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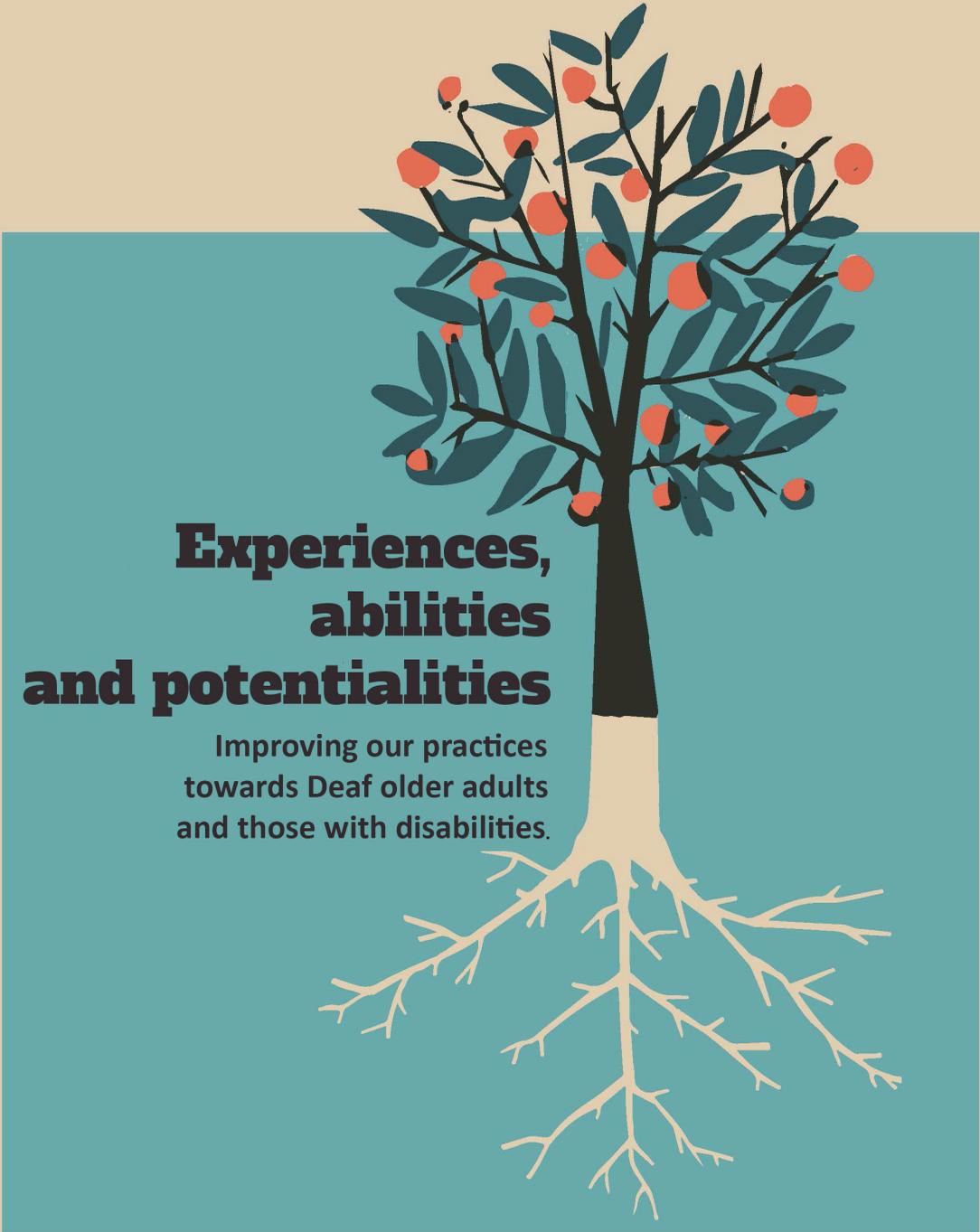
Experiences, abilities and potentialities

Improving our practices towards Deaf older adults and those with disabilities.

Centre for Research and Expertise in Social Gerontology

Participation sociale & villes inclusives

act
ageing + communication + technologies

Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal

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EDITORIAL

INTRODUCTION

KEY CONCEPTS

PERSPECTIVES

AVENUES FOR ACTION

STUDENT SPACE

Experiences, abilities and potentialities: Improving our practices towards Deaf older adults and those with disabilities

A corollary of the ageing population is an increase in the number of older adults with disabilities. In Quebec, 17% of those aged 65 to 74 years, and 31% of those aged 75 to 84, have moderate to severe disabilities that prevent them, to varying degrees, from carrying out their daily activities. This observation contrasts with images of successful or active ageing, which celebrate the absence of disability and the maintenance of high levels of activity. Moreover, Quebec's social policies on ageing do not really address the ways in which functional diversity can influence and sometimes complicate the trajectories of older adults. Yet more and more studies are confirming that Deaf older adults and those with disabilities are likely to encounter obstacles in carrying out daily activities. To better serve these individuals, it is essential that we take an interest in their knowledge, needs and aspirations. Two main questions will guide our reflections today: How to promote the inclusion and social participation of Deaf older adults and those with disabilities? How to improve our practices, notably by recognizing their experiences, abilities and potentialities?

As these questions indicate, the 2019 annual conference held by the **Centre for Research and Expertise in Social Gerontology (CREGÉS)** of the CIUSSS West-Central Montréal was an opportunity to learn about the lesser-known and recognized realities of Deaf older adults and those with disabilities. The event, co- organized with the **PSVI research partnership team (Participation sociale et villes inclusives)** and the **ACT project (Ageing + Communication + Technologies)**, was held on May 23 at Université Laval in Quebec City.

