



La Gang à Rambrou and  
Sans Oublier le Sourire  
present...



**A Toolkit for Reflection, Learning, and Action**

**To Accompany the Performance Video**

Developed by: **The Experiences of Social Exclusion and Inclusion Among People Aging  
with Neurodiversity and Their Families Research Team**

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



[www.creges.ca/en/aging-neurodiversity](http://www.creges.ca/en/aging-neurodiversity)

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## Toolkit for reflection, learning, and action to accompany the performance video: *Neurodiversity! Age together, Act together*

### Introduction

This Toolkit was created to support continued reflection, learning, and action based upon the key themes emerging within the performance ***Neurodiversity! Age together, Act together*** ([https://youtu.be/Y\\_oibKbB8rM](https://youtu.be/Y_oibKbB8rM)). The performance, which was presented by La Gang à Rambrou and Sans Oublier le Sourire, took place at the celebration event held on May 27, 2024 where we presented the findings of our research ***The Experiences of social exclusion and inclusion among people aging with neurodiversity and their families (2020-2024)*** (for a full description of the project, please follow the link: [The Experiences of Social Exclusion and Inclusion Among People Aging with Neurodiversity and Their Families](#)). On our website you will also find a [short introductory video about the project](#) that you can listen to.

Our project documented the stories of people aging with neurodiversity (45 years of age and older) and their family caregivers (parents and siblings) 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. The project also interviewed service providers in both public sector and community-based organizations about their perspectives on the challenges encountered by people aging with neurodiversity and their families, and potential responses. The objectives of the project were to 1) foreground the voices of older people living with neurodiversity and their family caregivers; 2) make recommendations for change to services and supports that are grounded in people's experiences and perspectives; 3) contribute to the development of inclusive policy and practice across sectors; and 4) advocate for programs and policies that better address the realities of, challenges facing, and agency enacted by neurodiverse older people and their family caregivers.

La Gang à Rambrou and Sans Oublier le Sourire, two community-based organizations working with neurodiverse people, joined forces to highlight the life experiences of the 21

people aging with neurodiversity aged 48 to 78 who were interviewed as part of the research project in Montreal and Quebec City. Drawn directly from the quotes of neurodiverse older adult (NDOA) participants, their stories took shape on stage in words and movement through artists who are themselves aging with neurodiversity. At times poetic, at times poignant, the performance leads us to think about what it means to age with neurodiversity, highlights strengths and resilience, and examines the challenges facing NDOA within schools, workplaces, the health and social service system, housing, and in society in general. It also includes important themes related to: identity, interests and belonging, mental health and addictions, mistreatment, lack of control over daily life, caregiving, and the important role of community organizations in the lives of both NDOA and their family caregivers.

This Toolkit is intended to be used by and with people living with, and aging with, neurodiversity of any age, family and friend caregivers, service providers, managers and policy makers, and students. It is meant to guide reflection, learning, and action using the video recording of the performance **Neurodiversity! Age together, Act together** for inspiration. Reflection, learning, and action can be undertaken by individuals on their own and at their own pace (for example, this can be self-directed) and can also be used in small groups or dyads in therapeutic settings, and/or workplace and community settings. The Toolkit is also intended for students in classroom or field education settings.

Our hope is that the conversations, reflections, learning, and actions that will occur as people engage with the performance video and Toolkit will foster understanding, recognition, and respect for adults aging with neurodiversity and their family caregivers. We also hope it will encourage service providers and decision-makers in public and community sector organizations to create and promote policies and services that enhance inclusion, respect, and dignity, and in which the rights of people aging with neurodiversity and their caregivers are celebrated and protected.

This Toolkit is divided into three sections and has been designed to promote learning, reflection, and action among the following cohorts:

- People living with, and aging with, neurodiversity of all ages.
- Family and friend caregivers.
- Service providers and students (public and community-based sectors and settings, including those related to health, mental health, disability, rehabilitation and readaptation, employment, education, recreation, housing resources, tutorship, etc.).

Each cohort in the above-named target audiences have their own unique section in the Toolkit, with designated activities tailored to the specific cohort. Each section begins with a definition of who the section is intended for, a list of objectives, a general outline and description of the process, and steps to explain how to engage with the material. While all of the activities use the performance as a stepping-off point and as a means of engagement, some activities also draw upon other material developed by the research team based upon the key findings emerging from our interviews with all three cohorts, namely people aging with neurodiversity 45+ years of age, family caregivers (both parents and siblings) and the service providers across public and community sectors who work with and support them. These other materials include the Individual life stories of some of the 21 neurodiverse older adults (NDOA) interviewed and/or some of the 15 family caregivers (parents and siblings) interviewed. We even have created podcasts for a few of the stories for those that prefer to listen and watch rather than read! Other materials also include some of the 15 infographics on the thematic findings of all three cohorts. These infographics include participant quotes and artwork created by members of the research team, neurodiverse older adult research participants, and members of Sans Oublier le Sourire who contributed their artwork to our study. Anytime we suggest viewing these other materials, we will provide the link that directs you to the exact location where these materials can be found.

Finally, each section contains **Two Activities** that can be used for reflection, learning, and action: **Activity 1** is related to *Intersectional Life Story Narratives and Life Line/Care Line*

*Drawings*, what they are and how to create one, either for yourself, with the person/people that support you, and/or with others like you!

**Activity 2** is based on the *Themes Emerging* from the performance (and *Theme Infographics*). In this activity, you can use one or all the *guided reflection questions* provided to think about, talk about, write about, or draw/colour about how you felt about these themes or what you thought about moments in the performance video. For many of the guided reflection, learning, and action questions, there will be a *'timestamp'* indicated so people engaging with the Toolkit can easily find the exact time and location of the video being referred to in the question. In the section specifically speaking to people living with, and aging with, neurodiversity we have also included a picture of what is happening in the performance at that time to help people remember the scene.

To prepare for engaging in the Toolkit activities, please have on hand paper and pencils, as well as colouring supplies (like coloured pencils, markers or paints) and prepare a quiet place to sit, either alone or with others.

There is no designated order or amount of time needed to use the Toolkit. Take your time and participate at your own pace and in your own way. You can pick or choose from questions or activities that resonate with you and/or your group. You may also want to come up with other activities that we have not yet considered. If you do, we would love to hear from you so that we can improve the Toolkit and enhance it's usefulness and accessibility for a wide variety of people.

We hope that you will find the performance video and accompanying Toolkit informative, and that it sparks your interest and engagement.

Sincerely,

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

## Definitions of important ideas we use in our research

Before we begin with the activities, we believe it is important to share with you the following list of words/concepts that are key to our research project and help to guide our approach and objectives. We consider many of them to be ethical principles. The disability community has identified how the use of language can be powerful and sometimes stigmatizing and we thought it was important to define certain terms included in this Toolkit.

If you prefer, we have also created a recorded presentation of these key terms using plain language to describe what we mean by these terms for you to watch or to use if you are leading a therapeutic or group activity (currently under construction).

### What is neurodiversity?

The term neurodiversity is an example of an umbrella term first developed by self-advocates and their allies in disability-rights communities to bring together a broad diversity of neurocognitive conditions that are mostly (but not always) diagnosed in childhood. The term neurodiversity has started to be recognized within health and social 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.

### What is social exclusion?

Neurodiverse older adults and their family caregivers face significant **social exclusion** throughout their lives. Interlocking oppressions create inequitable conditions that negatively affect people's health and well-being, social inclusion and agency. In other words, social exclusion occurs when we are blocked from participating fully in society - in our schools, workplaces, health care settings, and in our neighbourhoods (to name a few places) because of who we are (like for example, because of being older and/or having a disability and/or living on a limited income). Social exclusion limits our capacity to act, to choose, and to be included fully and meaningfully in the decisions that affect us.

