

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



Infographics

June 2024

www.creges.ca/en/aging-neurodiversity

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Infographics

Our research project explores experiences of social exclusion and inclusion among 21 neurodiverse older adults 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** that include **QUOTES FROM OUR PARTICIPANTS** as well as **KEY RECOMMENDATIONS** for **service providers and policy-makers** across sectors.

Our Project

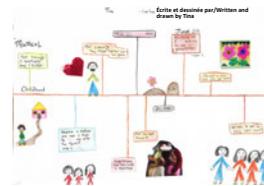
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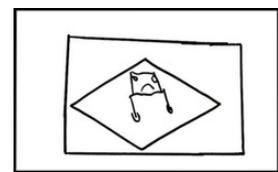
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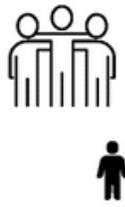
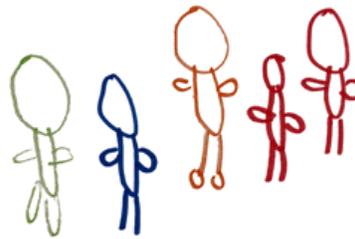
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Our research project explores experiences of **social exclusion and inclusion** among **neurodiverse** older adults and their family caregivers in Montreal and Quebec City. Our goal is to collect people's stories about their lives; their experiences 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 will also speak with service providers to gain their perspectives on the realities and challenges facing older adults living with neurodiversity and their families.

Neurodiversity

is a term developed by disability rights communities that has started to be recognized within health and social care service settings, and society at large. Neurodiverse people include those living with intellectual and developmental disability, autism, cerebral palsy, fetal alcohol spectrum, Down syndrome, among other conditions.



Social exclusion

Neurodiverse older adults and their aging family carers face significant social exclusion throughout their lives.

Interlocking oppressions create inequitable conditions that negatively affect their health and well-being, social inclusion and agency.

Our Objectives

- To develop recommendations that are grounded in people's experiences and perspectives.
- To contribute to the development of inclusive policy and practice across sectors.
- To advocate for programs and policies that better address the realities of, challenges facing, and agency enacted by neurodiverse older people and their family caregivers.

We spoke with...



- **21 Older adults** (45+ years old) living with neurodiversity
- **15 Family caregivers** (parents and siblings)
- **27 Service providers** within public sector services and community organizations



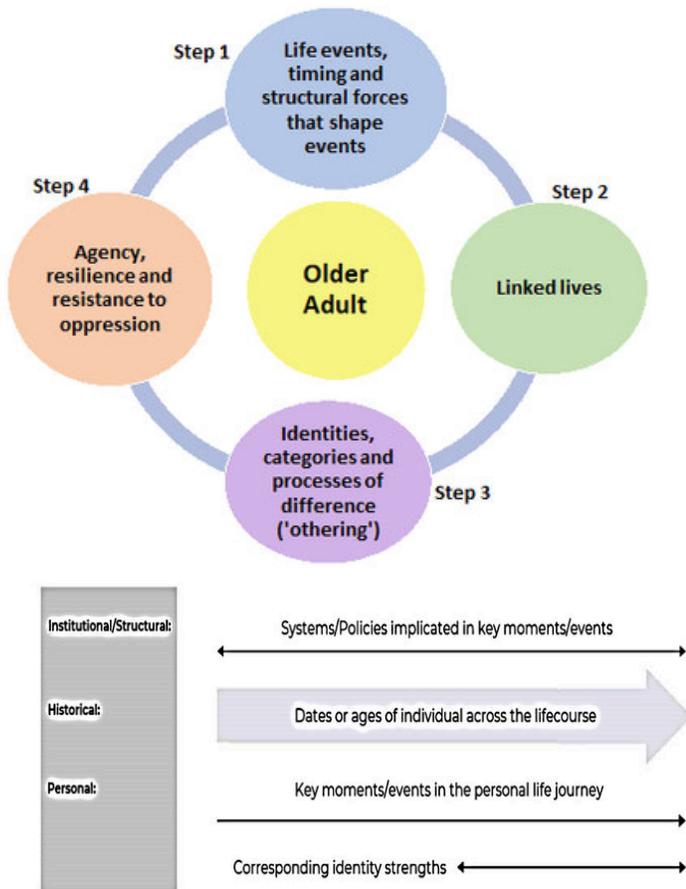
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Our project design at a glance: Using theory and method to co-create stories, and centre the voices of our participants!

Intersectional Life Course Perspective

The intersectional life course perspective, with its 4 linked 'steps', takes account of the key events in people's lives, and the ways in which they are shaped by social context, including socio-political and cultural themes within the broader society, institutions, and social history. People's agency, resilience and resistance to oppression is also highlighted

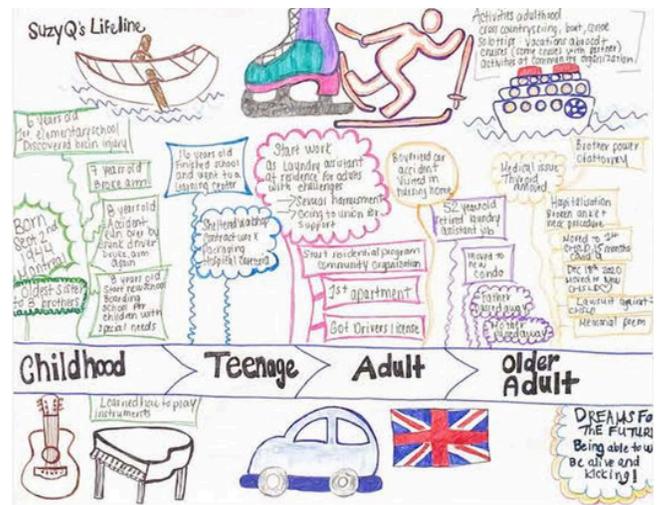


Life Story Narrative

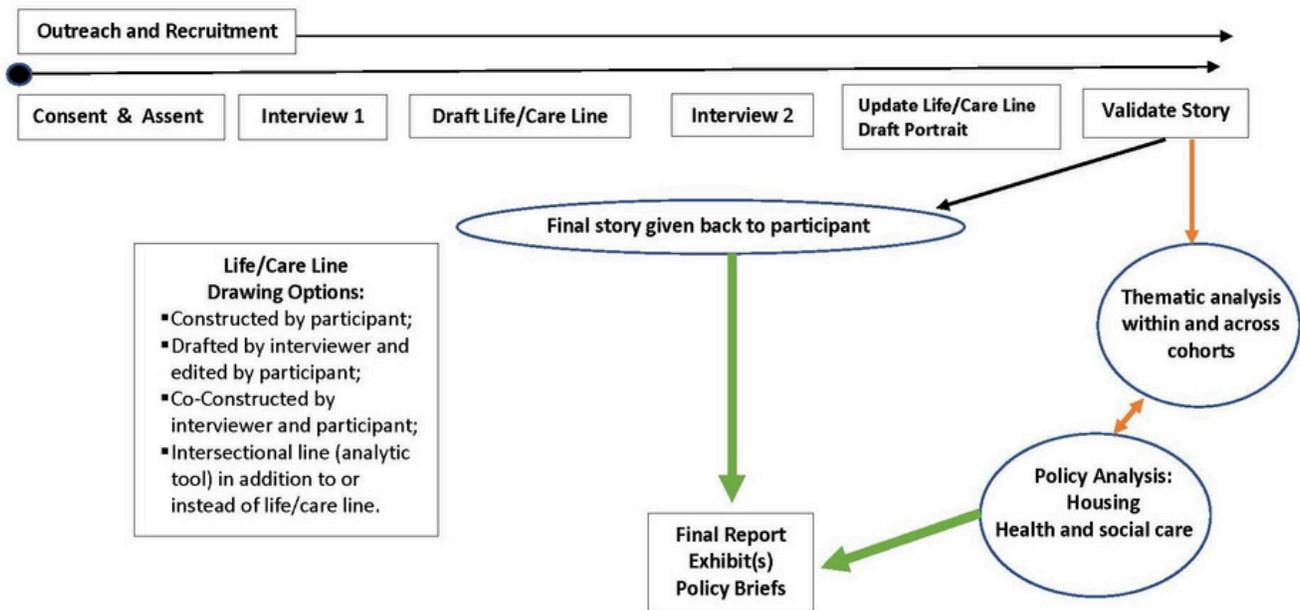
Life story narrative is a research method that centres on co-creation and powersharing through conversations between researchers and participants about their life experiences, important moments, events and relationships, and the meanings they attribute to them.

Intersectional Life Lines and Care Lines

is an arts-based, creative, and accessible research tool for engaging in conversations about people's lives, their strengths, and their challenges, all the while linking personal and historical experiences to institutional and political forces.



Our Research Process



Have fun making your own life line or care line!

Scan the QR code or find your copy on www.creges.ca/en/aging-neurodiversity



Our team...



Our research team!

Co-Investigators :

Shari Brotman (principal research and team lead-Montréal),
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Our advisory group!

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Véronique Tremblay, **Autisme Québec**

Our partners!

Thank you to our partners for their engagement in project development, recruitment, analysis, and knowledge mobilization!