Centre for Research and Expertise in Social Gerontology

🌐 www.creges.ca
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CENTRE FOR RESEARCH AND EXPERTISE IN SOCIAL GERONTOLOGY (CREGÉS)

CREGÉS assembles researchers, research-practitioners, students and collaborators from practice settings around a single mission: improving professional services and practices targeting older adults. This mission is based on the development of social research; the development, testing and validation of leading practices; the assessment of health and social service interventions and technologies (ÉTMISSS); and teaching and knowledge transfer activities. ❯

PSVI RESEARCH PARTNERSHIP TEAM ("PARTICIPATION SOCIALE ET VILLES INCLUSIVES")

www.villeinclusive.com

The members of the PSVI research partnership team [Social participation and inclusive cities] come from community organizations, municipal bodies, government agencies and universities. Since 2012 they have been engaged in a collaborative initiative aimed at making cities more accessible to persons with disabilities. While the standard image of autonomous, active adults without disabilities prevails in government decision- making—especially when it comes to urban planning—persons with disabilities, as a minority group, are not able to fully exercise their rights. The overall objective of the PSVI team is to rethink the urban landscape to allow people with disabilities to access shared spaces, thereby exercising their right to "create the city," be part of it and transform it.

ACT PROJECT (AGEING + COMMUNICATION + TECHNOLOGIES)

www.actproject.ca

ACTProjectConcordia

ACT_Concordia

ACT (Ageing + Communication + Technologies – actproject.ca) is an international, multidisciplinary project funded by the Social Sciences and Humanities Research Council (SSHRC). The project looks at the transformation of the experiences of ageing with the proliferation of new forms of mediated communications in networked societies. ACT investigates the various and often subtle ways in which "digital ageism" operates—the individual and systemic biases that create forms of inclusion and exclusion that are age-related. ACT initiatives are aimed at creating intergenerational connections, rethinking new media from the perspective of old age, and confronting digital ageism in all its forms.

The event was attended by 140 participants (50 via a webinar), including practitioners and managers from the health and social services network, and members of various community groups and associations. Researchers and practitioners from different fields (social work, leisure, communication and social gerontology), who generally have few opportunities to meet, had a chance to share their views on this pressing topic. Also in attendance were ten Deaf older adults from the Fondation des Sourds du Québec, along with Quebec Sign Language (QSL) interpreters. For some, it was a first-time experience. Their participation gave rise to fruitful discussions between Deaf and hearing attendees.

The conference provided a space for meeting and shared learning designed to:

- raise participants' awareness around the realities of Deaf older adults and those with disabilities;
- inform participants of more inclusive practices and support the self-determination of deaf older adults and those with disabilities;
- identify possible solutions and offer tools to promote social participation and interactions with deaf older adults and those with disabilities.

OVERVIEW OF THE DAY

The conference was opened by Isabelle Van Pevenage, the acting scientific director of CREGÉS, and Line Grenier, a researcher with the ACT project. Ms. Grenier presented **an introductory video created by members of the ACT team titled "Vivre Ensemble: Removing barriers for those who are ageing and disabled"** (Page 8).

The conference was led by Marc De Koninck, a community organizer at the CIUSSS de la Capitale-Nationale. In the morning there were two plenary sessions with talks on two key topics: **the social participation and the self-determination of Deaf older adults and those with disabilities.** There was a presentation by Émilie Raymond, a professor and researcher at CREGÉS and with the research partnership team run by PSVI ("Participation sociale et villes inclusives") and the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS). There was also a presentation by Martin Caouette, a professor and researcher at the Institut universitaire en déficience intellectuelle (DI) et en trouble du spectre de l'autisme (TSA), who also works with the PSVI team (Pages 12 and16).

One of the morning highlights, according to several participants who completed a post-conference survey, was the **testimony panel titled "Ageing as a Deaf person or as someone with disabilities,"** co-moderated by Élise Milot, a professor at Université Laval and researcher (PSVI, CIRRIS), and Véro Leduc of the Université du Québec à Montréal (UQAM)—Quebec's first Deaf professor— and a researcher (ACT project). On the panel were three older adults—Benoît Giroux, a crossing guard; Monique Boudreault, a retiree and volunteer; and Diane Paquet, a retiree. All gave inspiring and moving accounts of their joys, challenges and dreams. (Page 20)

In the afternoon, participants could choose among seven **workshops** (four via webinar). These interactive workshops explored different actions aimed at supporting the social participation of Deaf older adults and those with disabilities. The workshop topics were varied:

1. Technologies aimed at maintaining older adults with disabilities at home (Page 25)
2. A practical guide to include older adults with disabilities in seniors' organizations (Page 29)
3. Basic concepts in communicating with Deaf people (Page 33)
4. A simulation of sensory loss (Page 37)
5. A program aimed at promoting the social participation of older adults with or without a mental health diagnosis (Page 40)
6. The experience of double ageing for parents living with an adult with an intellectual disability (Page 43)
7. Practices that, outside of therapeutic interventions, promote access to arts and culture for Deaf people and those with a disability, along with a session on how to make a DIY vibrating cushion

During lunch there was a **student competition**. Marie-Hélène Lévesque, a health science student at the Université de Sherbrooke (audience award and 2nd science prize) presented a video on the Lifestyle Redesign program. Maude Beaudoin, a student in clinical and biomedical science at Université Laval (1st science prize) presented a poster on the experiences of caregivers of older adults living with disabilities with regard to available assistance and technical aids. (Page 47)

This training activity was recognized by the Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec (OTSTCFQ) and by the Faculty of Nursing at the Université de Montréal.