### **What is agency?**

**Agency** is the ability to act and to decide!

### **What is social inclusion?**

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 and to experience **social inclusion**.

### **What is relational autonomy?**

**Relational autonomy** suggests that decision-making is not something we do alone. Disability scholars and activists argue that no one is fully autonomous (completely independent). Most people make decisions with those who they are close to and/or who support them, such as our partners, parents, siblings, family members, and close friends. *All autonomy is relational*, meaning that our freedom to decide is shaped by our context and our relationships (people in our lives, community, our age, and our individual realities and needs). We are all inter-dependent.

### **What are resilience and resistance?**

**Resilience** is when we cope well and maintain our positive well-being even in the face of oppressive circumstances (like being excluded, bullied, or mistreated by people and systems). **Resistance** is when we push back against or challenge these oppressive circumstances. Resilience and resistance can be both individual and collective (like when we advocate for ourselves and others and when we work together to demand change in the way things work to create respect, inclusion, and improve support systems).

### **What is the social model of disability?**

We like this definition from the *Government of Canada Federal Disability Reference Guide* (<http://www12.hrsdc.gc.ca>) which references the World Health Organization in its presentation of what disability means: “Disability is a complex phenomenon, reflecting an

interaction between features of a person's body and mind and features of the society in which they live. A disability can occur at any time in a person's life; some people are born with disability, while others develop a disability later in life. It can be permanent, temporary or episodic. It can be mild or more severe. It can be the cause, as well as the result, of disease, illness, injury or substance misuse. People can have one or many different types of disability including those that are physical, mental, intellectual, neurological, etc. Because of its complexity, there is no single, harmonized "operational" definition of disability across federal programs. Reflecting this complexity are the different approaches to understanding the experience of disability. According to the traditional, bio-medical approach, disability is viewed as a medical or health problem that prevents or reduces a person's ability to participate fully in society. In contrast, the social approach views disability as a natural part of society, where attitudes, stigma, and prejudices present barriers to people with disabilities and prevent or hinder their participation in mainstream society".

### **What is the intersectional life course perspective?**

The intersectional life course perspective is a theory to explain the impact of life-long discrimination and oppression on the everyday experiences of older adults. It has 4 linked 'steps' to explore the ways that dominant systems and structures (like governments, institutions, and social groups) shape daily life: 1) *identity* (who we are, our position in society) and agency (see definition of agency), 2) *linked lives* (relationships with others including both informal ones (for example like our families, friends, neighbours, and peers), and formal ones (for example like service providers, government officials)), 3) "*othering*" (a process whereby individuals and groups are treated as different or "less than" by the dominant social group (mainstream, most powerful, governing, in positions of authority)), and 4) *resilience and resistance* (see definition). Oppression and discrimination are named as important factors shaping individual life experience and people's agency, resilience, and resistance to discrimination and oppression are highlighted.

## **What is disability justice?**

Disability justice is both an end goal and a political movement. Disability justice calls for the rights of people with disabilities in society and centres the interconnections between the diversity of the disabled community based on identity and social location (one's position in society). Disability justice is about the intersections between different forms of oppression like ableism, sanism, ageism, classism, racism, homophobia, transphobia and others. We provide an example of intersectional oppression here to explain further: Mary is a 67-year-old transgender, heterosexual, Black woman with an intellectual disability who lives in a family-type resource. She has a limited income and benefits from the Basic Income Program. In this description of who Mary is, we named the *intersections* of gender identity (transgender woman), sexuality (heterosexual), 'race' (Black), class (low-income), age (67 years old), and ability (intellectual disability). In understanding Mary's identity and the forms of oppression and discrimination she might face, it is important to take account of multiple and interlocking forms including transphobia/gender discrimination, racism, ageism, classism, ableism, and sanism. Fighting for disability justice in Mary's case would mean pushing back against all these forms of oppression and discrimination at the same time.

## **What is parallel aging?**

Parallel aging describes the situation wherein people with neurodiversity *and* their family caregivers (mostly parents) are aging at the same time. Parallel aging can often put pressure on caring relationships and lead to changes in the capacity of caregivers to provide support in the ways that they used to when both the neurodiverse person and they themselves were younger.

### ***Question for consideration after reading our definitions:***

Have you ever heard of these ideas before? What do they mean to you? Discuss, write or draw your answer and if you want, share your thoughts, writing or picture with others.

## Section 1: For people (aging) with neurodiversity



## **Section 1: People (aging) with neurodiversity**

### **Introduction**

In this section, we speak directly to people who are living with neurodiversity, and particularly those who are 45 years of age or older. We say people with neurodiversity who are 45 years of age or older are considered as “aging with” neurodiversity because many people in this age group have already begun to experience transitions that some older people experience, like new or worsening health problems, changes to their living environment to support their new needs or wishes, upcoming retirement from work, and transitions in their social or other recreational activities. It is important to remember that life-long social exclusion faced by people with disabilities often results in people experiencing health inequities and difficulty accessing services thereby contributing to ill health earlier in life than their non-disabled, neurotypical peers. Many in this age group are also facing what we call parallel aging (see definitions in the general section). Because of parallel aging, people with neurodiversity may be more likely to experience transitions in the care and support they have received from people like their parents because their parents are getting older too!

### **Objectives**

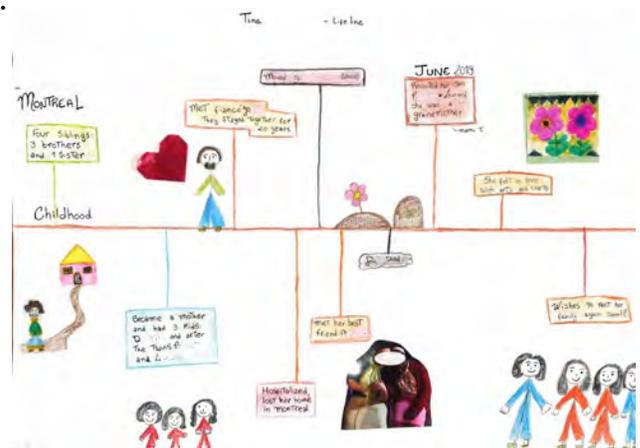
1. To create your own life line drawing on your own or with the support of others.
2. To watch the video of the performance *Neurodiversity! Age together, Act together* and think about or talk about what the video means to you.
3. To reflect upon some of the themes that were part of the performance, and write about, draw or discuss your thoughts with others.
4. To come up with you own ideas about what services and supports have been like for you.
5. To identify what has worked well and what needs to change in the system in order to feel included and supported.

## Activity 1: Sharing my story and creating my own life line!



### What is your life story narrative?

Life story narrative is a fancy way to talk about *storytelling!* This form of storytelling gives you an opportunity to share your life story with others about what you have experienced, what is meaningful to you, and who are the people that are important to you. We also want you to think about what your experiences with schools, government agencies, health services, workplaces, etc. were like for you and what services, programs or organizations you have been involved in (such as: having support from a social worker, intervention worker at home or in the community, work placement, etc.). We would like to learn whether these were good or bad experiences and whether the things you have gone through have made you happy, sad or mad! We want to know more about who you are, what you like to do, your interests/hobbies, proud moments/achievements, challenges you faced, and important people in your lives. We are also eager to learn how you would describe yourself- whether you see yourself as kind, or funny, or love dancing or swimming or any other kinds of activities. Below are two examples of life line drawings. Tina drew hers on her own and Batman's drawing was done with the researcher.