APPRENTISSAGE À LA VIE AUTONOME • TOWARDS INDEPENDENT LIVING

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l'île-de-Montréal

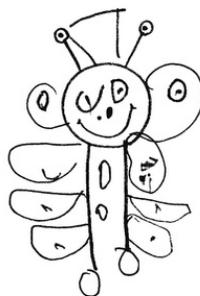
Québec

FQA
FÉDÉRATION
QUÉBÉCOISE
DE L'AUTISME

Une autre façon de communiquer



SAIRAH



Sans Oublier le Sourire

Les expériences d'exclusion et d'inclusion sociale 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 (2020-2024)

McGill School of Social Work École de service social

UNIVERSITÉ LAVAL
Faculté des sciences sociales
Centre de recherche en santé et en vieillissement

Centre de recherche et d'expertise
en gérontologie sociale

Fonds de recherche
Société et culture
Québec



www.creges.ca/en/aging-neurodiversity

www.creges.ca/vieillessement-neurodiversite

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
Suzu 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 daughter
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				

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Fonds de recherche Société et culture Québec



Aging

Neurodiverse older people (NDOA) experience aging similar to 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 due to 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 are able to do, reduced opportunities for adapted work, social or recreational activities, facing the death of their parents and/or other loved ones, feeling uncertainty about the future and who will provide care, etc. 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. Despite the fact that many faced aging with uncertainty, they also shared stories of hope, with some participants proudly speaking about feeling young at heart.



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

Themes

Aging is part of life

...it's difficult to explain, it's like a bit between the two... a little old, a little young... my heart is young but my head... yeah I am getting older...
(Audrey, NDOA)

I want to be alive and kicking! (Suzy Q., NDOA)

Well, if we're getting older [we] would look, I would look funny, eh?... I might live forever.
(Batman, NDOA)

I still feel young. (Christine, NDOA)

Fear and sadness

Me, aging makes me scared... not knowing what will happen... illnesses, the whole kit. (M. X, NDOA)

I don't want to hear about it [aging], it just makes me feel bad. (Christine, NDOA)

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)

Recognizing and adapting to changes

Well, I think that older people's physical capacities decline... because the ratio, it's 1 for 6, yeah for activities it's 1 for 6. But if I think about how my residents are doing, considering losses in physical health, maybe the ratio should be reduced... to be able to be closer, if something happens. Also I think about grouping them differently, but paying attention to each person's age, you know? (Linda, SP)

Before he wasn't like that... [My brother], you would say good night to him and he went to bed. But no more. Now he needs, I don't know if it is at the level of maybe, the level of emotion or security... Well sometimes I go to the grocery store, you know? Well now I have to really explain it to him, things like that. And I am often obligated to reassure... to try to understand his insecurity. Emotionally, he needs more, I don't know, more affection, more visits. (Linda, SP)

Early aging

Definition : a situation in which a person experiences health problems and other signs of aging earlier in life than the general population.

The physical well-being because... with age you can get arthritis - and I already have that. And I'm still young. (Johanne, NDOA)

Well, it is for sure that people with intellectual disabilities, they age more rapidly than others. I have two residents who are starting to wear adult undergarments for incontinence...they are getting older, they are more forgetful, and they're more tired. It just started happening, it looks like they are getting older... so their needs change also. But otherwise, their personalities are still the same. (Hugo, SP)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Themes

Loss and grief

There are different types of losses: the death of someone close, the loss of health resulting from aging or a serious illness, the end of a romantic relationship or friendship, moving, or other life transitions or changes.

No more parents. I would have wanted to die before my parents. (Mr. X, NDOA)

I mean it's scary but the process it's difficult for me to take, to look after myself. I don't like... when I take a shower it's a big effort because the instability of my legs even though the CLSC has given me a bar and even though... I dread it... (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)

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 I came here, 'cause [the workers] told me 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. (Tina, NDOA)

Parallel aging

Definition : a situation in which both the person living with neurodiversity and their family caregiver are experiencing aging at the same time, facing new health challenges, and can be interdependent on each other for care.

I take care of my maman alot, the parents, the house, I do the housework. That's it, 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)

Well, my parents are getting older...yeah I try not to think about it.. ok it's for sure that I am watching their hair go grey. It's like you try not to think about it. For sure they are getting older, me I am getting older so how could it be otherwise than aging. (Audrey, NDOA)

It's more at the level of my parents. Now all is good. They are still married. It has been almost 50 years. They are still together. They are in good health but it is inevitable that one day the phone will ring. And then, given that my parents are my main support system, well I have reason to be scared. (Frank, NDOA)

***For more on the perspectives of family caregivers regarding parallel aging, please refer to the Caregiving infographic.**

Uncertainty about the future

I actually really gotten sad because I don't know, I got no wishes [for the future]. (Batman, NDOA)

I don't know who will take care of me if it happens [that my parents can't] one day. I told them, they say don't talk, don't think about it [future] now. (Lisa, NDOA)

Yeah I will try to be the most autonomous I can, but no one knows what will happen in life... we don't know how it will end, it could be in a CHSLD or in a "group home" for seniors. (Audrey, NDOA)

She was in an intermediate resource, but because of many falls, the residence is not necessarily adapted so they looked for another milieu, so it often goes that way with aging. (Martine, SP)

End of life

When I was the manager, I was criticized for spending a lot of money in one of my residences. I had an older woman with a serious cancer, and when she had to be hospitalized at the end of her life, the last week, she was hospitalized for one week, and after that, she died. But me, I put someone there all the time, there was someone from my team there at all times with her, morning, noon and night, so that she would not die alone. She had no family, but to me they asked me to defend my budget. I was fed up with defending my budget. Me, my budget was spent so that someone would be with her, that we did not abandon her. And that is the human side, the humanity, that we forget about sometimes. (Iceberg, SP)

She stayed there [in palliative care] for 5 months. She was like waiting for housing, they wanted to discharge her. But at the same time, she had a very specific condition, there was no resource for her. The worst. Monsieur in the family type resource, he had moved to the Montérégie, but he said, "I am capable of taking her. I will make her a room". But he did not have the right, he was not on the territory and so who would manage that? So, he was not authorized. But still, he visited her. One night, I got a call about what happened, she had severe pain, they gave her a lot of morphine, and her heart eventually gave out... she died alone. And when I tried to get some information, they would not give me any. (Chantal, SP)

Once you talk about palliative care, we're [housing resource] not actually allowed to do it. We are looking at long-term care support, we hope that people will be able to stay here till the end, but that is a kind of new challenge that we're facing, how to do that properly. (Ellis, SP)



What would a vision of inclusive aging look like for people living with neurodiversity?

Answer : People aging with neurodiversity have the same rights as do all older people! Some indicators can be found in the Charter of Rights of older persons. Check out the table!



Photo, S.O.S.

All older persons, whether or not they must rely on others for care, have inalienable rights.

MORAL

- Remain in control of their own life until the end.
- Live in an environment that promotes their autonomy and dignity.
- Be free from isolation in their living environment.

MATERIAL

- Be comfortable and secure.
- Have the greatest mobility possible.
- Benefit from quality health and social services provided by competent professionals and in a way which respects confidentiality and choice.

SOCIAL

- Be heard, be encouraged to express oneself and to participate, be integrated as a full citizen.
- Feel validated, useful and respected.
- Benefit from favourable access to work and to learning opportunities.

This fundamental document reproduces most of the elements found in the Canadian and Quebec Charters. It goes further, however, in relation to older persons by putting an emphasis on the specific realities that older people confront, and which contributes to the fight against ageism that is often still ignored or forgotten.

Source : Observatoire Vieillessement et Société



Recommendations

- Recognize and honour the strengths and resilience of NDOA, especially in the face of numerous experiences of loss and bereavement over the life course and into old age.
- Adapt to the changing realities and needs of NDOA that are related to aging (for example, reduce provider/client ratios, adapt spaces to accommodate emerging physical and psychosocial needs, etc.).
- Recognize the unique experiences of loss and bereavement among NDOA, and create adapted accompaniment services in order to best support them through their grief.
- Talk with NDOA about their concerns about the future, including worries about their own aging and death, or the death of their loved ones, in a welcoming and supportive environment.
- Offer adapted and individualized care and support to NDOA at end of life, create tools for service providers to educate them.
- Develop new palliative care models that centre on making it possible for NDOA to receive services in the comfort of their own home/resource, all the while providing bereavement support to other residents, staff and family members.
- 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.



Caregiving

Love, NDOA



Family caregivers play an extremely important role in the care of people living with neurodiversity 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 of 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!

Themes

Enduring love and care

Me, I'm proud to go out with my boys you know, sometimes the world, they look at us and I don't know why... they admire us, that we are able to do this. Me, I take it like that. (Alessia, mom)

I said "your nails are long, eh?" He said, "yes". "Vicky will take care of it". So, I fixed it so he could be neat. He is always well dressed. It's not because you are disabled that you should be in a jogging suit all day. It is important for the family and I have continued that. I give him cologne. Then he says he smells good and he is content to go out. He is happy to see the family, but after, he asks after to go back to his place! (Vicky, sister-in-law)

There's a time when you decide that you accept the situation, you accept [the diagnosis] and then, me, I engage. (Annie, mom)

It became my job... because I adored her already [as children]... she was like my little baby. I took her under my wing and right away, in fact. The link was created, affection and everything. It's me that gave her... and for me too, we never got it [love] from our mother, but I needed to give her love. (Gates, sister)

Self-care

Lately, it weighed on me a lot, so I made a decision to work a bit less, change my schedule. Because it must be that I too have time to do my yoga, take care of my affairs. It's hard to balance everything with my sister, [but] I have to do things just for me. (Gates, sister)

System-wide service gaps and a lack of communication with service providers are among the most common concerns of caregivers. Please visit the infographic: **Gaps and challenges in health and social services** to find out more!



Changing family dynamics

You know, during those years, when our son was 13 years old, he [my husband at the time] told me "It's him or it's me", you know? So that's it, I said, to myself, this is my life. (Dadou, mom)

I think that my children are more aware, you know? More aware of life's challenges. I think we are more aware of life's fragilities as a family. (Rose, sister)

My partner doesn't understand. He always says why, but then again you have to realize maybe his knowledge about mental health issue is not that in depth. (Adora, sister)

Stress, burden and isolation

It's like living in Groundhog Day. You just keep doing the same things over and over again and saying the same things and some of the things that you say don't have any impact. (Clara, sister)

You begin to cry... why does my son have to do that [be aggressive towards me]? You know, I accept his intellectual disability but why does he have to do that? What does he want? I wish I could get inside his head. (Alessia, mom)

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

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Themes

Parallel Aging

As people age, challenges can shift and become amplified. **Parallel Aging** (sometimes called double aging) refers to the reality that both people living with neurodiversity and their family caregivers are aging at the same time! The consequences of parallel aging can put stress on care capacities, care arrangements, and caregiver health and well-being.

