

Aging Well Together: Promoting Brain Health for Aging Individuals with IDD and Their Families

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Volume 7, numéro 2, 2024

Caregiver Special Issue

URI : <https://id.erudit.org/iderudit/1111223ar>

DOI : <https://doi.org/10.33137/jrmh.v7i2.43071>

[Aller au sommaire du numéro](#)

Éditeur(s)

Ontario Shores Centre for Mental Health Sciences

ISSN

2371-2376 (numérique)

[Découvrir la revue](#)

Citer ce document

Philip, S., Chiu, M., Bobbette, N., Thakur, A., Fogle, A., Steel, L., Kelly, C., Lefkowitz, G., Baskin, A., Ries, H. & Lunsky, Y. (2024). Aging Well Together: Promoting Brain Health for Aging Individuals with IDD and Their Families. *Journal of Recovery in Mental Health*, 7(2), 41–49. <https://doi.org/10.33137/jrmh.v7i2.43071>

Résumé de l'article

Adults with intellectual and developmental disabilities (IDD) have been historically excluded from participating in aging-focused research, continue to experience barriers accessing appropriate health care, and encounter distinct challenges as they age compared to people without IDD. These challenges and their effects often extend to their immediate support system, including family caregivers, including parents, siblings, and other kin. Family caregivers, often in the role of 'perpetual caregivers,' can struggle to support aging adults with IDD as they also concurrently experience the effects of their own aging, potentially hindering their ability to provide lifelong care. As parents age, the burden of care may shift to others within this support network such as siblings who, due to various constraints (e.g., geographic location, personal obligations, and financial restrictions) can also experience challenging caregiving responsibilities. Research on the mental health of family caregivers has predominantly focused either on the impact of caregiving among parents of people with IDD (and to a lesser extent on siblings) or on late-life caregivers of aging adults without IDD. This leaves a significant gap in understanding how to support caregivers during mid-late adulthood as their family member with IDD ages or as they themselves undergo age-related changes.

In this paper, we provide a brief overview of research on family caregiving of older adults with IDD, followed by a description of a national effort, The Brain Health-IDD initiative. This initiative aims to develop strategies that will support the promotion of brain health in aging adults with IDD and their family caregivers. As part of this effort, family caregivers, both siblings and parents of adults with IDD are working together with researchers and clinicians to co-design, co-deliver and evaluate a virtual education program for families. The paper concludes by reflecting on the program's importance from the perspective of sibling and parent caregivers. This inclusive approach emphasizes the broader responsibility of supporting families navigating the challenges of disability and aging in mid-late adulthood, highlighting the need for support and awareness across all levels of care.



Aging well together: Promoting brain health for aging individuals with IDD and their families

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Keywords: IDD, lifelong care, aging parents

Abstract

Adults with intellectual and developmental disabilities (IDD) have been historically excluded from participating in aging-focused research, continue to experience barriers accessing appropriate health care, and encounter distinct challenges as they age compared to people without IDD. These challenges and their effects often extend to their immediate support system, including family caregivers - parents, siblings, and other kin. Family caregivers, often in the role of 'perpetual caregivers,' can struggle to support aging adults with IDD as they also concurrently experience the effects of their own aging, potentially hindering their ability to provide lifelong care. As parents age, the

burden of care may shift to others within this support network such as siblings who, due to various constraints (e.g., geographic location, personal obligations, and financial restrictions) can also experience challenging caregiving responsibilities. Research on the mental health of family caregivers has predominantly focused either on the impact of caregiving among parents of people with IDD (and to a lesser extent on siblings) or on late-life family caregivers of aging adults without IDD. This leaves a significant gap in understanding how to support family caregivers during mid-late adulthood as their family member with IDD ages or as they themselves undergo age-related changes.

In this brief report, we provide an overview of research on family caregiving of older adults with IDD, followed by a description of a national effort, *The Brain Health-IDD initiative*. This initiative aims to develop strategies that will support the promotion of brain health in aging adults with IDD and their family caregivers. As part of this effort, family caregivers, both siblings and parents of adults with IDD, will collaborate with researchers and clinicians to co-design, co-deliver and evaluate a virtual education program for families. The paper concludes with reflections from sibling and parent caregivers regarding the program's anticipated impact. This inclusive approach emphasizes the broader responsibility of supporting families navigating the challenges of disability and aging in mid-late adulthood and highlights the need for support and awareness across all levels of care.

Introduction: Needs of adults with IDD and their families as they age

Historically, adults with intellectual and developmental disabilities (IDD)¹ have experienced systemic marginalization and inadequate support, particularly in accessing healthcare and participating in research.^{1,2,3} While a large majority of research on IDD has focused on childhood, it is crucial to recognize that individuals with IDD spend most of their lives as adults and continue to encounter barriers throughout their lifespan.^{4,5} Quality of life for people with IDD continues to be lower than that of the general population^{6,7} and despite the increasing life expectancy among individuals with IDD, there is still much we do not know about how to support aging people with IDD.