## Step 1: Learning about life stories and life line drawings

This activity begins by learning about what life stories are and what life line drawings are by reading about or listening to the life stories of others.

1. At the beginning of the performance, Maria shares in the microphone a quote from Elisa which ends with her saying “...as my timeline will tell you”. Maria then acts out Elisa’s life line drawing by walking back and forth across the stage and moving her body to present the different quotes that describe Elisa’s life journey. Maria ends by singing “***Nobody can do what I can do. Let’s go! Let’s show!***” while the others encourage her by applauding and cheering. This is a life line in action! (*timestamp: 12:20*)



2. Listen to or read either [Audrey’s story \(podcast version\)](#) or [Tina’s story \(podcast version\)](#). Look carefully at Tina’s life line drawing that she did herself or Audrey’s drawing of boxes and words. Through pictures or words they both described the meaningful moments in their lives. This is a life line in art and words!

### Questions for reflection:

1. What did you think about Maria’s portrayal of Elisa’s life line in the performance? Despite her ups and downs over the course of her life, Maria ends by singing that she can do things that no one else can. What does this mean to you? Do you feel the same way about yourself? What can you do that is unique to you?



2. Our stories are never told in order! Usually, the most important things come out first, whether they happened when we were a child or when we were 30 years old or when we were 60 years old. So don't worry about where you start your story drawing. Go with what feels right to you and place the pictures you create of the memorable events in your life near the part of the arrow where it belongs (i.e. near where it says child, teen, adult (of any age) or now).
3. Be creative and draw above or below the line the meaningful moments, activities, people, places, and events that are important to you. These things can be positive or negative, make you glad, sad or mad to think about. These things are all important to your story!!
4. The life line could take as long as you want to draw. There is no time limit, and you can add or take away anything from your drawing at any time. It is your life and your choice what you put on your life line!
5. Finally, once completed you can share it with others and talk about what the pictures or words on your drawing mean for you. Tell your story and use your drawing as a guide! Your life story matters!
6. Remember that it is totally fine if you want to ask someone to help you decide what to include or even draw the pictures with you, but this is your life line and you must guide them about what to include and why.

**Prompts** (also available as a [Worksheet](#)): When you share your story, think about...

**Times:** When things happened and who was involved at the time. Like, for example:



When I was born



As a child



As a teenager



As an adult



Now: getting older

**Places:** Where you were when it happened...



Where you lived –  
at home or in  
another place



At school or work



At an organization



At a service



Somewhere else

**People:** Who is important to your story...



Family member(s)



Friend(s)



Animal(s)



Worker(s)



Someone else

**Activities:** What you like to do or what you enjoy...



Music



Movies



Art



Food



Something else?

**Feelings:** How you feel/felt about the things that happened or the people you were with...



Glad



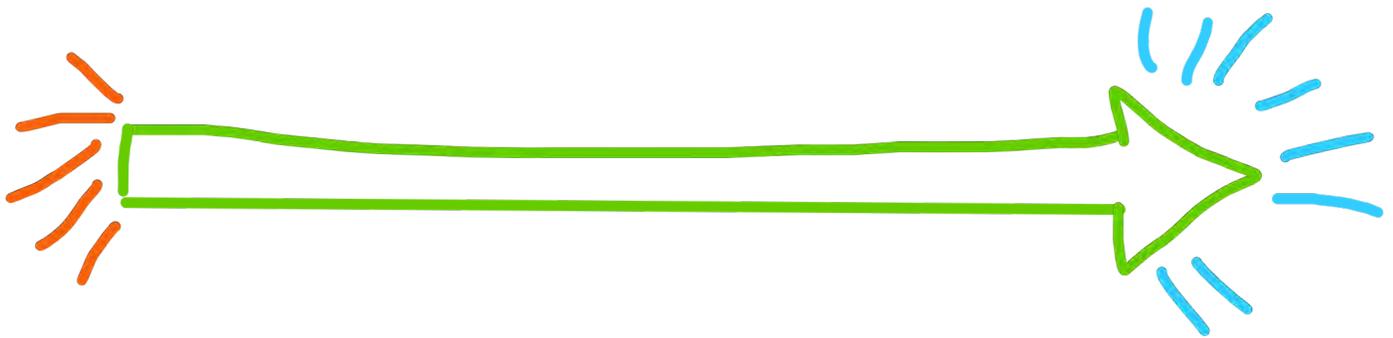
Sad



Mad

**Reflection question after completing the life line drawing activity:**

1. What did you think about doing your own life line? How did you feel when you looked at the final drawing or shared it with others? You can use the [My Feelings Chart](#) to describe how you felt about this activity.
2. Do you think that a lifeline would be a good tool to have when you are working with your support workers or in an activity group with others? Why or why not?



## Activity 2: Reflecting on the themes from the performance

This exercise can be used as a guide for reflection and discussion after watching the video of *Neurodiversity! Age together, Act together*. Consider the following questions.

### Guiding questions for reflection:

1. Write, draw, or insert images/pictures that identify the main emotions you felt while watching the performance. You can do this by yourself or team up with others. You can also use the [Feelings Chart](#) to colour in the emotions you felt.
2. What was your most favorite part of the performance and why?
3. What was your least favourite part of the performance and why?
4. The performance is a way to capture and share the thoughts, ideas, and experiences of people aging with neurodiversity. One of the themes that emerged was how people experience and feel about the services they receive (including experiences with workers, health care providers, in residential settings, etc.). During this part of the performance, the performers line up and pass along a blanket while they speak about both the good and bad things they have encountered with service providers. At one point, Carol squished a blanket when the quote from Elisa says, “*Workers? They change like underwear. It’s pathetic!*”. What do you think Elisa was trying to say here? François squished the blanket when the quote from Audrey said, “*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*”. (timestamp: 22:00-36:00) **What is your experience of having workers involved in your life?**



5. **What do you think service providers (workers) or decision-makers (like people who run or plan services) should know to better support people aging with neurodiversity?**
6. What it is like to get older was an important part of the performance. There were a diversity of perspectives on aging amongst NDOA represented in the performance, from it being a normal experience “I am still young at *heart*” (a quote from Christine) to “*I am worried about my health and about dying*” (a quote from Elisa). In the performance, Alexandre leaned over sadly while the quote from Audrey stated, “*...yeah I try not to think about it... You get older so they cannot do anything but get older too*”. Georgios moved sadly when the quote from Mr. X stated, “*Difficult, very difficult... I don’t have my parents anymore. No more parents. My parents are dead. I wish I could have died before them*”. (timestamp: 19:22) **What is getting older like for you? Do you worry about the future and what will happen as your family members get older? Who are you able to talk to about these feelings and concerns?**



7. Mistreatment in all its forms was a common theme raised by our NDOA participants. The performance shared many quotes with the audience and we have a few pictures below of these scenes (*timestamp: 25:45-28:53*). During one part of the performance, the performers placed a blanket around Marie-Josée (one of the performers) and gently put their hands on her shoulders while the quote from Johanne spoke about experiences of abuse and depression. This seemed to indicate support, during difficult times. (*timestamp: 25:45*) **Identify the people or organizations that support you. Are there any other supports you feel you need?**