Well, I don't put myself out there because of my health. I really don't have the strength to do a whole lot. I know that if I go and do it and then I overextend, I'm not going to be able to have my daughter come. (Cassie, mom)

A client was living with his mom, it was just the two of them, the mom ends up hospitalized and passes away. We do not even have the time to work preventatively and find solutions, and at that point we have to orient to residential. We're not really fulfilling our mandate but we are meeting the needs of the client. It's a repetitive theme that we are seeing. The parents really hold on until that last moment, when we would much prefer to plan it out. (Rebecca, SP)

My husband and I were looking forward to being able to travel, we wanted to be able to spend more time in Europe, 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)

It's important to see how long and hard those hours are when a caregiver is doing it 24/7 so that I can advocate for them or I can advocate for the client receiving that care who needs more support. (Hannah, SP)

Older parents who have older children, that too I can talk about for a long time, it's heart-breaking. Sometimes I have families that, at first glance, I find that there is neglect. And the last thing is to try to break isolation of families that live a double-aging, and to find responses that are adapted to their needs. (Chantale, SP)

Vigilance and advocacy

Vigilant in the sense that, if I didn't tell her how to get dressed for the weather, she wouldn't get it. (Clara, sister)

[Our kids] are always in contact with us. Mostly our daughter and her mom. She calls her whenever she finishes work... it's a continuous relationship. (John, dad)

I joined others at [community organization], and I embarked on the board of directors, then, we engaged in advocacy. It was a snowball kind of thing. That's how I began doing advocacy on rights issues and making demands for change. (Dadou, mom)

The squeaky wheel gets the oil. If he's not squeaking he's going to probably fall between the cracks and if we're not the ones bringing to their attention... if there's an issue, who's going to do it? (Luce, sister)

So I am at her service now, in the sense that I want my sister to have what she needs. All the necessary services and supports, I see to that. So that she is happy with how she is presently. When she was better, in better shape in the other residences, I saw that she lacked for nothing also. You know, she went bowling every Saturday, and she didn't need for money either. If the government allocations were not enough, I would compensate for that. (Laurent, brother)

Worries for the future

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

With aging, parents think "my child will go where when I die?" But if you are part of a CHSLD where your place is assured and you can finish your days there, that's one thing but if you are in an IR or FTR, there are no guarantees that you can leave your child there and they will be left in peace, to say "this is their forever home", you know? This instability is anxiety-provoking. (Marie-Claire, SP)

That's what's unsettling for us as a family, because we're not going to be there forever. If something happens to us, I'm very afraid of thinking what would happen to him... if we're not there. My hope is that I outlive him. (Luce, sister)





Are the challenges faced by sibling caregivers of neurodiverse older adults (NDOA) different from those of parents?



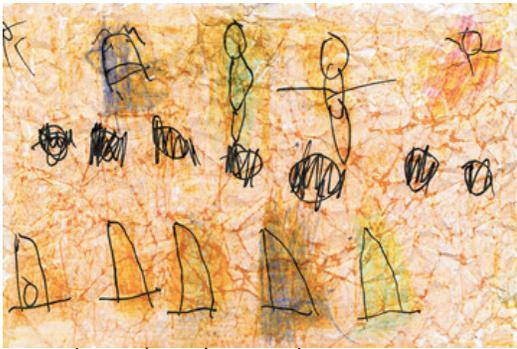
Photo, S.O.S.

Recommendations



- Promote the recognition of caregivers to NDOA, and reinforce mechanisms of collaboration and communication.
- Ensure that caregivers can benefit from resources that are specifically designed for them, including emotional, psychological, and financial support.
- Consider caregivers as equal members of the team, and ensure they are involved in all decision-making processes.
- Integrate prevention strategies into service delivery in order to move beyond a singular focus on crisis management.
- Develop education strategies and tools for advance care planning.
- Increase the availability and diversity of respite services and specialized services that address complex care.
- Ensure that measures in the Quebec 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.
- 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 that are tailored specifically to address needs in every region of the province.





New house (2016), NDOA living in a CHSLD

Housing

Social inclusion in housing for older adults with neurodiversity and their family caregivers is crucial for promoting overall well-being and quality of life. However, many still face obstacles. These obstacles include inaccessible housing options, limited support services, and discriminatory practices at all levels. There is an urgent need for collaboration to achieve housing justice so that people's inclusion, dignity, and self-determination are guaranteed!

Themes

Untimely and unwanted transitions

It [moving to IR] was a real ordeal for me... when I heard about it, I cried my eyes out. (M. X, NDOA)

Because it was an emergency respite. It wasn't through them. I spent a day taking steps and at the end of the day, they said "ok, she's staying here". So she stayed with this lady for, let's say, 3 years. The lady lost her health. Then she had another IR-FTR where things didn't go so well. After that, she stayed there for 2 years. After that, she went to another...She was in another one for 10 years. And after that, she was relocated. They closed the resource, so she was relocated to [name of municipality]. (Laurent, FC)

Unwanted surveillance

I have a problem with her [support worker], I don't know what to do. She's more concerned whether I take a shower, and that my apartment is clean other than my feelings... (Elisa, NDOA)

Privatization

The services must be improved, it's at the level of social housing. There is no social housing. It's just condo condo condo! There are only condos. (Jean, NDOA)

We're going into the private sector, you know, with untrained people. (Dadou, FC)

Self-determination and pride

...I think I love living on my own. I've always had people taking advantage of me. And right now, there's nobody really taking advantage of me. No! A lot of expenses, it's expensive on my own, really, but there's no one to take advantage of me. (Marilou, NDOA)

Being in an apartment... the freedom... you can do what you want, you can fall asleep in front of the TV and nobody tells you anything... I also like the peace and quiet...(Audrey, NDOA)

It's important in my life, you know I got an apartment, I was able to, I left my parents' house. (Annie, NDOA)

Use of restraints

The system always explained to me 'well it's safe, what we do is called something maneuver', I don't know what maneuver it was, but you don't do that. (Adora, FC)

Long wait lists

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, SP)

Lack of control over daily life

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)

Oh, that's another guy who is living in the same house as me. He could be annoying sometimes too, sometimes drives me crazy. 10 people living in same house there's co-workers and [residents]... living in this house. (Tina, NDOA)

Unclear strategies of policy implementation

I'd call it organizational abuse... the network ensures that people's rights are not respected... it includes unplanned transitions, exclusion from healthcare, accommodation that's not adapted. (Chantale, SP)

Early entry into long-term care

Well, you know, it's true that here they're placed in a home. But the challenge they face is to live in a community with other different people. To be rubbed shoulders 24 hours a day with every neighbor they didn't necessarily want to stay with in everyday life. And now they're in a home and they're different from everyone else. And especially with intellectual disability, because you know, there aren't many of them in housing. Which is not necessarily where they belong, I think, personally. You know, I'd like there to be centers for them. I'd really like them to get together and for people to be trained in ID so they can intervene better and understand them better. (Vanessa, SP)

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

Biomedicalization

The psychiatry hospital has been historically the place where people with intellectual disability and challenging behaviour are. There are few other settings. And the hospital will say 'well we're overflowing; we don't have beds -it's just adverse behaviours it's not psychiatry' so [the individual] is at a very high risk of being discharged repeatedly with no concrete plan of where to go, what to do. (Marco, SP)

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



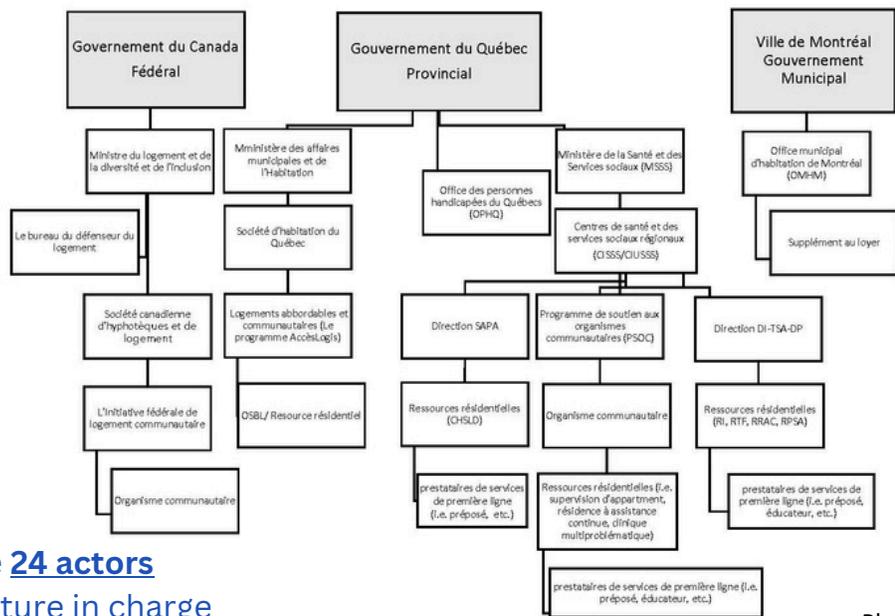


Do you know how many key actors are involved in the governance structure for housing people with autism and/or intellectual disability in Québec? Use the figure to count!

Answer: In 2022, there were **24 actors** within the governance structure in charge of housing people with autism and/or intellectual disability. What do you think of this number? Do you think it's easy for older adults and their caregivers to navigate such a system?

Structure de gouvernance logement/hébergement – Governance structure housing Montréal, Québec

Dickson, D. with Brotman, S. (2023)



Photo, S.O.S.