This new issue of Pluralages and recordings of the webinars, which are available online, will help to fuel thoughts and actions inspired by the conference. Those who were not able to attend will have an opportunity to understand the realities of Deaf older adults and those with disabilities.

> **To watch recordings of the webinars and see the presentations, tool and other content, visit the post-conference page at www.creges.ca/colloque-annuel-du-creges-2019/**

1. It is difficult to obtain reliable data on the number of Deaf older adults in the population, as they do not consider themselves to have a disability.

Vivre Ensemble: Removing barriers for those who are ageing and disabled

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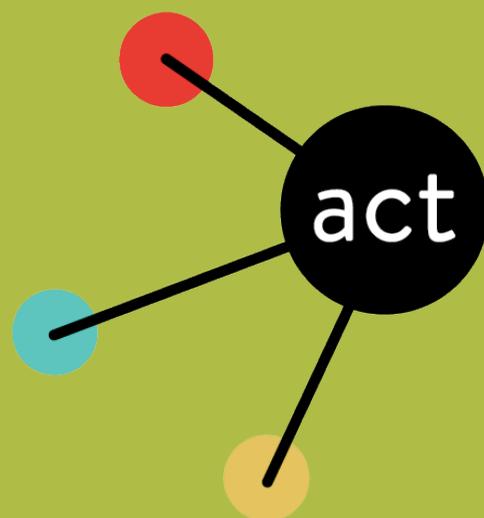
ageing + communication + technologies

By **Bipasha Sultana**
Master Student, Department of Communication Studies, Concordia University

▶ Watch the video

Members of our older population already face multiple challenges associated with ageing. These challenges are even greater for older adults with disabilities. In order to create a short video exploring precisely how these challenges come about, as people navigate a city that has many more strides to make in becoming age-friendly and accessible, four older adults living with a disability were interviewed.

THE MOTIVATION BEHIND OUR INTERVIEWS

ACT (Ageing + Communication + Technologies) is a research project led by Dr. Kim Sawchuk at Concordia University, which brings together researchers and community partners from around the world. As its name suggests, the project is designed to explore the ways in which mediated communications transform experiences of ageing within increasingly networked societies. Through ACT's partnership with

> *"recent failures so flagrant, preposterous and shameful, that they betray a sad reality: accessibility is too frequently an afterthought."*
>
> Allison Hanes, Montreal Gazette

the Centre for Research and Expertise in Social Gerontology (CREGÉS), Ash McAskill and I were asked to develop a short video, to be presented at this year's CREGÉS conference, focused on the realities of deaf and disabled older adults. Our video is titled *Vivre Ensemble* and consists of interviews with four older adults living with physical limitations. Our aim

was to offer a glimpse of how ageing and disability or deafness intersect and pose additional challenges to those affected, as they navigate a bustling cosmopolitan city like Montreal.

Like many other large urban centres, Montreal has been criticized for its blatant exclusion of residents with mobility issues. In an article published in the *Montreal Gazette* last fall, Allison Hanes sums it up poignantly, as she reminds us of "recent failures so flagrant, preposterous and shameful, that they betray a sad reality: accessibility is too frequently an afterthought."[1] She uses the example of the city's two brand new "super hospitals"— the McGill University Health Centre and the Centre hospitalier de l'Université de Montréal— both of which are equipped with bathrooms displaying faulty design elements such as soap dispensers that are difficult to reach and doors too heavy. While these details may appear trivial to some, their banality is what makes them frustrating— considering that incorporating accessibility features into their design would not have made a dent in the budget of this multi- billion-dollar project.[2]

THE MAKING OF THE VIDEO: MARC, LYNA, NABILA AND JULIE-ÉLAINE EXPRESS THEMSELVES

Our interview subjects are as diverse as their experiences with disability and deafness. During the spring of 2019, we met

with them, one by one, to ask about their unique experiences as adults who are ageing and deaf or disabled. Our questions included the following:

- Can you tell us your name and give us five words to describe who you are?
- What do the terms "accessibility" and "ageing" mean to you in terms of your experience of the world?
- Tell us three things that need to change in society that would be meaningful to you and your access needs?
- What are your biggest dreams for the future?
- We video-recorded their answers, resulting in a short film that is a composite of what they had to say.

ACCESSIBILITY

In defining accessibility, two of our interviewees agreed that it comes down to a question of rights. For both Marc and Nabila, it means having access to goods and services that meet all of an individual's needs. However, as Marc pointed out, such access also includes the freedom to acquire information at will, which can be a challenge for those like him, who are blind. "You look up there, there's a cable box up there. I can't access that cable box," he said. "The Videotron app isn't completely accessible either. It may be a small thing, but it's an important thing. Or whether you go to a movie and you want the closed caption or an audio description of what's happening in the movie, again that's information." ●

From right to left. Marc Baillargeon, Lyna Boushel, Nabila Nouara and Julie Élaine Roy

Lyna and Julie-Élaine explained accessibility in terms of challenging regressive perceptions. Lyna, for instance, described the ignorance that able-bodied people often reveal in their interactions with the disabled: "It's [about] sensitizing people to how they should handle the disability. How they should talk to you, look at you." To be addressed and looked at beyond one's physical and cognitive capacities was also at the crux of Julie-Élaine's understanding of accessibility: "It seems like we don't accept differences," she notes.

AGEING

In defining ageing, both Marc and Lyna explained how the barriers associated with their respective disabilities are compounded by the inevitable effects of ageing. "The ageing population is increasing and we're going to have to face a lot of accessibility issues with ageing," Lyna reminded us. She described these issues in terms of "knee replacements, hip replacements, strokes, people needing to go from one place to another, and we'll be needing help, we'll be needing transportation."