What we do know is that as individuals with IDD age, they often encounter numerous challenges, including declines in physical and cognitive functioning, increased dependence on family caregivers for assistance on daily tasks, and heightened risk of developing age-related health conditions⁸. These challenges can be complex, emphasizing critical need for comprehensive support from family caregivers and care providers⁹. Understanding the experiences and unmet needs of aging adults with IDD related to access and participation is essential in order to develop tailored approaches to support their health and wellbeing along the lifespan, and to be better informed to support aging family caregivers in their caregiving roles^{8,9}.

¹ We use the term IDD in this paper to refer to a broad range of conditions whereby people experience impairments in adaptive and/or cognitive functioning, beginning in the developmental period and are lifelong in nature (e.g., Down's Syndrome).

Family caregivers provide a range of assistance in various tasks, including daily life activities such as meal assistance, medication management, companionship, and life enrichment^{9,10,11}. More than 8 million Canadians are unpaid caregivers to individuals living with disabilities, chronic conditions, or severe diseases¹². The complex interplay of physical, mental, financial, and environmental demands in providing care for individuals with IDD may be overwhelming for families. At the same time, the role of caregiving can provide a sense of purpose, joy, and feelings of connection with whom they are caring for^{13,14,15}. However, throughout the process of caregiving and growing older, there can be instances where the demands outweigh the rewarding feeling, causing significant strain on caregiver wellbeing and surrounding relationships^{13,14,15}. As a result of caregiving responsibilities, family caregivers are less likely to have time for personal leisure, self-care, employment, and relaxation¹⁶. This lack of time can take a substantial toll on their health, affecting cognitive functions, emotional well-being, and physical health.

A Focus on Brain Health

Brain Health, as defined by the World Health Organization, consists of cognitive, sensory, environmental, physical, and behavioural determinants interconnecting to influence how the brain can adapt to change, adversity, and stress¹⁷. Decreased brain health may look like intensified feelings of worry and/or anxiety, and may impact nutrition, sleep quality, and exercise patterns, thereby affecting their overall quality of life as they age^{18,19}. There are unique considerations to promote brain health for individuals with IDD and their support system as they age which may include parents, siblings, and other relatives^{20,21}. Family caregivers of people with IDD may have concerns related to aging and their capacity to continue offering support^{22,23}. As caregivers themselves age, they experience their own changes in their mental and physical health, which may impact their ability to provide care. Caregiving responsibilities may have to shift to others, including siblings, who may face limitations, such as geographic distance and other personal obligations or competing priorities, leaving them feeling unprepared to care for both their aging parents and a sibling with IDD^{21,22,24}. For siblings who may be caring for their own spouses or children already, this would be an added responsibility to consider.

Addressing Family Caregiver Needs Through the Brain Health-IDD Initiative

Improving brain health is vital to keeping the mind and body healthy and strong^{25,26}. Recognizing this, we have launched Brain Health-IDD, a national capacity building initiative which is a collaborative effort involving a diverse team of researchers, clinicians, families, self-advocates, and organizations dedicated to enhancing brain health for aging adults with IDD and family caregivers. Through the delivery of virtual courses targeting clinicians, families, and self-advocates respectively, along with the creation of an ongoing community of practice network, the Brain Health-IDD program aims to educate and empower participants to identify and manage health-related aging

concerns effectively. Through this collaborative effort, we aim to promote brain health and improve the overall well-being of individuals with IDD and their support networks.

Objective

There is a significant gap in understanding how to support the brain health of family caregivers as they personally experience age-related changes while caring for their family member. The objective of this paper was to help address this gap through describing the experiences and needs of parent and sibling caregivers on our team related to brain health. This information was collected as a key part of our curriculum co-design process for Brain-Health IDD and will inform the creation of program content. In these discussions, the caregivers on our team offered reflections on how they navigate the challenges of disability and aging in mid-late adulthood, and their personal need for support and awareness. They also spoke about the importance of families learning from other families.

What are family caregivers telling us?

We interviewed six caregivers involved in Brain Health-IDD (4 parents and 2 siblings) to learn more about the importance of brain health and why capacity building efforts like Brain Health IDD matter. One family caregiver explained, "Upon receiving our child's diagnosis, many, if not most, caregivers of children with IDD also received the underlying messaging that to be a good parent we must put our child first, our other children or partner, (if we have one) second, and our own wellbeing, a distant third place. There was little to no discussion on how to balance the competing needs of other family members' wellbeing, let alone our own wellbeing. As we age, anxiety and chronic sadness, often undiagnosed, have become constant companions as we worry and advocate about issues each day, exacerbated with the relentless concern, "Who will take care of our child and all this responsibility when I am no longer here?" (Caregiver 3).