Recommendations



- Develop housing models that enable NDOA to age in place!
- Develop specialized training and create specialized teams/programs for individuals with complex needs.
- Create an integrated provincial inter-ministerial structure that brings together all the ministries whose policies touch the lives of NDOA (health, housing, municipal affairs, leisure, etc.) to improve coordination and collaboration with community and self-advocacy groups.
- Ensure federal funding for NDOA transferred to the province is used to create new housing projects or to adapt existing housing resources.
- Enhance oversight to ensure quality standards are met (i.e. re-implement random visits, impose sanctions and reinforce surveillance when problems occur or are reported).
- Include commitments to ensure a guaranteed number of housing units are reserved for NDOA in new social and affordable housing projects.
- Guarantee recurrent funding for organizations providing housing or accommodation.
- Create more residential housing options for NDOA with complex and co-occurring conditions.
- Redirect funding from private housing resources to publicly or community-owned housing resources.
- Increase funding for respite and other services for caregivers living with NDOA, as well as funds for renovation to support accessibility/autonomy.
- Include the voices of individuals with neurodiversity and their caregivers in housing policy decisions.



Click here for **I belong! Quebec Intellectual Disability Society's National Mobilization Campaign on Housing**

Mental health and addictions



Drawing by Shari, researcher

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. Older people with ND 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, older adults living with ND 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 neurodiverse older adults (NDOA).

Themes

Diverse mental health challenges

I'd say the biggest issue is really social isolation. For older people with ND in particular... their social network is incredibly small and most of their primary resources are a worker or staff in the public system. (Cory, SP)

Things that I went through in my life was hard. It was not an easy life. Going through an alcoholic mom, and abusive boyfriends was not easy. I had ups and downs in my life. (Johanne, NDOA)

It's just that my mother passed away and I wanted to take my own life. (Suzy Q, NDOA)

I think unsurprisingly, the most common [mental health challenges] are anxiety and depression. 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, SP)

Misdiagnosis

How do you come up with your impression [of schizophrenia] when you barely spend time with my brother and all the other report[s] by the staff [are] just saying he's really calm, he's quiet, he doesn't show any delusion? I read an article from John Hopkins. They did research on how prevalent misdiagnosis of psychiatric patients [is] It's the same with what's happening with my brother. (Adora, FC)

Addictions

I was hospitalized, that's why I came here. Because of 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... I don't wanna go back to that anymore - to drinking, and this and that. (Tina, NDOA)

I am 5 years sober! (Christine, NDOA)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Themes

Psychiatric hospitalisation

Because I had problems... It's my parents who placed me there [at the psychiatric hospital for 10 years]. Yeah, I didn't accept it easily. (M. X, NDOA)

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

I was on the [psychiatric unit], I remember when I first went there... and I got aggressive there too, many guys hold me down... no, no in the beginning I was too aggressive. It was all to calm down until they found me [a] home. I couldn't get a foster home for a long time. (Batman, NDOA)

There are shelters, but I don't feel comfortable sending them there because they're shelters where they have to go out during the day and they have to go back in the evening and a lot of them have problems with alcohol and drugs and I feel that sometimes they will get lost in the shuffle and we don't know what will happen to them. (Theresa, SP)

I can think of a few who have been [on the psychiatric unit] for a very, very, very long time, and I'm talking years. Because let's say they have a bit more acute needs and there's not necessarily a specific type of resource that can match their needs and therefore, they remain there for a very long time. I'm not going to lie, it's clearly not the optimal quality of life for them and for sure it's not a natural environment. It's an institutional setting and what we see often, and it's very unfortunate, some of them who stay there the longest, at some point there's just a sharp curve of regression. (Marco, SP)

Exclusion criteria and silos

They didn't know where else to place me. And because I was there [detention centre], ... I wasn't really a real criminal, it was just fines. They decided to put me in a transition place, and after, psychiatry... started. (Marilou, NDOA)

I filled in a depression questionnaire, nothing was said! No follow-up. Do I need a therapist? Nope, nothing. Did she even bring it up to her supervisor? It's crazy! (Elisa, NDOA)

Stigma

Yes, seriously they call it the zoo, colleagues that say 'you have to go to your interview with [the specialized ND and mental health team], good luck'. It is interesting to see that in the psychiatric milieu like there is real prejudice, not ill-intentioned, but it is the force of things on the realities of people with ND. (Thomas, SP)

Medication

Everything they gave me, you must know certain medications, well there was not one that I didn't get in psychiatry. Whether it was neuroleptics, or tranquilizers, or antidepressants, there's not one I didn't get. (Marilou, NDOA)

They've taken a lot of medication for many years and as they're aging, the side effects of those medications are being seen, whether it be the anti-psychotic medication and all of a sudden they're developing tremors or there's a condition with their heart, with their liver, and they are needing more frequent and different follow-ups from medical professionals. (Rebecca, SP)

Without the meds, I'm pretty not really all there. I have medication to take, antidepressants, anxiety meds, it's a lot to take. (Johanne, NDOA)

Lack of specialized services

Mental health providers will be like 'well, they can't engage with therapy so they're not eligible for the mental health programs in the centre'. They have additional needs so they're not really eligible for a lot of the housing options. Especially because there can be issues around hygiene, around appropriateness in certain environments, like co-habitation environments. Yeah, there's just a lot of stigma. And it also might be because they're older. I know that's another issue. (Stephanie, SP)

Mental health regroups many issues, but it is more like, 'who do we give 10 sessions to work on your depression?' So, it doesn't respond to their needs because our clients need accompaniment over the long-term. (Genevieve, SP)

[The readaptation centre] waiting list is a long time and then with people with underlying mental health issues it's even harder to place them. (Theresa, SP)

I find a huge red tape in terms of systemically between different departments. We cannot access mental health services through the CLSC for our clients if they have a diagnosis of autism or intellectual disability. They're like, 'you guys are the experts in working with neurodiverse individuals'. It's frustrating because neurodiverse people have mental health issues too! There's a huge comorbidity rate with various mental health issues. (Lily, SP)

The specialized intensive mental health team, one of their exclusion criteria is a diagnosis of DI/TSA except in exceptional cases. I think it's horrible. (Cory, SP)

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, SP)



What silos have you witnessed in the health and social service system? Can you name them all?

*Windy sunshine
Adult with neurodiversity
Drawing workshop*



Recommendations

- Reduce diagnostic-based exclusion criteria to ease access barriers to mental health and addictions programs and services.
- Train staff to counter misinformation, bias, and discomfort among mental health professionals.
- Develop specialized and trauma-informed support teams for people who have experienced psychiatric hospitalization.
- Avoid psychiatric labelling of people presenting with complex behavioural challenges by creating specialized interdisciplinary teams in every CISS/CIUSSS.
- Favour collaborative practices and policies to remove barriers to coordination between disability, aging, and mental health sectors.
- Improve interagency communication and collaboration between public and community-based sectors.
- Increase funding for community mental health and addiction services.

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Mistreatment



Mistreatment is a complex issue that can take many forms. Mistreatment can be physical, psychological, emotional, financial, sexual, and systemic. 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 neurodiverse older adults (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 mistreatment, challenge stereotypes, and use their experiences to help others.

Themes

Mistreatment at work

Yeah he [employer] said "It's not working to hire you." I said "how's that?" "You did something wrong yesterday." Excuse me? What thing? I never did anything wrong. I said to the madame "It's been 4 years that he promises to hire me then he finds fault every single year". Yeah, that's the real problem. (Jean, NDOA)

They [co-workers] say "You're not normal, you're retarded, you're stupid", to me. How come people make fun of me, I don't understand why. I feel like I'm the problem of everybody. (Lisa, NDOA)

I used to work with a woman who said I could not drive because I was retarded, we don't say that anymore, we say handicap. When I came back with my license, she was quiet. (Suzy Q, NDOA)

Family violence

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)

She [relative looking after me], she did terrible things to me. She sting me on my eye. And that wasn't nice. (Rosemary, NDOA)

Well, my sister was trained to serve our mother who adopted us. That was her life "I clean, I take care of maman, I clean", and that's it, that was her life. Except her body was crying out, when you have that many aches and pains, you say "no, something's not right here". (Gates, FC)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider

Bullying and harrasment

They simply harrassed me. I was harrassed terribly. For someone who has autism, someone who has Aspergers Syndrome, who doesn't know, I don't know how I managed morally, physically, and in every single domain to go out. (Marilou, NDOA)

Well, before I had the [community organization], there were alot of people who put labels on me. They were not nice to me. (P'tit Loup, NDOA)

It's because I was abused by my peers. At school, they would insult me, beat me up everyday. I would have to run to the teacher and like cling to her just to get them off of me. (Johanne, NDOA)

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. They will be 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, SP)

Sexual abuse and intimate partner violence

[A] few years later and that man came to my bedroom and locked the door, and he put my pants down and he raped me. (Anonymous, NDOA)

Oh god... it started when I was 33... he was the type of guy who would physically, emotionally, sexually... rape me. All the things you could think of that you would not want to get done by a man. I had no choice [but to go to the domestic violence shelter] because it kind of saved my children's lives. Because if I didn't move out of that environment, they said I would have not lived. (Johanne, NDOA)



Financial abuse and neglect

I've had clients who are living in really, really, very neglectful environments or I've had clients who have had stuff stolen from them. One of my clients literally was like "well, can I put in cameras, because the police aren't going to believe me" and I know that he's right, and the fact that he knew that too just really hurt, because this is one of my clients who's lower on the end of functioning and that was a really big moment... he knows the police look at him and automatically just assume that he doesn't know what he's talking about, like he's making it up. (Stephanie, SP)

Can you imagine these leftover patients that were in their rooms, undernourished, no water to drink and nobody to change their diaper. What do you think about that? They got rid of the previous owner 'cause he wasn't doing nothing for us. Nothing. He was pocketing the money. (Suzy Q, 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. Then at the hospital they told me "he doesn't eat, he doesn't eat". It doesn't make sense to be so thin. It was like they didn't give him much of anything. (Marie-Thérèse, FC)

