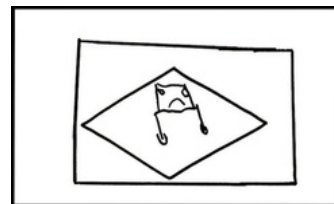
Mistreatment is a pervasive and life-long experience faced by many people aging with neurodiversity. Check out this infographic to learn more about the **different forms of mistreatment** people face and how some people are standing up against mistreatment. **Learn about the steps necessary to combat mistreatment**.



Drawing by Jasmine, community partner

Lack of control over daily life

Many neurodiverse older adults face challenges **asserting control over their daily lives** due to restrictions placed upon them by others. Explore our infographic to learn about how people experience these restrictions and how we can create empowering conditions that support autonomy and choice.



No title, NDOA
Drawing workshop in community organization

Gaps and challenges in the health and social service system

People aging with neurodiversity and their family caregivers often feel **overwhelmed, isolated or underserved** because of the many **gaps and challenges** in the health and social service system, including **poor communication, long waitlists, high turnover rates, and fragmented services**. Consult this infographic to learn about these gaps and challenges, and to consider how they can be addressed.



Drawing by Aglaé, research assistant

Parenting

This infographic sheds light on the challenges that **parents aging with neurodiversity** face, including a **heightened risk of child removal** and insufficient support. It also highlights their **strengths, hopes, and the enduring love** they feel for their children and grandchildren. Learn more about the services and support systems necessary to improve the lives of neurodiverse parents throughout their parenting journey.



My family by Tina, NDOA

The role of community organizations

Community organizations are crucial to helping people aging with neurodiversity and their family caregivers navigate and **access services, form connections, and make their voices heard**. However, they often need more resources to do everything they'd like to do. Check out our infographic to see **what makes community organizations so special and how we can best support them**.



Happiness for me is... (2023),
collective work
NDOA and socio-community worker at the
Senior's Club

Identity, agency, activities, and pride

People aging with neurodiversity share their unique **identities, experiences, strengths, and achievements**, emphasizing meaningful aspects of their lives while reflecting on the barriers they've overcome. Check out this infographic for their insights and lessons on **how they want to be treated**.



Drawings taken from
Batman's life line

Each infographic has its own list of recommendations for inclusive policies and programs specific to the theme addressed. Below we present some cross-cutting recommendations for your consideration:



Cross-cutting recommendations

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

We are deeply grateful to all of our participants for sharing their stories with us over the 4 years of the project! We hope that their words, and our project, will inspire reflection and action among each and every one of us! Our goal as a research team is to centre the voices of older adults, their family caregivers and the service providers who support them in order to sensitize, educate, and advocate for more inclusive and integrated policies, programs, and services that better respond to the needs and wishes of people aging with neurodiversity and their families.

Please stay in touch with us as we continue our work!



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