Lyna's observation of the need for improved transportation is echoed by Nabila, who explained how her dependence on the Société de transport de Montréal's adapted transport service confronts her with a dilemma. When using adapted transport for a family outing, Nabila can only be accompanied by one individual, which means she has to choose between her two daughters and husband. It goes without saying that adapted transport is her only option for travelling around the city, since Montréal's metro and train stations are not wheelchair- friendly. Frustrations with the lack of

accessibility in Montreal's 50-year-old public transit system (elevator access is available in only 14 stations out of 68, and only on two lines), are further echoed by the Regroupement des activistes pour l'inclusion au Québec (RAPLIQ), a Montreal- based disability rights group which, in 2017, filed a class-action lawsuit against the city as well as the Société de transport de Montréal (STM) and the Agence métropolitaine de transport (AMT) for violations of Quebec's Charter of Human Rights and Freedoms.[2]

At the heart of Nabila and the RAPLIQ's concerns is a blatant exclusion of those with reduced mobility from the city's conception of the "public." How public is a city's public transit if it excludes members of the population it is mandated to serve? >

GENERATING HOPE THROUGH DISCUSSIONS AND CREATION: PUTTING VIVRE ENSEMBLE INTO PRACTICE

Conversations about the increasing older population are often tinged with language evoking a burden and marginality. These, however, ultimately reflect the ageist, ableist and audist attitudes that inform our society's "solutions" for dealing with the demographic shift currently taking place.

It is imperative to amplify the diverse perspectives and experiences of older adults—including those living with a disability and those who are deaf—in order to approach ageing as the complex, multifaceted and universal process that it is.

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1. *Montreal has long way to go on accessibility.* By Allison Hanes, The Montreal Gazette, November 5, 2018: https://montrealgazette.com/opinion/columnists/allison-hanes-montreal-has-long way-to-go-on accessibility

2. *Court approves class-action lawsuit against Montreal, regional transit authorities.* By Howard Cohen, Global News, May 29, 2017: https://globalnews.ca/news/3487667/court-approves-class-action-lawsuit-against-montreal-regional-transit-authorities/

The social participation of older adults with disabilities: toward more inclusive practices to prevent discrimination

Émilie Raymond

*Professor, School of Social Work and Criminology, Université Laval
Researcher, CREGÉS, PSVI and CIRRIS research partnership team*

Summary by **Marie-Éve Vautrin-Nadeau**
Doctoral student, Department of Communications, Université de Montréal

▶ Watch the webinar recording

Émilie Raymond teaches at the School of Social Work and Criminology at Université Laval. She was the keynote speaker at the 2019 annual conference held by the Centre for Research and Expertise in Social Gerontology (CREGÉS). Her presentation on the social participation of older adults with disabilities provided an overview of the participatory action research project she led between 2014 and 2018 on active ageing with dignity.

How can we promote the inclusion of older adults with disabilities in leisure activities? For the Compagnie des jeunes retraités du Plateau de Charlesbourg (CJR), a community organization founded in 1994 and based in Quebec City, this became a pressing question just over five years ago when half of its members were over the age of seventy. Together with Émilie Raymond and a team of professionals from the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS), the organization looked into how it could make its activities more accessible to members who were living with or developing functional limitations, both age-related and not. This is how the "Active Ageing with Dignity" project took form, with a focus on the social participation of older adults in a post-industrial context. This issue "lies at the intersection of two phenomena: an ageing population and a reassessment of state interventionism." [Translation][1]

For Émilie Raymond, the conference was an opportunity to present a [practial guide](link) (GIPIO)[2] for the inclusion of people with disabilities in organizations for older adults, developed as part of this action research project. Drawing on the Human Development Model – Disability Creation Process (HDM-DCP) conceptual framework developed by Patrick Fougeyrollas, an anthropologist by training and a regular researcher at the CIRRIS, the guide aims to share knowledge, expertise and interpersonal skills resulting from the project. Organizations for older adults which, like the CJR, are seeking to adopt an inclusive approach, will find the following four avenues for action useful. ●

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DEVELOP A COLLECTIVE, LONG-TERM STRATEGY

"An organization seeking to become more inclusive must develop its overall capacity in this regard, rather than adopting individualized or small-scale measures," noted Émilie Raymond, who believes exclusionary situations stem from the organizational structure rather than members themselves. She

> *"An organization seeking to become more inclusive must develop its overall capacity in this regard, rather than adopting individualized or small-scale measures."*
>
> Émilie Raymond

added that it is better to "become stronger together," noting that the project was guided by symbolic interactionism, an approach allowing researchers to interrogate forms of social exclusion and inclusion. Developed in the United States in the 1930s, this approach "examines the concrete nature of inter-individual interactions.[3]

[Translation] The internalization of values based on able-bodied privilege tends to make individuals with disabilities disengage. Inclusion should therefore be part of daily practices and interactions.

In this regard, is organizational change possible? Can an organization become more inclusive? These questions were foremost in the minds for Émilie Raymond and her team as they worked with CJR volunteers throughout the action research project. If stigmatization is based on implicit power relations, lasting organizational change can only occur when these relationships are challenged. According to Émilie Raymond, "the first step towards a solution is for the organization to focus on inclusion and make it a shared goal." The GIPIO was designed to meet the challenge of inclusion in organizations for older adults. Although change requires time and sustained effort, it is important to remember that "on the road to ageing, disabilities are quite commonplace." For the benefit of all, it is therefore important to identify and implement social inclusion strategies.