Resilience

I was a member of the users committee. It was a lot for us to help ourselves, and also help others with certain problems like young people with autism and everything...there were a lot of things we talked about. We did the tour of all of that, but things changed, things must change. (Audrey, NDOA)

Things that I went through in my life was hard. It was not an easy life. Going through an alcoholic mom, and abusive boyfriends was not easy. I had ups and downs in my life. I had a deep depression... I'm still on medication for it. And it influenced me to tell others "be careful, look for the signs of abuse". (Johanne, NDOA)

It is an initiative of our organization to equip its members to better protect themselves, to give them enough strength and confidence so that their next friend is a little less toxic than the previous one. And if they find themselves in a situation where they are really stuck, they can come say, "I need help." It's about helping them as best as we can, and then rebuilding from there and working again with the family. We're talking about self-determination and empowerment. (Iceberg, SP)

Institutional mistreatment

I'd call it organizational abuse... the network ensures that people's rights are not respected... it includes unplanned transitions, exclusion from healthcare, accommodation that's not adapted. (Chantale, SP)

It was [painful early life medical treatment] in my opinion a kind of abuse, you know, by the medical system. (Clara, FC)

There's a lot of negligence [in the criminal justice system] ... I'm not mincing word[s]. After my brother was arrested, I was not allowed to speak with him. I said [to the police officer on the phone] "could you please take care of him?" I was crying. [The following morning] they called me by videoconference from jail, and [my brother] he was... crying "Adora help me, help me". (Adora, FC)

He went to prison last year and it was terrible. He was just dysregulated, just acting impulsively so they would keep sending him into isolation. (Marco, SP)

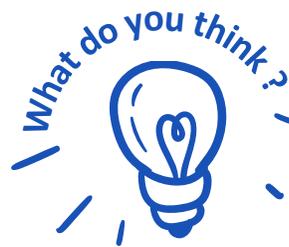
Imagine a scenario, we just had lunch but I'm still hungry. I didn't get enough, what do I do? Can I ask for snack? Am I gonna upset someone? And if I do ask and they say no you already ate, am I allowed to say, hey that doesn't sound right, he was kind of mean, that felt kind of bad. I'm hungry, but I guess I'll just suffer through it because I'm not allowed. They might not know enough to say you just mistreated me, and I know what my rights are and I'm gonna follow up. (Mike, SP)

Racism

I don't think it's fair to have a patient come down from the North and say, well, you know you can't go back home. And this person is sort of thrust into a White society and they're not getting the cultural benefits of home. I think a lot of them really, really missed that. It's not quite the same as residential schools, but you know they lose their language, they lose their cultural identity. (Theresa, SP)

You see Joyce Echaquan, how she's being treated, that is just a tip of the iceberg in our healthcare system. If you go in to use any facility, you're scared... I better just be quiet and just keep my health card and don't say a peep. (Adora, FC)





Now that we've explored what mistreatment is all about, can you imagine what well-treatment might look like?

Photo, S.O.S.



Recommendations

- Raise awareness about the Quebec “Act to combat mistreatment of seniors and other persons of full age in vulnerable situations” in disability and neurodiversity sectors.
- Put in place education tools to better inform NDOA and their caregivers about the Act and the process in place to make a formal complaint or report a situation of mistreatment.
- Train professionals working with NDOA about the Act, emphasizing their obligation to report mistreatment, and their responsibility for putting in place targeted intervention strategies in order to combat mistreatment in their professional practice/workplace.
- Simplify and accelerate the complaints process and make it more accessible to service providers across the network of public and community sector services.
- 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, etc.).
- Enhance oversight to ensure quality standards are met (i.e. re-implement random visits, impose sanctions, and reinforce surveillance when problems occur or are reported).
- Ensure better monitoring of the quality of life of NDOA who are represented by the Public Curator.



Click here for a comic book about mistreatment



santebd.org

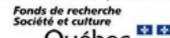
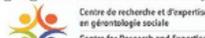


Click here for a definition of mistreatment



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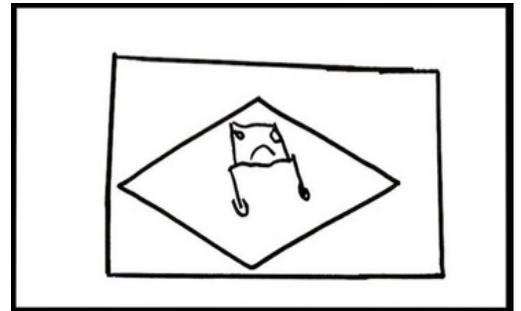
The experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-24)



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Lack of control over daily life

People living with neurodiversity struggle with being able to assert control over daily life decisions, choices, and activities. This situation persists, and often intensifies, as people get older. Agency (self-determination) can be restricted in many ways. Neurodiverse older adults in our study described experiences of controls and restrictions put in place by both formal (service providers) and informal (family) caregivers. Sometimes controls are used to ensure cooperation, maintain order, or produce desired behaviour. At other times, control measures are put in place out of concern, with the goal of protection from harm. Unfortunately, controls can go against the wishes, preferences, and choices of neurodiverse older people who expressed feeling frustrated, sad, angry, or resigned because of restrictions placed upon their spending, where they live, who they are allowed to see, what they eat, what they wear, how they spend their time, when they go out, and where they can go.



No title, NDOA
Drawing workshop in community organization

Themes

Finances

Do I have any control of my life? Not really. Except for the stuff that I don't tell her, like the money... I am competent to make my own decisions, I'm just not allowed to, not really. And what gets me angry is that my sister, in spite of it all, only allows me \$20 every two weeks. And this past Christmas, she put the kibosh on me using cash. I have to do my grocery with debit, and no cash back. And yet, she considers me mooching off my friends when they pay for me. I don't have the money. (Elisa, NDOA)

I don't want to talk against them, but I think most of the delegates from the curator's office, they have a very, very big case load. The expectations are not always very clear to them, from what I understand. And often times, realistically they're gonna meet their client once a year, once every two years in some cases. I mean they're supposed to be taking care of their finances and care. They might be able to go over budget, whatever contracts they sign, their housing situation, their medical care decisions. And yet they might have met them twice in the last four years, and you think wow that's kinda crazy. But I don't think it's for lack of care or lack of will. I think it's from lack of resources on their end. (Marco, SP)

Her sister is convinced that she is very disabled, when it is really very mild. Her sister thinks she can not manage or budget or anything. Because her salary, I deposit it in the account of my participant but it is not her that manages it. And when she wants to have, let's say \$20 because they are going out as a group, let's say to a restaurant, then her sister doesn't allow it. It is impossible that \$20 in a year to go out to eat makes one suspicious. (Iceberg, SP)

Relationships

The first few years, I was not so good 'cause I missed my fiancé and I wanted to be with him, instead of living here. I realized when I came here, 'cause [worker] told me after awhile, 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. (Tina, NDOA)

If I ask her [my mother] if I can see my boyfriend, she says no. (Lisa, NDOA)

Unwanted and untimely transitions

It [moving to IR] was a real ordeal for me... when I heard about it, I cried my eyes out. (M. X, NDOA)

Couple of months, [they said] Christine you are going to go to Ottawa, bring all your clothes by plane and go to Ottawa. I didn't know anybody. (Christine, NDOA)

When [my brother was moved suddenly], when he arrived, he was in 1000% crisis. He did not want to be there. (Adora, FC)

Food choices

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)

I would love to [cook] but I don't think I can do that here. If I had my own equipment like my own stove or anything but my room is too small. (Rosemary, NDOA)

Getting older living in a group home... it's harder because you have to have the food that they want. (Johanne, NDOA)

Appearance

Yeah, I got my style, but [they] won't let me. I can't force them, I might get in trouble. (Batman, NDOA)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Themes

Schedule and outings

Sometimes I arrive a bit late. They bother me a bit about it. Instead of coming back at 9:30pm, sometimes I came back at 11:00-11:30pm. Yeah, that is why they restricted my hours after that. (M. X, NDOA)

It contributes to his social exclusion in the sense that, at the level of visits or support, people do not go out in the community. They have no more social role. My 'monsieur' is 68 years old. It was not that long ago that he had a job and he drove. And now he is in a CHSLD. He does not go out anymore from the CHSLD. There is no-one that visits him. He mentioned to me the other day that he has never had a choice in his whole life. It was never him that made decisions about important things, like living in a CHSLD. He said "I never had a choice, because I am deaf and because you know, there was never anyone who asked me what I wanted". (Claude, SP)



What conditions need to be met for people to be able to fully enact agency in their daily lives?

One possible answer!: When we are supported by people we trust, when our opinions are respected, when we have opportunities to participate fully, and when we live free from discrimination and stigma, then we are living the best conditions to enact agency.

Activities

I went to church when I was younger, but I didn't like it. Mom and dad would go together and all that. I was young. But not anymore. 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. Oh, it's okay. I'm used to it now since I'm staying now. I like it here at [residence]. (Tina, NDOA)

Fundamentally, my son will need to feel belonging, a project where he can integrate, like a stage. You know, return to a stage or something that stimulates him, and that he would be interested in, like I said, he is an artist. He would love to work in a video club but we never had a worker who found a place for him. It was always a stage in a [fast food restaurant], to clean. (Thérèse, FC)

Space and privacy

I'd rather be a little lonely than me having a roommate 'cause there's no stress. (Elisa, NDOA)

When you're older and you've been used to living on your own or in a more open setting, and being autonomous... and suddenly you come here and well dinner is at four and then you do your laundry at this time, it can be very hard to accept cause it prevents you from being able to use whatever autonomy you have, right? Because things are dictated to you. For them it's very hard to accept and then it can lead to, you know, oppositional behaviours and things like that. I mean I wouldn't want to be somewhere where I'm being told what to do every time and asked to follow a strict schedule, right? (Marco, SP)

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, FC)

But I don't come down because it's too early because the workers wanna get a rest and it's too early for them 'cause I get up very early in the morning, [so] I go in my pajamas and get dressed in my room and hang around in my room and not listen to my radio because another worker does not want me to... Too early and too loud. (Tina, NDOA)

They Go Together!!