Family violence



Bullying



Teasing and being excluded



Multiple forms of mistreatment

8. Housing came up time and again as an area of priority and concern. The housing environments amongst our participants were diverse and included living with family, in private market or social housing units with support from service providers, in community-based non-profit housing resources, and in public sector-affiliated residential resources. Some NDOA in our study spoke of living for periods of time in psychiatric hospitals for different reasons related to mental health challenges or addictions. NDOA shared both the problems they encountered and what good housing looks like for them. At the beginning of the performance the performers moved to several quotes which addressed both good and bad experiences of housing. Audrey's quote in specific described living alone and being able to do what she wanted as *"freedom!"* (timestamp: 17:30), while Tina's quote suggested that living with many people could be challenging, *"Yah ten people live in this house, residents and coworkers"*. (timestamp: 17:09). **What is your housing experience? How many different places have you lived in your life?**



9. Lack of control over daily life is a common experience among NDOA. Controls come from many sources including both informal (family) and formal (service providers). At one point François shared Elisa's quote related to a strategy for limiting her sister's control over her finances by stating *"Do I have any control of my life? Not really. Except for the stuff that I don't tell her, like the money... because it's my money!"* and everyone says *"ssshhhh"* in response (timestamp: 23:00). Control over finances is but one example of the controls NDOA face in their daily lives. In another segment about living in a group home, the performers move to the quote by

Johanne, “Getting older and living in a group home is hard because you have to eat what they want”. (timestamp: 16:35) **Do these examples resonate with you? Do you feel you have control over your life and your decisions? How can residential resources adapt their practices to better ensure agency and choice among NDOA residents?**



**10.** During the performance, all the performers danced while participants’ quotes about the activities they enjoy and the pride they feel in who they are were shared. It was an exciting and joyful moment as everyone in the audience clapped along to the music. (timestamp: 32:45) A striking part of the performance happened when the performers helped to dress Georgios in a Batman costume to represent the story of the participant who called himself Batman. (timestamp: 28:56) This scene seemed to indicate the importance of interests and personal strengths. Think about your interests, what is important to you, and how you describe yourself. We often forget about our strengths and interests, and it is important to sometimes remind ourselves and others! **What are your strengths? What and or who helps to promote your strengths and positive identity?**



## Section 2: For family and friend caregivers



*A special thank you to Sans Oublier le Sourire for their permission to use this photo in our research*

## **Section 2: Family and friend caregivers**

### **Introduction**

In this section, we speak directly to people who are caring for or supporting a family member or friend aging with neurodiversity, and particularly those who are 45 years of age or older. We say people with neurodiversity who are 45 years of age or older are considered as “aging with” neurodiversity because many people in this age group have already begun to experience transitions that some older people experience, like new or worsening health problems, changes to their living environment to support their new needs or wishes, upcoming retirement from work, and transitions in their social or other recreational activities. It is important to remember that life-long social exclusion faced by people with disabilities often results in people experiencing health inequities and difficulty accessing services thereby contributing to ill health earlier in life than their non-disabled, neurotypical peers. Many in this age group are also facing what we call parallel aging (see definitions in the general section). Because of parallel aging, people with neurodiversity may be more likely to experience transitions in the care and support they have received from people like their parents because their parents are getting older too!

While the performance is based solely on the quotes of our older neurodiverse participants, there are many themes presented that will resonate with family and friend caregivers such as parallel aging, challenges faced within health and social services such as those related to staff turnover, a lack of inclusion of caregivers in planning, service silos, housing transitions, and discrimination. In this section, we have based our reflection, learning, and action activities on both the performance video and four of the thematic infographics that share the perspectives of caregiver participants.

After watching the video of the performance please read the following 4 infographics which are available in the [Infographics Booklet](#):

- a. Caregiving
- b. Gaps and challenges in the health and social service system
- c. Mental health and addictions
- d. Mistreatment

### **Objectives**

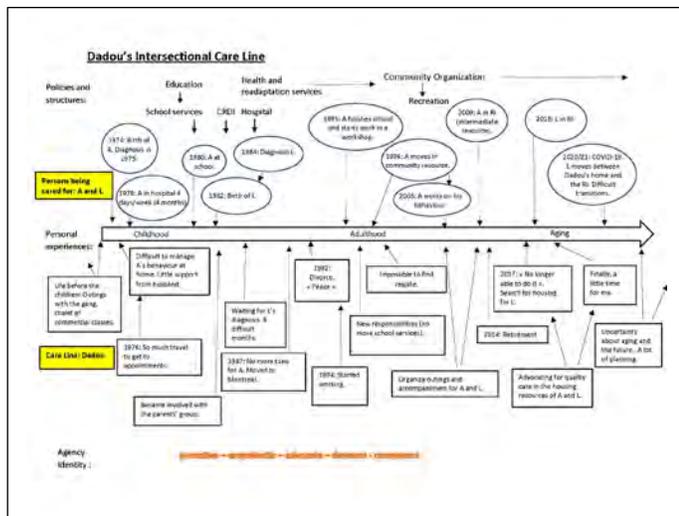
1. To watch the video of the performance *Neurodiversity! Age together, Act together* and the 4 infographics that centre the voices of caregivers and to think about or talk about what the themes presented mean to you.
2. To think about and share your own life experience with others, either by writing or drawing your own care line or by writing a journal about your care journey or by talking about your stories with others, using some of the ideas in the performance to stimulate ideas.
3. To reflect upon some of the themes presented, and write about, draw or discuss your thoughts with others.
4. To explore strategies for promoting self-care and personal growth among family caregivers.
5. To come up with your own ideas about what services and supports have been like for you and to identify what has worked well and what needs to change in order to feel included and supported.

## Activity 1: Intersectional life story narrative and care line drawing

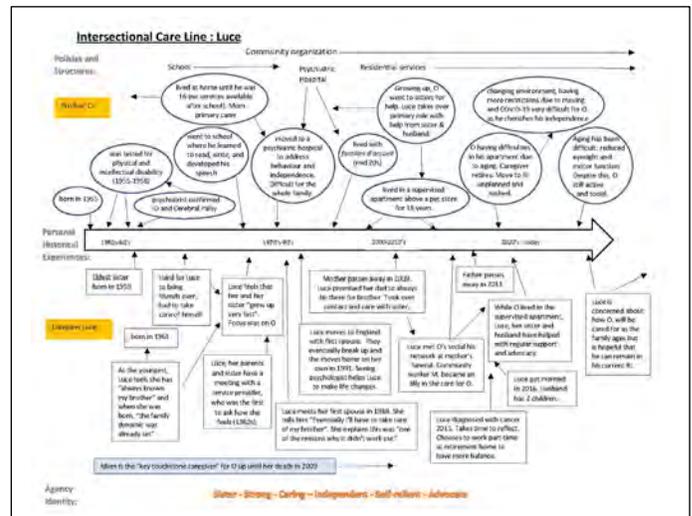


### What is an intersectional life story narrative and care line drawing?

Life story narrative is a fancy way to talk about storytelling! Storytelling is about sharing your story of your caring journey with others and naming what happened to you in relation to the person you are caring for, and what is meaningful to you, whether positive or negative. An intersectional life story narrative pays attention to interactions with systems and structures like government programs and policies, institutions, programs, services, and professionals that you encounter in your role as a caregiver. Importantly, storytelling centres on how caregivers think and feel about the things that have happened to them and to the person they are caring for. The care line drawing is an arts-based, creative, and accessible tool for engaging in conversations about your life, your strengths and your challenges. Below are two examples of care lines created with two caregivers in our study.



Dadou's Care Line (mother)



Luce's Care Line (sister)

## Step 1: Learning about life stories and care line drawings

This activity begins by learning about what life stories are and what care line drawings are by reading about or listening to the life stories of others.