ADOPT AN ORGANIZATIONAL PERSPECTIVE

Émilie Raymond explained how "The *Compagnie des jeunes retraités* had an inclusion policy in place, to which they added a code of conduct highlighting the organization's values, which could be invoked in situations where inclusion was under threat." Stressing the importance of involving decision-makers from the outset, so as to leave nothing to chance, she also noted changes that had to be made to the CJR's programming. Given the desired shift in mentalities and practices, the strategy also required

communication activities. For Émilie Raymond, knowledge mobilization, information and awareness activities are an essential part of bringing about lasting organizational change.

SHOW THE DIFFERENT WAYS IN WHICH AGEING AND DISABILITY INTERSECT

Since the early 2000s, ageing has been associated with health, activity and productivity. At the Second World Assembly on Ageing, held in Madrid in 2002, notions of decline and dependence were rejected in favour of a normative model of active, positive ageing (a preventive approach aimed at promoting health and well-being) put forward by the World Health Organization (WHO).

According to this model, positive ageing involves adopting an active, stimulating lifestyle—for example, by engaging in leisure activities (physical, cultural, etc.) and contributing to family and community life.[4]

However, Émilie Raymond pointed out that this model does not take into account the realities of certain individuals, since disabilities are a blind spot in ageing policies: "From 1982 to 2002, there was a shift from a discourse of decline and dependence to more triumphalist discourses . . . which could include certain norms that are not always compatible with situations of disability." Noting that older adults with disabilities are not necessarily a minority— close to 17% of Quebecers aged 65 to 74 years live with ⊙

moderate to severe disabilities, and this number is closer to 40% among people aged 75 and older[5] —the researcher stressed the importance of initiatives focused on solidarity. "We believe disability is a normal part of a person's life trajectory," she said, noting the importance of promoting of a more realistic view of ageing through a variety of means (videos, promotional activities, training sessions, workshops, etc.).

CHANGE HABITS BY ORGANIZING ACTIVITIES FOR ALL

For Émilie Raymond, it is crucial to adopt an approach based on universal accessibility, which means focusing on the group and not just individuals. When holding and organizing activities for older adults, it is important to take into account the variety of conditions they may have: "Becoming more inclusive means adapting services and activities, re-examining what we do and finding the right tools." The GIPIO, which is available online free of charge, is a valuable resource in this regard.

1.   Raymond, É., Gagné, D., Sévigny, A., Tourigny, A. (2008). *La participation sociale des aînés dans une perspective de vieillissement en santé : réflexion critique appuyée sur une analyse documentaire.* Quebec City: Institut national de santé publique du Québec.

2.   Raymond, É., Tremblay, C. and Compagnie des jeunes retraités du Plateau (2018). *Guide pratique pour l'inclusion des personnes ayant des incapacités dans les organisations pour aînés.* Quebec City: Centre for Interdisciplinary Research in Rehabilitation and Social Integration.

3.   Le Breton, David (2012 [2004]). *L'interactionnisme symbolique*. Paris: Presses universitaires de France.

4.   Québec Government (2009). *Favoriser le vieillissement actif au Québec.*

5.   Institut de la statistique du Québec (2017). *La mortalité et l'espérance de vie au Québec en 2016.*

GUIDE PRATIQUE POUR L'INCLUSION DES PERSONNES AYANT DES INCAPACITÉS DANS LES ORGANISATIONS POUR AÎNÉS (GIPIO) Table des matières

The self-determination of older adults with an intellectual disability

Martin Caouette

Professor, Department of Psychoeducation, Université du Québec à Trois-Rivières
Researcher, Institut universitaire en DI et en TSA (Trois-Rivières), PSVI and CIRRIS

Summary by **Marie-Éve Vautrin-Nadeau**
Doctoral student, Department of Communications, Université de Montréal

▶ Watch the webinar recording

Martin Caouette is a professor in the Department of Psychoeducation at the Université du Québec à Trois-Rivières (UQTR) and a researcher at the Institut universitaire en déficience intellectuelle (DI) et en trouble du spectre de l'autisme (TSA). He was the second speaker at the CREGÉS conference. As a researcher associated with the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS) and the PSVI (Participation sociale et villes inclusive), he recently conducted a literature review on intellectual disability (ID) and ageing.

Martin Caouette, a psychoeducator by training, introduced his talk with two definitions of self-determination, also known as "agency" in intervention settings. He stressed that self-determination involves "all of the skills and attitudes that allow a person to act directly on his or her life by freely making choices that are not influenced by external agents."[1] Citing special education professor Michael L. Wehmeyer, Dr. Caouette added that a self-determined behaviour presupposes the possibility of "acting as a principal causal agent in order to maintain and improve one's quality of life."[2] [Translation] For practitioners this is an important issue, since support is ideally aimed at increasing, or at least maintaining clients' agency.

Individuals living with an intellectual disability are identified by comparing them with those whose psychological and cognitive development is considered normal in light of available scientific knowledge. An intellectual disability, associated with different adaptive capabilities and intellectual functioning, as well as greater support needs, is usually detected before the age of eighteen years. Generally speaking, humans develop the foundations of self-determination during childhood and test these abilities during adolescence. So, what about people with an intellectual disability? According to Martin Caouette, this question remains to be explored.

How can we better support older adults with an intellectual disability? What does the literature say?To begin his research on the self-determination of older adults with an intellectual disability, Martin Caouette conducted a scoping literature review. "A group of students and I examined the scientific literature, exploring what we knew, especially in terms of providing support [to facilitate self-determination]," noted the researcher, adding that his team selected 23 scientific articles, all published in the past ten years. The content was grouped according to four themes: employment and retirement, leisure activities, health and end-of-life care, and accommodation. Martin Caouette described the main observations ❯

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revealed by studies, noting that they open up interesting avenues for both research and practical applications.