Relational autonomy suggests that decision-making is not something we do alone. Most people make decisions with those who they are close to and/or who support them. *All autonomy is relational*, meaning that our freedom to decide is shaped by our context and our relationships.

Agency is the ability to act and to decide!

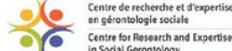


Recommendations

- Advocate to improve the social conditions that would support the full agency of neurodiverse older people.
- Develop processes and practices that centre relational autonomy in public sector services, including within the Public Curator's Office.
- Help older adults by assisting them in learning new skills and doing tasks on their own (rather than doing things for them), thereby fostering their autonomy. (Tim, NDOA)
- Caregivers should get to know the older adults and consider older adults' interests, likes, and goals when designing older adults' living spaces and care routines. This might involve bringing the older adult a DVD player to watch movies in their room, inviting them on outings, arranging visits with their significant others, and taking them to their favorite spots. The goal should be to maximize their choice and find adapted solutions to their needs. (Thomas, SP)
- Decision-makers should avoid generalizing or making assumptions when working with neurodiverse older adults. It is critical to recognize the needs identified by older adults themselves when allocating resources, making policy decisions and providing services. (Stephanie, SP)

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Gaps and challenges in the health and social service system



Neurodiverse older adults (NDOA) and their family caregivers (parents and siblings in the context of our study) 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 agreed that though many people have received good quality care from people they trust over the years, the gaps and challenges in the health and social service system overshadow all the good work that is being done by dedicated professionals on the ground. All of our participants shared that something must be done at the policy level to rectify the many problems in the system.

Themes

Barriers to access

Oftentimes, within the public network, they will be very rigid on making sure the person was diagnosed to allow them into their services. For example, someone who did not have a former diagnosis of for example ASD or ID before the age of 18 and now he's 55, well, he might not get access to housing. He might not get external follow up within those specialized services because they say he doesn't have a diagnosis so he doesn't meet the criteria. So, I'd say overall it's by far the biggest challenge those people will face. (Marco, SP)

Even when they *do* have a diagnosis, the system is not set up for older adults. Basically 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, SP)

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, SP)

Often, their diagnosis will result in them being labelled, which means that suddenly, people will say "well, it is not my service, it's not me that deals with that". And addressing the issue takes much longer, because it takes time to find the right person who can respond. (Claude, SP)

Unaddressed health care needs

In the case of this person, in fact it has been years since we underscored that she had knee pain, that she was less and less mobile. And the CIUSSS brought up the fact that she had behavioural problems. And then we said, "Yes, but look how her legs bend. She really has significant signs of arthritis". Except that it took years before she got mobility aids, and also years before she even got an appointment. (Chantale, SP)

At the doctors, when I go to the doctor alone, I don't know what to say to him because he asked me how can I help you, this and that, and I say I don't know. (Tina, NDOA)

He was younger but he was really violent. And I can tell you why. He would wake up at night and begin to hit everything, he hit his brother, he came to our bed and hit us. At one point, when he was hospitalized for two months ... when he was seen [by the dentist], he had a lot of abscesses under his teeth that hurt him a lot. And for him, when he had pain he had no way to tell us, "I'm in pain" ... later, when we returned for follow-up he shouted, he did not want to stay there... a nurse said to me, "Madame, are you not capable of getting your son to stop shouting?" ...the hospitals, when dealing with people with [ND] they just throw their hands up in the air. Everyone does that... and nobody cares. (Alessia, FC)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider

Themes

Staff turnover and bureaucratic burdens

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)

The social worker changed five times in two and a half years... yeah, five times... so people re-ask the same questions, because they don't know my clients. So it's repeat, repeat, repeat... fill out documents... answer their questions, because they re-ask everything about them. Seriously, it's hell. But really, I am not exaggerating the word. (Hugo, SP)

We do so much paperwork. And you try [but] it's impossible to keep up with all the paperwork they demand. We end up going to visit our clients one or two a day. (Marie, SP)

We don't get ahead. It's a lot of bureaucracy, a lot of paperwork, a lot of notes, no-one knows anyone and we find ourselves forgotten. Then we begin again. (Gates, FC)

Lack of training

I think that training people on site, well it's certain that we are far from being aware of aging. There is a lack of knowledge I believe. (Martine, SP)

Lack of integrated service options

It's as if they are left on their own, you know? The systems are so taxed right now, they've cut down on so many services, that they're in the situation right now where if it becomes an emergency, they take care of it, but at the same time it's not the same people. (Luce, FC)

But it's not the fault of Ginette the social worker or..., it's the fault of a machine that has not considered, or predicted that the population will age, the neurodiverse population will age also, you know? (Chantale, SP)

No-one ever spoke out for them, no-one said, "Wait a minute. This isn't right". It's not because someone has a disability and is aging that they no longer have any rights in life. We are in Québec, there has to be something. Nobody said that. (Linda, SP)

Silos and limited intersectoral collaboration

So, right now those services are accessed through SAPA (aging) and they are very much based on care acts, so feeding someone, hygiene routine, stimulation. Whereas our clients' needs [are] out of that box. And they [home care workers] have a set time that they allot... it's 30 minutes to feed someone. But some of our clients, it takes 45 minutes to an hour. When we want to access services we're hit with the fact that our clients have a need and the services that are offered are not responding to that need. (Rebecca, SP)

...it is more the case with significant behavioural challenges, where things are super-specialized... there are not enough specialized services for older adults. Often when they get to a certain age, then they must change the directorate of service. They will be transferred from ID-ASD to SAPA. But at the CRDI in Québec City, there was once a specialized team that focused on older adults. With the fusion, I cannot say why, they removed that service. They dissolved that team, but they had a great expertise with neurodiverse older people, ID-ASD, but it doesn't exist anymore. It is like that expertise dissolved a bit. (Marie-Claire, SP)

No one to talk to - no one who knows - no one who cares

I never stopped asking for services, but I have not been able to put my hand on someone who knows the field, and there has been no resolution for many years. I went to a psych, and I pronounced the letters, ASD. It was like he was close to making in his pants. (Frank, NDOA)

We have a lot of questions, all kinds of things happen, but we have no-one to refer to... And it's like we are not listened to because we are the third person... we have the impression that they always think we are exaggerating our needs. (Annie, FC)

We caregivers who are sacrificing so much to take care of our family members are treated like [we're] on the cusp of being a criminal [by the curatorship process]. (Clara, FC)

[It's] horrible. I disagreed with them. You know, you can never disagree with the doctor and clinical team eh, no way! [They think] you don't have the qualification to disagree with them. (Adora, FC)

Only in a crisis...

I know we should not have to wait for a crisis! If there is a crisis, what will they do? When you are in crisis, and you have a tooth that hurts, for example, well, it hurts, it hurts! What will they do? They will call me in the middle of the night? What is happening doesn't make sense. (Vicky, FC)

There are pieces of the puzzle missing. The chain is not connected at every level, and to me it's so important that there's continuity, that there is communication and that the welfare of my brother is the focal point. And right now [my brother] is at the receiving end of the decisions that are being made as a whole without necessarily having his best interest in mind, because they're probably overwhelmed and underfunded and stretched to the limit... And for me, I have to re-explain every time... I feel it's reactionary... "ok if you were in an emergency, we're going to do something. So, if there's a fire, we'll try to address it". And [otherwise] let the chips fall where they may. (Luce, FC)



In what ways can you promote inclusive approaches to improve the care experiences of neurodiverse older adults (NDOA) and their family caregivers?



Recommendations

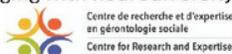
- Integrate a life course approach in all facets of service provision, thereby ensuring long-term and continuous interventions and follow-up.
- Remove barriers to access based upon strict diagnostic criteria.
- Create integrated, intersectoral, and specialized services for NDOA and their aging family caregivers.
- Provide ongoing training on the unique realities and needs of NDOA and their aging family caregivers.
- Embed interagency collaboration within and between public and community sector services as a best-practice standard of care.
- Include NDOA and their family caregivers in all aspects of decision-making and advance care planning.
- Reduce bureaucratic systems that impinge upon the best-practice goals of service providers.
- Promote fair and equitable caseload distribution based on the needs of NDOA and their family caregivers.
- Increase funding for public and community sector services geared specifically to NDOA and their family caregivers.



Drawing by Aglaé, research assistant

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Parenting



Many neurodiverse people want to become parents and to have a family of their own. This dream often remains an important part of older adults' central narrative. Unfortunately, neurodiverse adults across the life course face significant barriers when expressing their desire to be parents, including having their dreams ridiculed or dismissed as unrealistic or unhealthy. Feelings of loss related to this experience of stigma can have a long-lasting impact and resurface as people get older, leading to a sense of isolation and regret.

When neurodiverse people do have children, they often face unique challenges. Some are able to rely on their relatives for support in managing daily life, like their own parents (their child(ren)'s grandparents). Neurodiverse people who have had the opportunity to raise their child(ren) experience the same loving relationships in the face of life's ups and downs as do all parents. Unfortunately, for many neurodiverse parents, the risk of removal of their child(ren) by child welfare services is not only common but oftentimes inevitable. Among those who have experienced separation from their children due to child welfare involvement, the opportunity to watch their children (and by extension their grandchildren) grow, and to maintain ongoing relationships with them, is literally taken away. NDOA parents in our study who had their children removed from their care at a young age, shared that they had little support or explanation as to why this happened, nor any access to an advocate during legal proceedings. These experiences have led to a lifetime of unacknowledged grief and loss.