After watching the performance, please also listen to or read either [Dadou's \(parent\) story \(podcast version\)](#) or [Luce's \(sister\) story \(podcast version\)](#), or both, if you have the time!.

### Questions for reflection:

1. At the beginning of the performance, Maria shares in the microphone a quote from Elisa which ends with her saying “...as my time line will tell you”. Maria then acts out Elisa’s life line drawing by walking back and forth across the stage and moving her body to present the different quotes that describe her life journey. Maria ends by singing “*Nobody can do what I can do. Let’s go! Let’s show!*” while the others encourage her by applauding and cheering. (*timestamp: 12:20*) This is a life line in action!

What did you think about Maria’s portrayal of Elisa’s life line in the performance? Despite her ups and downs over the course of her life, it ends with singing that she can do things that no one else can. What does this mean to you? Do you feel that the person you are caring for or supporting might feel the same way about themselves?



2. What did you feel or experience after reading or listening to Dadou’s and/or Luce’s story? Was there anything that resonated with you as a family/friend caregiver? Do you think their care lines reflected their journey?

## Step 2: Drawing your own care line

To understand the experiences of participant caregivers who took part in the study, co-constructed care lines were created to identify the significant events and people in their caring journey.

Before beginning it is important to let you know that none of our caregiver participants chose to draw their own care line, relying instead on the research team to create the intersectional care line from the narratives shared during their interview process.

Caregivers expressed that the time-consuming nature of their care limited their capacities and energies to engage in a drawing exercise. You may feel the same way and it is totally up to you if you want to try drawing your own care line. Remember that it is totally fine if you want to ask someone to help you decide what to include or even create the care line with you/for you, but you must guide them about what to include and why.

If you choose to do the drawing exercise, the following list of steps can help you to create it.

We have also created a [Worksheet of Life Line and Care Line Prompts](#) that can help you.

1. Use the [Care Line template](#) to think about the meaningful events that have happened to you and/or to the person you are caring for throughout your caregiving journey. Inside the arrow you can write different stages in your life or different years or dates.

Think about where you want to begin your care story/care line. It can be anywhere and anytime in your care journey that is meaningful for you. Some participants began telling their care story when the person they were caring for was born or when they themselves were born (to provide more historical context to their lives), and some began their story from the point in their lives when something important happened whether big or small. For example, you can put childhood to the left near the beginning of the arrow and being an older person or turning 50, or just TODAY at the right end. You can also choose to put the date or age of when you first began

your caregiving journey on the left of the page. Think of the arrow as your caregiving journey from some point of time you choose up until now!

2. Second, situate both your own experiences (below the line) and the key moments in the life of the person(s) you are caring for or supporting (above the line). What distinguishes a care line from a life line is that the care line situates both the caregiver and the person they are caring for on the same line because caregiving and care-receiving is a relationship between two people. Don't forget to add words that describe who you are and what you see as your strengths at the bottom of the line. Look at the care line illustrations on page 28 for a visual example of what the final care line can look like.
3. Third, be creative and draw meaningful moments, activities, people, places, animals and events that are important to your story. These things can be positive or negative, it doesn't matter as it is all part of your journey. Just draw what is important to your care journey and who you are as a person. This could take as long as you want to draw. There is no time limit, and you can add or take away anything from your drawing. It is your care journey and your choice what you put on your care line!
4. Finally, once completed, you can share your care line with others and talk about what the events on your drawing mean for you. Tell your story and use your drawing as a guide!

**Reflection questions to consider after completing the care line drawing activity:**

1. Did you learn things about yourself by drawing or writing about your own care line?
2. Do you think that a care line would be a useful tool to use with family caregivers in counselling sessions or in self-help groups? Why or why not?

## **Activity 2: Reflecting on themes from the performance and infographics**

This exercise can be used as a guide for reflection and discussion after watching the video of *Neurodiversity! Age together, Act together*. The performance is centered on the experiences of neurodiverse older adults (NDOA); however, the research project is grounded within the experiences and perspectives of neurodiverse older adults, family caregivers and service providers. The infographics on themes emerging from our project include quotes from all three cohorts. We have therefore chosen to base the following reflection, learning, and action questions on both the performance video and the following infographics which, we believe, have particular significance for family and friend caregivers as well. Before beginning the reflection exercise, please read the below thematic infographics that can be found in the [Infographic Booklet](#).

- a. Caregiving
- b. Gaps and challenges in health and social services
- c. Mental health and addictions
- d. Mistreatment

### **Consider the following questions;**

1. As a family caregiver, what resonated with you as you watched the performance and read the infographics?
2. If there was a performance on family caregivers, what would be the main themes? Are there any quotes within the caregiving infographic that you think should be included if we did a play on the experiences of caregivers?
3. Parallel aging (the reality that care situations and contexts can significantly change as both people with neurodiversity and their family caregivers age) was an important theme emerging from our project and was represented within the performance and the Infographic on Caregiving. In the performance Alexandre leaned over sadly while the quote from Audrey stated, “...yeah I try not to think about it... You get older so they cannot do anything but get older too”. Georgios moved sadly when the quote

from Mr. X stated, *“Difficult, very difficult... I don’t have my parents anymore. No more parents. My parents are dead. I wish I could have died before them”*.

*(timestamp: 19:22)* What does parallel aging mean to you? How do you experience parallel aging in your own caring journey?



4. There were a diversity of perspectives on aging amongst NDOA represented in the performance, from it being a normal experience *“My heart is still young”* (a quote from Christine) to *‘I am worried about my health and about dying’* (a quote from Elisa). *(timestamp: 18:30)* Is this something that you can relate to within your caregiving experience? How have you thought about/planned for the aging process within your caregiving journey? What supports might be available for you to plan for the future? What is missing?



5. The Caregiving infographic points to the many challenges that caregivers face but also identifies the theme of enduring love and care. Do you experience some positive aspects of care? If yes, what are they? If no, what gets in the way of feeling positive about your role or relationship with the person you are caring for or supporting?



6. In the *Caregiving Infographic* many caregivers spoke about feeling a sense of burden or about not having time to pursue their own interests or dreams. Do you feel like you have no time for yourself to enjoy activities that you used to enjoy or to take advantage of your retirement? What services would you need to make this possible?
7. The performance is a way to capture and share the perspectives of aging with neurodiversity in order to shape policies and practices. During one segment, the performers all stand in a row and pass a blanket along while the quotes speak about both the good and bad things older adults living with neurodiversity have encountered with service providers. At one point, Carol squished a blanket when the quote from Elisa says, “*Workers? They change like underwear. It’s pathetic!*”. (timestamp: 33:00-36:00) Does this segment speak to your experience as a family caregiver in navigating the health and social service system? How did you feel when hearing all these quotes about challenges with the system and with service provision?



8. Mistreatment was identified as a prevalent issue. In one segment of the performance, the quotes spoke to child abuse and neglect, bullying in schools, sexual harassment and violence, mistreatment in the workplace, etc. (timestamp: 25:42-28:53) How does this resonate within your own experience as a caregiver? How do you think this issue can be addressed in practice?