EMPLOYMENT AND RETIREMENT

In terms of employment and the transition to retirement, Martin Caouette pointed to various issues, notably the importance of addressing the occupational challenges of older adult with an ID, who constitute an emerging population. For him, it is important to think about the ways in which existing organizations can adjust to the ageing process of those they support.

"It is not sufficient for them to open their doors and offer recreational activities to all. The staff must also make sure the setting is welcoming for the target population."

Martin Caouette

In brief:

- Jobs do not match the aspirations of older adults with an intellectual disability.
- There are few occupational options available to this population.

- As they approach retirement, older adults with an intellectual disability do not see how they can spend their time in a satisfactory way.
- For older adults with an intellectual disability, retirement tends to be associated with illness and reduced social participation.

LEISURE ACTIVITIES

Martin Caouette pointed to a variety of issues with regard to leisure activities, noting that people do not necessarily lose interest in such activities as they age. Considering the prescriptive nature of activities organized in foster families, he added: "If there is one area where a person should be able to express his or her preferences and make choices, it's leisure activities." Work environments generally provide plenty of opportunity for social interaction.

Upon retirement, many face increased isolation. Martin Caouette noted that recreation centres can give older adults with an intellectual disability room to manoeuvre by allowing them to use their skills and express their preferences. These environments must be adapted to the functional capabilities of users: "It is not sufficient for them to open their doors and offer recreational activities to all. The staff must also make sure the setting is welcoming for the target population."

In brief:

- There is a negative correlation between age and the possibility of choosing one's leisure activities.
- Individuals with an intellectual disability aged 50 years and over are less independent in making decisions regarding their leisure activities.
- The inclusion of individuals with an intellectual disability in non-segregated structures increases the range of leisure activities they can choose from.

HEALTH AND END-OF- LIFE CARE

Martin Caouette cited two key studies on decision-making with regard to the care to be provided to people with an intellectual disability: one by Tuffrey-Wijne et al. (2009)[3] and the other by Wagemans et al. (2010).[4] "These studies show that several decisions are made about the health of individuals who are not directly involved in the process. They also reveal that older adults with an intellectual disability have little information about their health." Noting the protective attitude of medical personnel and loved ones, he highlighted a little-documented dynamic in clinical practice—namely a lack of consultation with end-of-life patients who have an intellectual disability. In general, doctors ▸

grant decision-making power to families, excluding older adults from the process.

For Martin Caouette, an intellectual disability negatively influences decision-making and care arrangements. For example, decisions can be made to withhold treatment in order to accelerate death, given that the person has an intellectual disability.

In brief:

- The family's viewpoint takes precedence over the wishes of older adults with an intellectual disability.
- The majority of professionals want to respect the end-of-life choices of individuals with an intellectual disability, but do not know how to involve them in decision- making processes.
- At end of life, supporting the target population poses an enormous ethical challenge.

LIVING ARRANGEMENTS

Ageing is associated with changes in living arrangements. Those with an intellectual disability tend to have few options at retirement. Since these individuals are not very involved in decisions regarding accommodation, they tend to think they have little control, especially since for some of them, a move from their neighbourhood and recreational

environment is inevitable. "In Quebec, a classic situation is for a person to spend most of his or her life with a foster family. There comes a time when the foster family ceases to play this role." Martin Caouette also described the phenomenon of "double ageing," which occurs when parents take care of a child with an intellectual disability for most of his or her life, but eventually can no longer do so: "Sometimes the health of one or both of the parents means that an adult child [with an intellectual disability] has to move."

When a transition becomes necessary, it tends to happen quickly without consulting loved ones. Despite the constraints faced by the target population, there is room for optimism. According to Martin Caouette, some residential settings truly promote self-determination: "When the setting is closer to the community, when we are more interested in habitats than institutions , the living environment affords greater control, both for older adults and adults with an intellectual disability."

1. Wehmeyer, M. L. (1996). *Self-determination as an educational outcome: Why is it important to children, youth, and adults with disabilities?* In D. J. Sands, & M. L. Wehmeyer (Eds.), Self-determination across the life span: Independence and choice for people with disabilities (pp. 17-36). Baltimore, MD: Paul H. Brookes.

2. Lachapelle, Y., & Wehmeyer, M. L. (2003). *L'autodétermination.* In M. J. Tassé & D. Morin (Éds.), La déficience intellectuelle (pp. 208-209). Montreal, QC: Gaëtan Morin.

3. Tuffrey-Wijne, L., Bernal, J., Hubert, J., Butler, G., Hollins, S. (2009). P*eople with learning disabilities who have cancer: an ethnographic study.* British Journal of General Practice, 59(564), 503-509.

4. Wagemans, A., Van Schrojenstein Lantman-de-Valk, H., Tuffrey-Wijne, 1., Widdershoven, G., & Curfs, L. (2010). *End-of-life decisions: An important theme in the care for people with intellectual disabilities.* Journal of Intellectual Disability Research, 54(6), 516-524.

Testimony panel – Ageing as a Deaf person or as someone with disabilities: challenges, joys and aspirations

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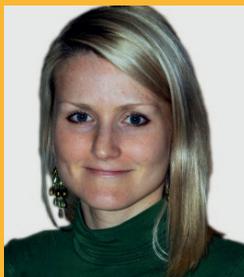
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Diane Paquet
Retiree

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Summary by **Marie-Éve Vautrin-Nadeau**
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Over the past few decades, public testimony has become an essential social and cultural intervention strategy for various minority groups. In diverse settings, it is a tool for individuals and organizations to raise awareness, since visibility in the public and media space ensures "the social acceptance for which all are striving"[1] [Translation]. In keeping with the goal of the 2019 edition of the CREGÉS conference—namely to improve practices vis-à-vis Deaf older adults and those with disabilities—the organizers decided to include a testimony panel.