The enduring love that NDOA parents feel for their children (and grandchildren), whether or not they have an opportunity for sustained relationships with them as they age, demonstrates their courage, strength, and resilience.

Themes

Enduring love

I was super thrilled because I had wanted to have a little girl and that's probably some of the happiest moments... And it seemed like things were kind of coming together for us and we had our little family and things [were] really good... [After child welfare services removal] I was still allowed visits with my daughter, regular visits. So that was the one thing that really pulled me through. (Tim, NDOA)

[My sons and I] laugh a lot about my autism, that's for sure. All my things, they are kind to put up with me... there is not one free space on the walls. And me, I am autistic... there are some who like things clean and simple but me, I am the opposite. I love putting stuff everywhere, I love stuff! (Annie-Pierre, NDOA)

The most important part of my life? My kids. (Tina, NDOA)

They want to keep up their relationship with their children and often they want to do more, they want to be able to provide for their kids even though they are grown. (Nellie, SP)

Oh yes! I babysit my daughter's children. I watch my grandson. My grandson loves me alot. He says "Grand-maman, be careful my grand-maman!" Oh yes. (Brigitte, FC)

Unique challenges of raising children

But, you know, both of us [my autistic son and I], I know we are both super anxious. Anxiety among autistic personnes... it's like a second... it's like my shadow. You know, we experience about 1000 times the anxiety as non-autistic people. That, we have to accept. It's like it comes with autism. It's like we have too much in our brains, sometimes it raises our anxiety. So, oh my god, it makes two anxious people at our house. (Annie-Pierre, NDOA)

We really don't know how many older ND parents are out there. Those who raised their kids alone or with support from partners or family. What are their challenges? The system really needs to do a better job of reaching and supporting these parents throughout their lives, even as they get older and maybe have grandchildren of their own too. (Chelsea, SP)

Who is on this infographic?

This infographic represents the rich and unique reflections of NDOA parent participants and one family caregiver participant whose NDOA daughter has children of her own. To help us better understand the context of their stories, we undertook two additional interviews with service providers working directly with neurodiverse parents in Quebec.

Pseudonym	Age	Description
Annie-Pierre	49	Parent - raised her children
Johanne	46	Parent - child welfare services involvement, lost custody
Tina	60	Parent - child welfare services involvement, lost custody
Tim	52	Parent - child welfare services involvement, lost custody
Brigitte	72	Family caregiver, grandmother (NDOA daughter has children)
Chelsea	45	Service provider with 11-20 yrs. experience in the health and social services system
Nellie	40	Service provider with 11-20 yrs. experience in the health and social services system

Child welfare services (CWS) involvement

For many parents that had child welfare [interventions], they felt misunderstood, discriminated against because of their disability. They felt like their kids didn't receive good social services and sometimes this harmed their relationship with them. Having workers coming in and out asking a lot of questions. (Nellie, SP)

I was frustrated because the judges wouldn't let me talk, they wouldn't let me present my side of the story. They said we need to put her with another family. This, after maybe a 10-month battle or so in the courts... (Tim, NDOA)

Yeah, 13 years maybe. And that's a long time going to court back and forth, back and forth, back and forth. I tried to get custody of them back with me, and all this stuff. It was not easy... And them trying to say I was not a fit parent. It's very hard on a parent. Which was not true, I was a fit parent. (Johanne, NDOA)

And I had no chance of getting her back. [My older daughter] was a baby about maybe one, two years old, something like. I don't remember, long story. 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, NDOA)

Being separated

They [my kids] don't want to see me or nothing because I was a bad mother. Somebody told me I wasn't a bad mother, I have to accept that they don't want to see me 'cause they moved on with their life and all that. (Tina, NDOA)

I buried my emotions. I buried [them] deep down, just so I wouldn't have to deal with it because it was just too, too painful, too painful. (Tim, NDOA)

Themes

Finding support

My family was there, but I went through it by myself. And I have my family to support me but that was about it, really. But I think if maybe I had had a better support group, I might have found it more [easy], I want to find it easier to get through that time. (Tim, NDOA)

And the second time, after I had the baby, he [father of children] was there all the time, and it went downhill. And me running to my mother's with the one-and-a-half-year-old cause he was being abusive, he kicked my hand, I have a scar on it, from it. I still have it. My thumb was black and blue. So, I had to take the baby and me, and go to my mom's for five days. (Johanne, NDOA)

The system is focused on the idea of offering 'des épisodes de services'. So that certainly has placed a barrier, particularly within this parenting service. And it's something that needs to be advocated for, because, as parenting is a lifelong journey, people's needs are going to change. The parents' needs are going to change. And so are the children's needs going to change. Contexts are going to change. There can be grandchildren. Needs can evolve. So, it is really important to have support services that support people as they are, as they transition, and as needs evolve. (Chelsea, SP)

Community access is important. A lot of the people I am thinking about don't have big spaces where they can host a big Easter or Thanksgiving dinner where budget is also a concern. If they could be with their children in community spaces where they can host a holiday meal. Some of them would really enjoy that and it would reduce isolation and give them a place to celebrate. (Nellie, SP)

Sometimes my sons drive for me now, because I get stressed... I have these sensory overloads around the city a bit everywhere. (Annie-Pierre, NDOA)

Aging with hope

What I want in life? Well, I want my kids again, that's all I want... I wish I could see my kids now. I wanna see them. I really miss them. (Tina, NDOA)

I saw him [my son] at Christmas, and that was fun – last year and this year. Even though we weren't allowed last year [pandemic]. I didn't care, I said, "I'm going to see my child, I have my shots". (Johanne, NDOA)

But, I thought maybe there was a chance that I would still be able to be in my child's life... If you look around, I have pictures of my daughter, my little girl everywhere. So, I'm constantly thinking of her, you know? Even though she lives on the other side of the continent, so I haven't seen her for a number of years... that's pretty hard. (Tim, NDOA)

...it's a feeling of pride for [some] that they raised their kids and so their daily pressures are done. For some, if they had follow-up with child welfare workers, that chapter is far behind them. And some of those sources of trauma are behind them. And for some of them it is a sense of pride that they have moved through it and gotten past it and for the most part they feel proud of their kids and proud of themselves. (Nellie, SP)



How can we empower older neurodiverse parents and their families?

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Heart by Tina NDOA



Recommendations

- Recognize the right to parent, acknowledge the diversity of parenting roles, and the right to inclusive services and supports.
- Acknowledge and engage in conversations about the desire to parent among neurodiverse people.
- Build intersectoral, inter-generational, trauma-informed, and life course parenting support services.
- Encourage peer mentorship programs that foster positive relationships between NDOA parents and their children and grandchildren.
- Explore inter-generational residential/housing programs with supports so families can stay together.
- Enhance the connections between NDOA and their children, particularly among families that have experienced child welfare involvement by supporting contacts and visitations, inter-service collaboration, and communication throughout the life course.
- Ensure access to community-based resources for celebrations and visitations and promote community engagement.



The role of community organizations in the lives of people aging with neurodiversity and their family caregivers

Community organizations play a fundamental role in the lives of people aging with neurodiversity and their caregivers. In addition to offering essential services based on a comprehensive approach adapted to multiple needs, they are places where people forge new social ties, assert their identity, and make their voices heard. However, full recognition of the specific contribution of these community organizations remains a challenge. In particular, community organizations need to obtain sufficient and recurrent financial resources to ensure the continuity of services over the long term, and to develop new ones to meet the needs of neurodiverse people as they age.



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

Themes

Learning, entertaining, creating

Well, I'm learning a lot. [The community organization], sometimes it's about information and mutual support, and there are people who come to give training sessions, meetings, information sessions, and informal discussions over coffee. (P'tit Loup, NDOA)

Like tonight, we're going to do mandalas or play board games, like tomorrow we're having a disco night here. Thursday we have something else, maybe board games on Friday, we'll see inside. Next Friday we're going to eat upstairs if the weather's nice on the terrace, and then we're going to get ice cream afterwards. (Annie, NDOA)

That's it, but as soon as they started at [the community organization], there were camps. Winter camps, summer camps. She went there. And then, we found out that there were other things. She went for respite care. She didn't lack leisure activities. She didn't lack stimulation. (Laurent, FC)

Contribute, making your voice heard

Yeah, he's the founder [of the community organization]. So, I went to the board of directors. I said, "I would like to honor the memory of [a founder]." I said, "I would like us to maybe create a room in his name." You know, there's another [community organization] that named a room after a deceased person. It was the person's room. And at one point, I said, "Why don't we..." and then I said, "Why don't we create the [a founder] award?" Everyone was on board! (Jean, NDOA)

I went to conferences, I have gone many times to give presentations. I was in schools... to inform people about [an organization that defends the rights of people living with intellectual disabilities] and to share my story. (P'tit-Loup, NDOA)

Yeah, yeah, I called the restaurant. And it's [the worker] who started organizing these activities, so she helped me to gather names. We looked at it together to make a schedule for the activities. (Annie, NDOA)

We also organized consultations with individuals, caregivers, and with professionals, to better understand what they experienced as family members or caregivers of aging individuals. (Maude, SP)

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider



Themes

Accessing an independent home to call one's own

But here we're good [non-profit community-based housing]. We have a terrace on the 5th floor, we have a little garden, I planted cucumbers and the cucumbers have already come out, along with the carrots. And in my apartment, I have a terrace, a little balcony where I planted a tomato plant, a pepper plant. (Annie, NDOA)

Here, it's subsidized housing. There are support workers, and when you need help, they assist you. Yeah, that's it. That's how it works. (Lise, NDOA)

So, being a community support worker at [non-profit housing for people with ND] is primarily a role of accompaniment, I would say, providing support through various daily situations for tenants with mild intellectual disabilities... And it's really support, but with a self-determination approach. So, we highly value the control they have over their lives. They are independent, they live alone. That's still something! (Pascale, SP)