9. In the mistreatment infographic, service provider Chantale shared her belief that mistreatment is systemic when she stated, *“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”*. What do you think about this quote? Do you agree or disagree?
10. Concerns about mental health and addictions were also presented in the performance and Infographic on *Mental health and addictions*. This includes a quote from participant Tina who shared the consequences of drinking too much was that she ended up being mandated to move to a residential resource, *“I was put here by court of law... yah I put myself here”*. (timestamp: 15:33) All the performers repeatedly moved to participant Elisa’s quote about living with *“depression and anxiety”*. (timestamp: 20:18) In the mental health and addictions infographic, service provider Thomas shared, *“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”*. Are these issues that you have faced in your caregiving journey? If so, how did you navigate them? What resources would you need in order to better support the person you are caring for address substance use or in dealing with co-occurring mental health issues? Do you agree with all of the caregivers and service providers who spoke to the silos and access barriers for people living with co-occurring neurodiversity and mental health challenges that were represented in the *Mental health and addictions infographic*? What needs to be put in place to help you navigate these silos?



11. Issues and concerns related to housing were a common theme in our findings. The housing environments amongst our participants were diverse and included living with family, in private market or social housing units with support from service providers, in community-based non-profit housing resources, and in public sector-affiliated residential resources. Some NDOA in our study spoke of living for periods of time in psychiatric hospitals for different reasons related to mental health challenges or addictions. NDOA shared both the problems they encountered and what good housing looks like for them. At the beginning of the performance the performers moved to several quotes which addressed both good and bad experiences of housing. Audrey's quote in specific described living alone and being able to do what she wanted as *"freedom!"* while Tina's quote suggested that living with many people could be challenging, *"Yah ten people live in this house, residents and coworkers"*. (timestamp: 15:57) What do you think made the difference for participants in experiencing housing as either good or bad?



12. What do you think service providers (workers) or decision-makers should know in order to better support people aging with neurodiversity and their family caregivers?

### Section 3: For service providers and students



## **Section 3: Service providers and students**

### **Introduction**

In this section, we speak directly to service providers who are caring for or supporting a client, service user, resident, community member or patient aging with neurodiversity and/or their families, as well as students studying to become service providers in the future. We say people with neurodiversity who are 45 years of age or older are considered as “aging with” neurodiversity because many people in this age group have already begun to experience transitions that some older people experience, like new or worsening health problems, changes to their living environment to support their new needs or wishes, upcoming retirement from work, and transitions in their social or other recreational activities. It is important to remember that life-long social exclusion faced by people with disabilities often results in people experiencing health inequities and difficulty accessing services thereby contributing to ill health earlier in life than their non-disabled, neurotypical peers. Many in this age group are also facing what we call parallel aging (see definitions in the general section). Because of parallel aging, people with neurodiversity may be more likely to experience transitions in the care and support they have received from people like their parents because their parents are getting older too!

Service providers play a key role in the care and support of people with neurodiversity across the life course and into old age. Service providers work in the public health and social service system, in residential resources, in adapted work settings, in the educational system and in socio-professional, recreational, and support activities in the community. There are also workers who provide support from community organizations for persons with disabilities and or organizations that support older adults. Service providers’ roles are varied across sites and sectors of care but it is without a doubt that wherever they work, service providers will often be a part of the lives of NDOA and their family caregivers. Worker critical self-reflection has been identified as a central facet of inclusive and equitable practice and the following section helps to identify potential personal reactions, unpack our power as service providers, reflect on meaningful practices, and identify some actions for change. It also requires the identification of systemic barriers that impact the

daily lives of people aging with neurodiversity and their family caregivers. By reflecting on our practice and macro level variables, we can deepen our understanding of the realities and needs of NDOA, enhance our skills, and drive meaningful change in the systems in which we work that are meant to support neurodiverse older adults and their family caregivers.

While the performance is based solely on the quotes of our older neurodiverse participants, there are many themes presented that will resonate with service providers and students, such as the issues of parallel aging, housing, mistreatment, mental health and addictions, and challenges faced within health and social services such as those related to staff turnover, lack of intersectoral dialogue, and service silos. Still, there are many other themes and issues that emerged in the interviews with caregivers and service providers. In this section, we have based our reflections, learning and actions activities on both the performance video and several *Thematic Infographics* which detail the themes emerging from the project with quotes from all three cohorts (people aging with neurodiversity, family caregivers, and service providers from public and community sector organizations). For the following activities, please watch the video, and read the 6 thematic infographics listed below. We highly recommend that you read the entire Infographic Booklet when you have the time and based on your interest and the focus of your work (and the work of your organizations) or the focus of your studies. You can alter some of the reflection questions to consider other Infographics that you find relevant or interesting either alone or collectively with your colleagues. All the infographics we suggest reading below can be found in the [Infographic Booklet](#).

- a. Gaps and challenges in the health and social service system
- b. Housing (link)
- c. Lack of control over daily life
- d. Mental health and addictions
- e. Mistreatment
- e. Caregiving

## **Objectives**

1. To deepen understanding of the experiences of neurodiverse older adults (NDOA) and their family caregivers and how their perspectives can be centered in practice.
2. To reflect upon strategies that enhance inclusive and responsive support to NDOA and their family caregivers.
3. To learn about and practice narrative storytelling and life/care line drawings as an innovative and holistic tool for direct practice with neurodiverse clients, service users, residents, members and/or patients, as well as with family caregivers.
4. To explore how the identity, resilience, and strengths of NDOA and their family caregivers can be embedded in practice.
5. To examine how a life course approach can impact the delivery of services to NDOA and their family caregivers.

## Activity 1: Using life story narrative storytelling and life line and/or care line drawing exercises with your clients, service users, residents, members and/or patients



### What is an intersectional life story narrative and life line and/or care line drawing?

Life story narrative is a fancy way to talk about storytelling!! When clients share their stories with service providers who ask questions about what is meaningful to them over their life course and when service providers co-create and share decision-making power through conversations about how stories are shaped and shared, then they are engaging in narrative storytelling. We make it intersectional when we add reference to the institutions, programs, and services that clients have been involved with over their entire lives, whether these were positive or negative experiences and when they are given opportunity to think about and name who they are, what they are proud of, and to identify their strengths and agency (in the forms of both resilience and resistance to oppression). Life line and care line drawings are arts-based, creative, and accessible tools 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.

### Step 1: Learning about life stories and life line and/or care line drawings

This activity begins by learning about what life stories are and what life line drawings are by reading about or listening to the life stories of others. Prolonged engagement with service users has been identified as a best practice as it creates opportunities to build rapport and therapeutic relationships that are essential in supporting service users across settings. Despite this evidence, the current service system framework is guided by 'episodes of service' which can limit prolonged engagement and provide intermittent and staggered care instead of support over the lifecourse. This leaves clients, service users, residents, patients or caregivers without the consistent support that they may need, ultimately

hindering their ability to age meaningfully and to fully participate in their communities. Clients with intersecting social identities may also experience injustice and marginalization as they navigate different systems (i.e. the health and social service system, criminal justice system, child welfare system). As service providers, we need to be mindful of these potential layers of disadvantage, advocate for change, and acknowledge the impact this could have on many different parts of a client's life. Addressing this gap also requires a paradigm shift towards more holistic and sustained engagement practices. As service providers, your role is crucial in fostering environments that empower neurodiverse older adults.

### **Examples of Life lines and Care lines:**

1. At the beginning of the performance, Maria shares in the microphone a quote from Elisa which ends with her saying “...as my *time line* will tell you”. Maria then acts out Elisa's life line drawing by walking back and forth across the stage and moving her body to present the different quotes that describe her life journey. Maria ends by singing “*Nobody can do what I can do. Let's go! Let's show!*” while the others encourage her by applauding and cheering. (*timestamp: 12:20*) This is a life line in action!
2. Listen to or read [Audrey's Story \(podcast version\)](#) and/or or [Tina's Story \(podcast version\)](#). Then listen to and/or read the caregivers [Luce's Story \(podcast version\)](#) and/or [Dadou's Story \(podcast version\)](#). Each story has an example of a life line or care line (either drawn or written by the participants alone or in collaboration with the research team). Through pictures and words, they all describe the meaningful moments in their lives and journeys. These are life and care lines represented in art and words!