The panel opened with a brief introduction by the two moderators. Véro Leduc is a professor in the Department of Social and Public Communication at the Université du Québec à Montréal (UQAM) and Quebec's first Deaf university professor. She is also a researcher associated with the ACT project (Ageing + Communication + Technologies). Élise Milot is a professor in the School of Social Work and Criminology at Université Laval and a member of the PSVI and CIRRIS research partnership team. For both hosts, the panel was an opportunity to hear the voices of those concerned. This article is an account of the testimony of three guest panelists: Monique Boudreault, a retiree and volunteer; Diane Paquet, a retiree; and Benoît Giroux, a crossing guard.

1. MONIQUE BOUDREAULT'S TESTIMONY

Monique Boudreault is 77 years old. As someone who was born without hearing, she has witnessed the progress made in recent years in terms of Deaf people's access to services (e.g., educational services). This improved access is tied to technological advances. Although there is still room for improvement, notably in closed captioning on television, digital technology has brought about major improvements in the lives of Deaf people: "Technology helps you manage on your own. Now you can get a Ph.D. and learn all kinds of things."

On the topic of access to services, Monique pointed to the invaluable contribution of interpreters: "If we didn't have interpreters we'd have more limited options in terms of education." Invited by Véro Leduc to describe the struggles of Deaf people to have their rights recognized, she mentioned the key role of the Office des personnes handicapées du Québec (OPHQ): "The OPHQ said we were entitled to services, which resulted in those services being developed." Monique has represented Quebec at a national conference on Deaf older adults and has visited various settings, including hospitals, where she has witnessed the isolation felt by Deaf people living far from urban areas: "Services are more accessible in the city . . . There is still work to do [in Quebec and outside the province], and it really touched me to see how people's realities differ, depending on where they live."

Having worked for the government and also as a special education teacher, Monique is now focusing her energy on volunteer activities: "In 2010, I got involved in the Miss Deaf contest. I also volunteer with community kitchens and help with [the delivery of services to] people with disabilities. I like to be active!" She described the path of her son who is also Deaf: "[Patrick] is a physician. He lives in the US and his son is Deaf . . . so we have both hearing and Deaf people in the family."

Her aspirations reflect her activist side: "There are many people who say they want to learn Quebec Sign Language or QSL. [Sign languages are] recognized in lots of places but not yet officially in Quebec." Véro Leduc noted the latest legislative ⊙

From right to left: Véro Leduc, Monique Boudreault, Benoit Giroux, Diane Paquet and Élise Milot

"Technology helps you manage on your own. Now you can get a Ph.D. and learn all kinds of things."

Monique Boudreault

developments regarding the recognition of sign languages, including QSL: "Canada will be passing a federal law on accessibility. The Senate has already approved the recognition of sign languages. We will soon have official recognition by the government. It will be a historic moment." Clapping her hands in approval, Monique added, with a twinkle in her eye: "More and more hearing people are learning basic QSL—enough to say hello, for example. I find

their efforts really touching." For Monique Boudreault, social advocacy is clearly a source of pride and joy!

2. DIANE PAQUET'S TESTIMONY

Diane Paquet is 67 years old. She was been living with the effects of polio since she was eight. She described how, at the time of her diagnosis, in 1959, society did not accommodate people with disabilities: "You weren't given a chance. I worked for a

school board and in schools. When I'd arrive somewhere, people would tell me they weren't going to do my job for me. You have to prove that you're capable of working and that you have a right to be there. You have to develop a thick skin and strong self-esteem in order to cope." Today Diane is retired. She deeply values her family and lasting friendships: "I have a lot of friends in different fields. Friendships help you feel good about yourself. They make you happy. I have two friends I've ⊙

known since I was ten years old." She has shared her life with a "great man"who is quadriplegic (Diane describes herself as tetraplegic). She talked enthusiastically about their son: "I have the most amazing son in the world. I could talk to you about him and my spouse all day long."

When asked about her aspirations, Diane immediately said independence: "[Like people with disabilities], we age faster, not intellectually speaking, but physically . . . Your one goal is to maintain your independence as long as possible, so you can keep doing [your activities and] avoid becoming isolated. As an ageing person with a disability, the less able you are to do things, the less you go out and the more isolated you become." As someone who appreciates the simple joys in life, Diane feels it is best to take things one day at a time.

3. BENOÎT GIROUX'S TESTIMONY

For Benoît Giroux, whose age was not mentioned, learning is one of life's great pleasures. Despite facing some challenges as a boy, including teasing, he loved going to school: "I gained a lot from it and today I can read, write and count." He said he finds the adult world more accepting,describing the

support and love he receives from friends and family. He was very close to his grandmother. When she died, his uncle has stepped in and made sure his nephew had good working conditions at his new job. When Benoît found that being a dishwasher was too demanding, given his fragile health, his uncle urged him not to accept the unemployability status proposed by his doctor. Instead he became a crossing guard and is thrilled to have a job that suits him and gives him some independence: "Since starting this job, I never get sick. It's been a real blessing for me," he said.