Other family caregivers echoed similar sentiments, expressing challenges such as, "Looking after myself. Looking after my kids. Who's going to keep doing it? So, there's this heavy, psychological burden, thinking about all of this and honestly, what's going to happen in the future?" (Caregiver 4).

Another caregiver voiced, "Many families are truly coping on their own without day-to-day supports for years and years. There is no plan for moving forward... aging parents are responsible for much more than day-to-day caregiving—they must manage everything from health care to finding ways to fill their loved one's day meaningfully" (Caregiver 4).

This recurring fear regarding the future is shared among caregivers, creating a collective concern about the uncertainties that lie ahead. For siblings, discussing the future does not happen as much as it should. One sibling talked about their parents'

unspoken plan or hope that as a sibling they would take over care, without a clear roadmap of how to navigate this responsibility: “It seems like no one really has a plan; honestly...” (Caregiver 5).

These quotes highlight the pressing need for support structures to be accessible for caregivers (parents and siblings especially) as they navigate the complexities of caring for aging adults with IDD. Thus, the development of effective strategies and interventions becomes critical to support the brain health of both caregivers and those who they are caring for. Highlighting this concern, one family caregiver expressed, “Personally, my greatest fear as an aging individual is losing cognitive ability” (Caregiver 1). Another caregiver emphasized the importance of raising awareness about the profound changes that can occur with aging, stating, “There's a pressing need for more awareness about the profound changes that can occur as you age – physically, mentally, and psychologically” (Caregiver 5).

Recognizing the significance of brain health, interventions directed at enhancing cognitive well-being in this population can contribute to improving the quality of life and care for aging adults with IDD and their family caregivers^{17,25,26}. Expressing the vital connection between brain health and resilience, one caregiver emphasized, “My resilience and strength (mental, physical, and spiritual) to deal with these issues depend on my brain health. My physical and mental flexibility rely on brain health” (Caregiver 1). Another family caregiver added an insightful perspective, stating,

“So, why does brain health matter to an aging caregiver?... we need to be reminded, yet again, to find manageable ways to care for our own well-being. The many difficult and challenging feelings we have pressed down for years have hurt us. We don't know if we are forgetful because we are getting older, or because we're exhausted, or if our lack of self-care has actually impacted our mental health in a more serious way” (Caregiver 3).

Advantages of Involving Parents and Siblings as Teachers

Collaboration with family caregivers is critical to the successful delivery of the Brain-Health IDD program. Both parents and siblings emphasized the advantages of involving them as teachers. As one caregiver expressed, “I believe, also, that we understand, firsthand, the fatigue, the struggles, the firefighting, and also the very small milestones that may seem insignificant to people outside of lived experience” (Caregiver 1). Another caregiver expressed, “There is no substitute for hearing from those with lived experience. In partnership with experts in the field, people with lived experience can help participants make connections between the research and the reality” (Caregiver 2).

Another caregiver highlighted that individuals with lived experience can help participants connect the research findings to the realities they face. Additionally, hearing from family members themselves adds credibility and empathy to the discussion. As one caregiver voiced, “I think when it comes from us as well as people who are in the same boat, it

really adds credibility. It adds some compassion. We're talking about people we love” (Caregiver 4).

As important as it is to create resources for and to educate other families, one caregiver also highlighted that the responsibility to address these challenges should not lie with families alone.

“The improvement of knowledge needs to be well beyond family caregivers but include scientists, clinicians, and health care workers of all ranks. Families have enough on their plates” (Caregiver 6).

The reflections offered from caregivers demonstrate the need to hear their stories, experiences, and perspectives. Their experiences highlight the unique difficulties, resilience, and rewarding feelings that shape the path of caring for adults with IDD later in life. As heard from some of the caregivers, the struggles, the fatigue, and small victories they experience in their everyday life can often be unnoticed in the eyes of others who have not experienced it. The testimonials showcase the immense impact that firsthand experience can bring to discussions. Additionally, the importance of improving brain health emerges as a crucial theme in ensuring healthy aging and overall well-being. The Brain Health-IDD initiative aims to advocate and demonstrate the power of collaborative efforts by actively engaging adults with IDD, family caregivers, and service providers within the co-design process.

In this paper, we call for a change in perspective, one that recognizes the significance of brain health, the struggles caregivers face, and advocates the need for a more inclusive approach to support both adults with IDD and family caregivers at all levels of care. As one caregiver highlighted, “Mental health is brain health” (Caregiver 1). We cannot focus on improving brain health for individuals with IDD alone without considering family caregivers. Their overall well-being is interconnected with the health and wellness of those they care for. It is imperative to note that brain health matters for everyone; caring for the brain health of individuals with IDD and their caregivers is not only life-changing but essential.

Funding:

This work was supported by CIHR (Grant BH3-191304) with supplementary support from MITACS awarded to Serrina Philip.

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