## Questions to think about or discuss:

1. What did you think about Maria's portrayal of Elisa's life line in the performance? Despite her ups and downs over the course of her life, it ends with singing that she can do things that no one else can. What does this mean to you? Do you feel that your client(s) might feel the same way about themselves? Why or why not? How can you encourage positive identity and self-esteem amongst your clients despite life's challenges and restrictions?
2. What did you think about after reading or hearing the stories of Audrey, Tina, Dadou and Luce and seeing their life line or care line drawings? Why do you think Audrey and Tina used such different ways of drawing their own life line of meaningful events, activities, and people in their lives? What did you learn from their stories?

## **Step 2: Drawing a life line/care line with your client, resident, service user, member or patient**

In this section, we use the word "client" to refer to anyone you work with in your setting, for example clients, residents, service users, organizational members, and/or patients. We will refer to you, the service provider as "the worker".

The life line and care line are tools that can be used either with the person (aging) with neurodiversity that you are working with or with their family/friend caregiver. The life line and care line are useful to use as they provide a visual representation of a person's journey, highlighting meaningful moments and experiences that have shaped their identity. It also helps us understand who is important in the individual's life, revealing their support networks and relationships that can enhance their well-being and facilitate more personalized services and supports. This tool can encourage deeper conversations, promote self-reflection, and help workers understand the unique stories of each individual, ultimately guiding more tailored and effective support practices.

In order to further understand a client and support them in telling their story, workers can use the life line as a tool within their practice. The life line can be created by the client and/or be a collaborative effort depending on the preference and/or access needs of the client. It can be used within the assessment process to build rapport and get to know meaningful people and events in the client's life or during the intervention process with the client to deepen understanding of the client and their family. It could also be conducted when there is a new worker who comes on board to ease the transition process or within a group activity to build positive identity and self-worth. It is always important to explore the life line approach with the client to identify whether or not they think it would be a useful and meaningful activity. Some clients may also choose to engage in the activity within the group but chose not to share it with the group. Clients should be supported in defining how they wish to participate in this activity and who they want to share it with or not. We provide more detailed instructions on how to build the life line below.

The role of the worker is to help clients to draw their own life line or care line. Remember that it is totally fine if your client wants your help to decide what to include or even asks you to draw the pictures, but they must always guide you about what to include and why. Another option is to choose relevant pictures from magazines to cut out and paste onto the line or you can draw the picture they want included and then they can colour it in.

For detailed instructions on how to complete the life line with your client, please refer to **Section 1**. For instruction on how to complete the care line with your client, please refer to **Section 2**.

1. Using prompts with your clients: It is important to note that understanding what a life line or care line is and how to create one can be complex or appear complicated for some people. To facilitate a process that is satisfying and productive it is important to adapt your strategies to the needs and wishes of each client or client group. Using prompts is a helpful way to get the conversation started. Here is a [worksheet on prompts](#) for you to consider (link also included in both Section 1 and

Section 2). The [prompts worksheet](#) is a visual tool that can stimulate discussion on different topics that are generally relevant across life course experiences for each target group. Narrative storytelling and life/care line drawing go together and the process usually moves back and forth between “sharing a story” and “drawing, colouring or choosing a picture that represents the main feelings experienced at the time of the event or about the situation/person being spoken about or that represents the event itself. This is a sharing and creative process combined!

2. The [Life Line](#) and [Care Line](#) Worksheet templates are a means of both explaining and creating the line. If your client finds the Worksheet too confining or small for their creative energies, you can simply use a big piece of paper to create the line. Make sure to have some coloured pencils or markers near you that your client(s) can use to draw their life line or care line with your support and/or collaboration.
3. It is important to remember to ask the client(s) to think about where they want to begin their life or care line. It can be anywhere and anytime in their life that is meaningful for them. Some participants began their drawing when they were born, and some began their drawing from the point in their lives when something important happened, whether big or small. This includes when their caring journey began among family caregivers. Not everyone remembers their childhood for different reasons. Some participants explained that they had a difficult childhood and did not want to remember it in their drawing. It is totally up to them where their drawing begins!

4a. If your client is a NDOA encourage them to be creative and include above or below the line the meaningful moments, activities, people, places, and events that are important to them. These things can be positive or negative, it doesn't matter. What is important is that they include the key things that are meaningful to them in their life journey. The prompt questions are included in Section 1. Simply work with them to draw what is important to their story and who they are as a person. There is no time limit on how long it takes to complete a life line, and clients can add or take

away anything from their drawing at any time. It is their life story and so always should be their choice!

4b. If your client is a caregiver, the care line is a little bit different in that the caregiver puts the meaningful events experienced by the person they are caring for at the top of the line and the corresponding events that they themselves experienced at the bottom of the line. There is no time limit on how long it takes to complete a care line, and caregivers can add or take away anything from their drawing at any time. It is their care story and so always should be their choice!

5. Finally, once completed your client(s) can share it with others and talk about what the pictures or words on their drawing mean to them. Ask them to share their story and use the drawing as a guide!

**Reflection questions to consider after completing the care line drawing activity:**

1. Have a conversation with your client(s) about how they felt about the exercise and if they learned anything about themselves by telling their life story and in doing or seeing their own life line or care line? They can use the [Feelings Chart](#) to describe the emotions they felt when sharing different aspects of their story.
2. What was your experience like in using the life line or care line exercise with your client(s)? Did you learn anything new about your client?
3. Do you think that a life line or care line would be a useful tool to use with people (aging) with neurodiversity and/or family caregivers in your practice? Why or why not?
4. How could you encourage narrative storytelling and life line or care line activities in your organization? What would facilitate or hinder this practice?

## **Activity 2: Reflection, learning, and action about emerging themes**

This exercise can be used as a guide for reflection and discussion after watching the performance video of *Neurodiversity! Age together, Act together*. The reflection questions listed for the activity can be used with practitioners, as well as with students in the field. The performance is centered on the experiences of neurodiverse older adults (NDOA), however, the research project is grounded within the experiences of neurodiverse older adults, family caregivers *and* service providers. As such, Activity 2 includes both the performance video and 6 of the *Theme Infographics* that we created to showcase the themes emerging from the study that cut across all three cohorts (see introduction for which 6 infographics to read). NDOA, family caregivers, and service providers all spoke at length about the complexities of navigating the health and social service system, residential and other resources, as well as pointing to the gaps in health and social services, lack of specialized supports, siloed service provision, and the frequent changes of health and social service providers. There are many questions and avenues for reflection listed here; more than is possible to address in 1 session! Consider multiple workshops or sessions for your work setting. Take the time needed to think about each of these areas and plan concrete actions to address the issues or realities presented. Pick any questions that best reflect the kind of work in which you, your team, and/or your organization are involved!

### **Questions to guide reflection, learning, and action:**

1. As a service provider to a NDOA and/or a family caregiver of a NDOA, or as a student preparing to provide services in the future, what emotions were evoked while you watched the performance?
2. What part of the performance was most impactful for you and how does this link with your education or practice? What did you learn that will be helpful in better understanding and supporting NDOA and their family caregivers?
3. There were a diversity of perspectives on aging amongst NDOA represented in the performance, from it being a normal experience *'My heart is still young'* (Christine's

quote) to *'Aging makes me scared... not knowing what will happen, illnesses, the whole kit'* (Mr. X's quote). (timestamp: 20:25) Is this something that you can relate to within your work with NDOA and their families? Is there room in your practice to discuss aging, death, and dying or is it a topic that is avoided? How comfortable are you with these issues? What needs to change to make more room for these conversations in practice?