Encouragement, support, and help

Right now, I have [the community organization] where I still receive encouragement. (Hélène, NDOA)

She knows me very well, that's why I joke she should give a Elisa 101... it was before the unveiling of my mom, and I was talking about suicide, things were overwhelming... and I remember my [service provider at community organization] spoke to me and I didn't [have] to stay overnight [in the hospital]... (Elisa, NDOA)

M. [service provider from community organization] became an ally all the way through, especially in the last years, because my brother is getting older and has gone through some issues, you know, he became less and less autonomous. So, we had to make some decisions and so the fact that we have some allies and some support, helped us along. (Luce, FC)

Our mission is to provide matching with volunteers and individuals we call "mentees" among our members who experience isolation due to various issues. This could include mental health issues, physical disabilities, or intellectual disabilities, which encompasses all intellectual disabilities. We also have a few individuals with autism. So, the matching means that with the volunteer, always the same person, the mentee engages in activities outside of their home. We do not offer friendship visits. It's only outings to destinations based on their interests. Going for a coffee, shopping, etc. (Judith, SP)

Creating links, belonging to a community

It's like a place... I've been with them for a long time, since '83-'84. It's like a family to me. (P'tit Loup, NDOA)

Alright. So, he used to go to [the community organization]. He liked it. He did dancing, theatre, improv. He did a bit of everything, really. He took all the classes he could. And even back then, he experienced integration. So compared to others, he had a lot of abilities despite his disability, you know. So, he was very much appreciated and all that. So, that period went well. (Thérèse, FC)

I think what we do really does make a difference and lets people actually stay at home longer because we're actually meeting various needs and not just hygiene needs or not just medication administration. And I think we also built a community for people to make friends and rebuild trust in health and social services, particularly for a generation of older adults... who absolutely have been through the worst of the worst. (Stephanie, SP)

And when you're a member at [the organization], you're a member for life. So, we even have people who attend activities less frequently, but we have workers who do rounds, and every month we make sure to visit our group who is in long-term care... [member's name] who is in their resource, we keep them. And I think that's something that characterizes us, and really a standard that I wouldn't want the organization to lose, you know? (Chantale, PS)



Photo, S.O.S.



**What is your favourite community organization?
Why?**

The unique contribution of community organizations to the agency of NDOA is centred on the following three principles:



Relational Autonomy

Taking charge of daily tasks, taking care of yourself and your living environment with the support of people you trust when needed

Participating in new activities, going to places you enjoy

Expressing ideas and points of view



Empowerment

Being informed

Making choices and proposing ideas with the support of people you trust

Making your goals and dreams come true

Participating, contributing, speaking out and speaking up

Representing your point of view on a committee, board of directors, as part of an organization



Solidarity

Having a place where you feel a sense of belonging

Feeling comfort and trust with those that help or support you

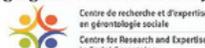
Working, sharing, and doing things with your peers, communities of belonging, and allies



Recommendations

- Better recognize and fund community organizations working with people aging with neurodiversity and their families.
- Increase the number of non-profit organizations providing housing with social support for people aging with neurodiversity, using a variety of configurations (for example, number of units, services offered, composition and mix of population groups, etc.) to meet multiple and diverse needs.
- Promote and support intersectoral collaboration between the health and social services network and community organizations.
- Increase community respite services for caregivers of people aging with neurodiversity.
- Introduce future health and social service professionals to the importance of community interventions with NDOA.

The experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-24)



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Identity, Agency, Activities, and Pride!

The final infographic of the series celebrates the unique identities, strengths, and achievements of our neurodiverse older adult (NDOA) participants. We showcase their resilience by sharing quotes about the many ways in which they recognize and value their own worth and abilities. The quotes presented focus on meaningful aspects of NDOA's lives in their own words, including: relationships with family, faith, leisure activities and interests. Additionally, the participants' reflections shed light on their perseverance in overcoming barriers, pushing back against stigma and discrimination, and joining others in order to educate and advocate for change. Finally, we present some of the important lessons NDOA shared about how they want to be treated by the services providers that work with them. These lessons can provide valuable insights about how to make our interactions and approaches more inclusive.



Drawings taken from Batman's life line

Themes

Identity and pride

Yes, I was, at 68, volunteer of the year... I have my plaque at my house. (Dédé, NDOA)

Who's a good boy? I'm the good boy! (Batman, NDOA)

It was 13 years ago that my parents helped me financially to buy my first car. I paid it all off, a used car. I never thought I would be capable of having a car in my name, but it's my third car that I pay out of my pocket, my second. (Frank, NDOA)

The fact that I am still here, is a miracle. I think I get my strength from my mom, well, because of her. She was a Holocaust survivor, she's been through hell, I've been through hell, as the timeline will tell you... (Elisa, NDOA)

Yeah, my mom, it's like me! My mom had a big heart too! (Rosemary, NDOA)

It's like all my life I felt a bit incompetent in many areas of my life. And then, for the first time [after my autism diagnosis], I cried because I was proud of myself... (Annie-Pierre, NDOA)

Wu loves living alone because "when he is on a boat, he prefers to be the captain." (Wu, NDOA)

I love living alone. Now I think it is part of my personality being autistic. Some people prefer to be alone but I love it! (Marilou, NDOA)

Faith

Next father's day, I will just lie in my bed and listen to country music. I will hold my bible and think of my mom and dad. Sometimes when I sit down... my family [who passed away] are with me, my mom and dad, my brother, my baby. (Christine, NDOA)

Love of family

...good memories about my mom... when I eat bread and jam, peanut butter, every time I eat with jam, I have memories of my mom. (Christine, NDOA)

The best thing about me is being an aunt to my nieces and nephews... [Growing up was] fun, fun... I have five beautiful sisters who love me. (Lisa, NDOA)

Things I love to do

I like to draw, craft, this and that. I feel good [when I create art] because when I have nothing to do, I like doing things like crafting and all that... yeah, my creation. (Tina, NDOA)

I like watching Elvis, all of them, Kenny Rogers, Johnny Cash, the Beatles... spend time with my roommate M, watching Elvis with him if he wants to. (Batman, NDOA)

For me it is about being busy, not necessarily at work, but to keep busy... mostly to be happy in what I am doing, even if it is just activities to get me out of the house. To have like other things to talk about besides just being home. (Audrey, NDOA)

I can read. I'm reading my favorite book Heidi, and I got the little princesses too in my drawer. It's a book, Heidi is a book I can never put down. (Suzy Q., NDOA)

I liked riding the metro system. There were many years that I would get on the metro and ride it till the end of the line and then come back. (M. X, NDOA)

I draw and I knit. I love knitting. I already made a bag, a beautiful bag made entirely of wool, and we stuffed it. (Lise, NDOA)

Oh I like to spend time with my wife and doing different things together. Enjoying life together. We have a lot of interests in common, so that helps. We like to watch tv together and things like that. Sometimes we like to travel when we can, we do different things together during the summer. (Tim, NDOA)

Pushing back against stigma and discrimination

The important thing is to defend my rights. Me, I am happy to save the world and I am generous. (Hélène, NDOA)

I went to conferences, I have gone many times to give presentations. I was in schools... to inform people about [an organization that defends the rights of people living with intellectual disabilities] and to share my story. (P'tit-Loup, NDOA)

[Some workers] were hard... they had to understand... because I have disabilities, so, I have trouble understanding things. (Johanne, NDOA)

Labels go on jars, not on people (P'tit-Loup, NDOA)

Agency means having the right to do and to decide!



Drawing by Aglaé, research assistant

NDOA: neurodiverse older adult
FC: family caregiver
SP: service provider

Important lessons for service providers

Recognition and that's what I will want when I get to be that age. Somebody saying, "Oh no, he's a person", you know. I don't need to be recognized for all the things that I've done, but just when you're talking about dignity, just **so the person can still have their dignity.**
(Tim, NDOA)

Yes, I think that you have to see us as people... Often we are spoken to as if we are 3 year-old children, but we are 50, 60, 75 years old... for sure you shouldn't speak to us using 100 dollar words, but speak to us normally... Because I am capable of thinking... but it takes a bit more time, but it doesn't mean that I don't understand... It's very insulting. **It is important to speak to us normally, to be courteous, and always look us in the face, with honest eyes...** I would say that to the people who will work with us, it is a nice effort on their part, but for us also, because it would be easier for us to explain ourselves, and after to feel understood... Things will change when the world wants to change, people who surround us... doctors, nurses, personal support workers... even if we have an intellectual disability, we are the same as anybody else on the street. We have the same feelings, values, beliefs.
(Audrey, NDOA)



What are your favourite activities?

In what ways can you empower neurodiverse older adults (NDOA) to self-actualize, feel a sense of belonging, and realize their hopes and dreams?

Recommendations

- Respect neurodiverse older adults' (NDOA) inherent dignity and right to self-determination.
- Ensure the use of accessible language and adapted approaches to take into account the unique situations, needs, wishes, and realities of NDOA.
- Take the time necessary to understand NDOA, including learning about their backgrounds, identities, relationships, interests, and sources of happiness.
- 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.
- Create opportunities to celebrate and honour NDOA through the development of ongoing and sustained relationships of care using a relational autonomy approach.
- Make room at the decision-making table for NDOA and their allies as equal partners in the development of programs and policies.

Brotman, S., Deshaies, MH., Pacheco, L. (2024)



Final thoughts...

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 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!



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.
- **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, and (3) comprehensive supports for social inclusion, that centre on people's rights and dignity.
- **Address** the issue of parallel aging among people aging with neurodiversity and their parents within public policies and front-line services (notably in housing, home care, respite, and mental health).
- **Improve** training initiatives on the intersection of aging and neurodiversity targeting service providers at all levels and across all sectors.
- **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.
- **Create** an independent inter-ministerial structure in order to collaboratively address all issues relating to disability, neurodiversity and aging in Québec.

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