

The Crisis Facing Older People Living with Neurodiversity and their Aging Carers : A Social Work Perspective

Shari Brotman, Tamara Sussman, Laura Pacheco, Daniel Dickson, Lucyna Lach, Emilie Raymond, Marie-Hélène Deshaies, Zeldia Freitas et Élise Milot. <https://pubmed.ncbi.nlm.nih.gov/33900151/>

WHAT IS NEURODIVERSITY (ND)?



"Neurodiversity" is a term developed by disability rights communities that has gained recognition worldwide.

The identities and social locations of people with ND are diverse and include those living with an intellectual and/or developmental disability, autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), Down syndrome, among other conditions. People with ND have a diverse range of experiences and support needs.

CHALLENGES FACING OLDER ADULTS WITH ND AND THEIR FAMILY CARERS

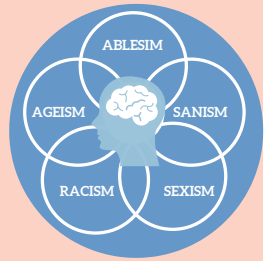
SOCIAL EXCLUSION

Older adults with ND and their aging family carers face significant social exclusion throughout their lives. Interlocking oppressions are implicated in creating unequal conditions that negatively affect their health and well-being, social inclusion, and agency.



INTERLOCKING OPPRESSIONS

"The ways in which social identities associated with categories of difference (ie. race, class, ability, gender, and age) interact to produce unique experiences of oppression and/or privilege" (Hulko et al., 2020).



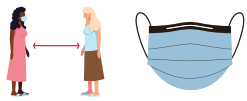
CONSEQUENCES OF SOCIAL EXCLUSION

- POVERTY** People with ND are more likely to live in poverty (Morris et al., 2018).
- HOUSING** Limited housing options and a lack of opportunity to engage socially (in informal and formal contexts) have been identified as major sites of social exclusion (Alzheimer's Society of Canada et al, 2017; Walker & Hutchison, 2018).

HOW DOES COVID-19 AFFECT OLDER ADULTS WITH ND AND THEIR FAMILY CARERS?

1 A BIOMEDICAL APPROACH TO CARE

A narrow focus on medical care meant that the psychosocial needs of older adults with ND were largely overlooked, particularly during the early months of the pandemic.



Interruption of:

- work/day programs for socialization and the building/maintenance of daily living skills.
- face-to-face contact between service providers and their clients.
- At-home services and supports.

IMPACT ON FAMILY CARERS

LOVED ONES LIVING IN CONGREGATE HOUSING

COVID-19 restrictions created a lot of stress and distress for family carers who were restricted from entering sites in order to support their loved ones.

LOVED ONES LIVING AT HOME

Significant increase in the hours and types of care provided by family members living with an older adult with ND due to reduction/disruption of services. This resulted in added stress and distress for family carers.

2 THE REDEPLOYMENT OF SERVICE PROVIDERS

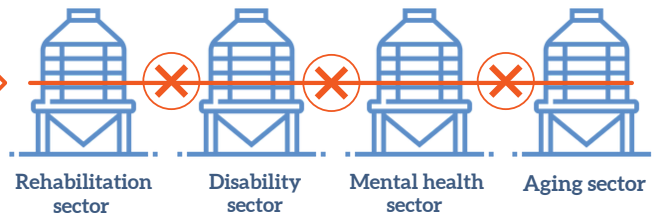
The need for an immediate response to the COVID-19 crisis led to the redeployment of service providers to other sectors.

This redeployment and the shut-down of services led to:

- Significant barriers to addressing social isolation, stress, and grief.
- A disruption in the relationships between older adults with ND and their personal support workers, with little acknowledgment of experiences of loss and grief.

3 LACK OF INTEGRATED SERVICES

Older adults with ND have complex realities and needs which require the integration and coordination of inclusive services. The lack of specialized knowledge and intersectoral dialogue limits the capacity of the health and social care service system to respond appropriately.



The health and social care system is very challenging for older people with ND and their families to navigate.

RECOMMENDATIONS

- Create formal mechanisms for collaboration between different sectors and enhance training for service providers.
- Include older adults with ND and their family carers at the decision-making table to understand their realities, find solutions, and advocate for their needs.
- Move beyond physical health and functioning and prioritize the delivery of emotional, psychological, social, and recreational responses, including opportunities for social inclusion.
- Consider respite as an essential service.
- Create peer-led initiatives for service providers to debrief, discuss and explore ethical dilemmas in their work with older adults with ND and their families and share strategies and solutions.
- Provide psychological, social, and emotional support to carers and help them navigate the care system.