4. Mistreatment was identified as a prevalent issue. In one segment of the performance, the quotes spoke to child abuse and neglect, bullying in schools, sexual harassment and violence, mistreatment in the workplace, etc. (timestamp: 25:42-28:53) How does this resonate within your practice? How do you think this can be addressed in practice? For example, can the issue of life-long experiences of mistreatment be addressed within clinical supervision or in the development of a security plan with a client? Within a specialized training? In advocacy, and empowerment initiatives? Do you and your organization know about the [Quebec Act to combat maltreatment of seniors and other persons of full age in vulnerable situations](#)? Have you ever had a training on your obligations to respond and to report mistreatment in all its forms under the law?



In the mistreatment infographic, service provider Chantale shared her belief that mistreatment is systemic when she stated, *"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*". What do you think about this quote? How can your work setting or professional association advocate to address systemic or organizational abuse?

5. Concerns about mental health and addictions were also presented in the performance and Infographic on *Mental health and addictions*. This includes a quote from participant Tina who shared the consequences of drinking too much was that she ended up being mandated to move to a residential resource, "*I was put here by court of law... yah I put myself here*". (timestamp: 15:33) All the participants moved to Lisa's quote about being hospitalized in the psychiatric unit of a hospital, "*I didn't like the hospital, reminds me of a prison*". Finally, all the performers repeatedly moved to participant Elisa's quote about living with "*depression and anxiety*". (timestamp: 20:18) Are these issues that you have faced in your practice? If so, how did you navigate them? What resources would you need in order to better support NDOA with substance use or dealing with co-occurring mental health issues? Do you agree with all of the service providers who spoke to the silos and access barriers for people living with co-occurring neurodiversity and mental health challenges in the *Mental health and addictions infographic*? How might you help NDOA navigate these silos? How might you advocate to change them?



6. Issues and concerns related to housing were a common theme in our findings. The housing environments amongst our participants were diverse and included living with family, in private market or social housing units with support from service providers, in community-based non-profit housing resources, and in public sector-affiliated residential resources. Some NDOA in our study spoke of living for periods of time in psychiatric hospitals for different reasons related to mental health

challenges or addictions. NDOA shared both the problems they encountered and what good housing looks like for them. At the beginning of the performance the performers moved to several quotes which addressed both good and bad experiences of housing. Audrey's quote in specific described living alone and being able to do what she wanted as *"freedom!"* while Tina's quote suggested that living with many people could be challenging, *"Yah ten people live in this house, residents and coworkers"*. (timestamp: 17:22) In the Lack of control over daily life infographic, caregiver Adora stated, *"When [my brother was moved suddenly], when he arrived, he was in 1000% crisis. He did not want to be there"*. What do you think makes the difference for participants in experiencing housing as either good or bad? How do you think choice and attention to the rights of NDOA can be better incorporated into an inclusive housing strategy?



7. Lack of control over daily life is a common experience among NDOA. Controls come from many sources include both informal (family) and formal (service providers). At one point François shares Elisa's quote related to a strategy for limiting her sister's control over her finances by stating *"Do I have any control of my life? Not really. Except for the stuff that I don't tell her, like the money... because it's my money!"* and everyone says *"ssshhhh"* in response. (timestamp: 23:00) Control over finances is but one example of the controls NDOA face in their daily lives. In another segment about living in a group home, the performers move to the quote by Johanne, *"Getting older and living in a group home is hard because you have to eat what they want"*. (timestamp:16:35) Do these examples resonate with you? How can residential resources adapt their practices to better ensure agency and choice among NDOA residents?



8. Parallel aging (the reality that care situations can significantly change as both people with neurodiversity and their family caregivers age) was an important theme emerging from our project and was represented within both the performance and the infographic on Caregiving. In the performance Alexandre leaned over sadly while the quote from Audrey stated, “...yeah I try not to think about it... You get older so they cannot do anything but get older too”. Georgios moved sadly when the quote from Mr. X stated, “Difficult, very difficult... I don’t have my parents anymore. No more parents. My parents are dead. I wish I could have died before them”. (timestamp: 19:25) What does parallel aging mean to you? How have you helped caregivers think about or plan for future transitions that arise from aging or dying (advanced care planning)? What supports might be available for you to help NDOA and their caregivers plan for the future? What is missing?



9. Participants shared that identity, resilience, favorite activities, and pride were very important to who they are, and this was also represented in the performance when everyone danced while many quotes spoke to the variety of activities that participants engaged in that gave their life meaning. (timestamp: 32:45) How can strengths and resilience be highlighted within your practice?



10. The performance is a way to capture and share the perspectives of aging with neurodiversity to shape policies and practices. During one segment, the performers all stand in a row and pass a blanket along while the quotes speak about both the good and bad things older adults living with neurodiversity have encountered with service providers. At one point, François squeezes a blanket while a quote from Audrey is shared, *“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”*. Right afterward, Carol squished a blanket when the quote from Elisa says, *“Workers change like underwear, it’s pathetic!”*. (timestamp: 33:00-36:00) Does this segment speak to your experience as a service provider working with NDOA and their families who are trying to navigate complex systems of care? How did you feel when hearing all these quotes about challenges with the system and with service provision?



11. Participants described that service providers did not always understand or adapt their practice based on NDOA needs and realities. In what ways can you promote inclusive approaches to improve the care experiences of NDOA and their family caregivers? How can your experiences be shared to help create changes?

12. In the Infographic on the *Gaps and challenges in the health and social service system*, many service providers spoke of the challenges faced by clients and by workers. These included silos, service austerity, long wait lists, and restrictions that impede the worker from engaging in the kind of support they think is needed and ethical. Do you experience these challenges in your own setting? How might they be better addressed by policy, at the the governmental or organizational level?

13. Right near the end of the performance, the performers passed around the microphone and each one spoke a quote with a message for service providers. For example, Alain quoted participant P'tit Loup when he said, "*Labels go on jars, not on people*", and François quoted Audrey when he said, "*Look at me with honest eyes*". (timestamp: 36-39:17) What did you learn from these and the other messages?
14. In your work setting (public health care system, community, education), what are concrete actions that can be initiated within your organization to support the aging process (needs and wishes) of neurodiverse adults? Of their family/friend caregivers?

**Additional reflective questions specifically for students:**

15. As a student, what were your main reactions to the performance?
16. What did you learn about the experiences of neurodiverse older adults and their aging family caregivers that will be important for you to consider in your education and future practice?
17. Dealing with difficult experiences such as mistreatment, grief and loss (i.e. related to the aging process or death of a loved one), and co-occurring mental health challenges were highlighted during the performance. What insights have you gained from hearing the perspectives on these topics from NDOA themselves? How will you explore this in your education and future practice?
18. Do you have opportunities in your classrooms and fieldwork settings to explore the realities of NDOA and their family/friend caregivers? Why or why not? What is needed to improve education and why is this important?

## Conclusion

We are deeply grateful to all our participants for sharing their stories with us over the four years of the project! We hope that their words, and our project, will inspire reflection, learning, and action among each 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 and 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!

We welcome your feedback, so please send us any comments or suggestions you have about this Toolkit or any other aspect of the project via our webpage ([www.creges.ca/en/aging-neurodiversity](http://www.creges.ca/en/aging-neurodiversity)).

**Thank you!**