Benoît said he receives support from those close to him, especially his uncle, who has been his guardian since he was 11 years old. He also talked about his social life. He belongs to a social club in Quebec City, and participates in all kinds of activities where he meets different people. He has been in a loving relationship with his spouse for 30 years. At the time of the conference, he was about to move in with her. After many years on a wait list, the two lovebirds will finally have adjacent supervised apartments. "We were patient," he joyfully exclaimed.

When asked about his aspirations, Benoît said he dreams of visiting Walt Disney World. He has seen the show

Disney on Ice more than once and wants to discover even more Disney magic. He also wants to travel to Italy—an obvious choice for a practicing Catholic and someone who loves good food!

4. CONVERGING PATHS

Despite their different physical conditions and personal stories, the paths of all three converged to a certain extent. Through their participation in the conference, the panelists underlined the importance of involving Deaf people or people with disabilities in public conversations around ageing, and in decision-making bodies as well. Their realities are not isolated or unique: they highlighted the importance of continuing the struggle for adapted services in order to promote inclusion and a greater social acceptance of disability. Such personal accounts show people's diverse realities and experiences of ageing as well. Workers and researchers working with ageing populations would do well to listen carefully.

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Technologies aimed at maintaining older adults with disabilities at home

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▶ Watch the webinar recording

The latest Quebec data on older adults' use of technology challenges the ageist stereotypes that suggest this population is technophobic. In fact, according to a 2018 report by the CEFRIO, an organization dedicated to research and innovation, 85% of people between the ages of 65 and 74 use the Internet. In addition, 70% of those aged 75 and older use the Internet as well. A total of 60% of older adults use the Internet every day. This population mainly uses a computer or tablet to go online, since they have not adopted smartphones as readily as younger generations[7]. Along with these more common technologies, additional technological tools are now available for this growing population. For example, home automation (based on the integration of voice-based technologies, monitors and control panels) is used to support older adults' daily activities and increase their independence.[1]

Since the 1980s, there has been a growing body of research on the use of technology to overcome older adults' loss of independence.[2] Technology developed specifically for this population has the advantage of taking sensory and cognitive challenges into account.[3] However, it is quite rare for technologies to be developed specifically with and for older adults in order to offer products adapted to the realities of ageing. Furthermore, there is little solid evidence showing how effective technologies are in maintaining people in their homes.[4] This is largely because technologies are being developed so quickly that research cannot keep pace.

So how do we choose among all the available products in stores and online? How can we make informed decisions? It is important to know which technologies can help people stay in their homes and what the related challenges may be. There are also research projects under way in Quebec to develop technologies adapted to the needs of older adults.

ISSUES RELATED TO THE USE OF NEW TECHNOLOGIES

It is one thing to have access to various technologies. When choosing a product, various elements need to be considered: "What exactly do I need this

> *"The latest Quebec data on older adults' use of technology challenges the ageist stereotypes that suggest this population is technophobic"*
>
> Mélanie Couture

for?" Generally speaking, technology can be used for the following:[5] 1) memory support, self-care and activities of daily living; 2) treatment and interventions; 3) safety, security, monitoring and reassurance; 4) training; 5) management and coordination of care by professionals or the individual; and 6) social interaction and engagement. Technology can also, of course, be used for entertainment.

Health and social services professionals have the necessary skills to assess older adults' situations and identify their main needs. Some may help to choose technologies adapted to the person's condition and can teach the person how to use technologies they already own. For example, smartphones offer a variety of functions and apps to support people with sensory or cognitive difficulties. The majority of phones have a voice recognition feature, a calendar and an integrated "magnifying glass." To learn more about

these features, people can do research online and find tutorials (e.g., on YouTube). There are also a variety of communication apps such as Skype and Whatsapp. More recently, voice assistants like Google Home and Alexa have emerged on the market. These can be connected to other devices in the home.

Technical elements can be a barrier to older adults' adoption of different technologies. Sometimes the technology is too complicated and difficult to use. In addition, the person's home must allow for the proper installation and connection of these systems.[6] The cost of purchasing, using and maintaining these technologies can also be an issue for some people.

Psychological factors associated with technologies can also influence their use, which is why it is important to assess our own openness to change and learning before purchasing products. In Quebec, 40% of older adults are open to the idea of integrating technology in their homes.[7] Some technologies are more acceptable than others to Quebecers. Approximately one-third of those surveyed said they would consider using fall detection devices, smart bulbs and plugs, and medication reminder apps. However digital wall calendars and robots were less appealing ⊙

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(only 22% and 12% of respondents were interested, respectively). Some people opt not to use technology, because they feel it will make their disability even more visible.[8]

It is also important to question the effects of technology on privacy, since different types of information are required for their use. People need to be able to determine who manages this information and who has access to it. Cameras and other monitoring technology can be very intrusive for some.[9,10] For others, it is preferable to have monitoring technology in place rather than asking for help from loved ones, in order to protect their privacy.[11] Each person has to determine an acceptable balance between autonomy and privacy. For example, if a family caregiver is informed of the older person's movements via the latter's smartphone, this could be reassuring for all concerned. However, it opens the door to discussions about when and why the person is leaving the house . . . .

EXAMPLES OF CURRENT RESEARCH IN QUEBEC

Our research team is currently developing Quebec technologies with and for older adults, including those with cognitive deficits. One of these technologies, called COOK, is designed to promote independence in meal preparation by providing assistance adapted to people's needs.[12] The system consists of a tablet and detectors in the kitchen and on the stove. The user is accompanied step by step in the preparation of meals, and also receives audio or written cues to help them cook safely. The independent safety system with integrated sensors in the home is designed to reduce the risk of fire associated with using a stove. If a high-risk situation occurs, the user is alerted. If he or she does not correct the situation, the stove is automatically locked.

We are also working with health and social services establishments to develop lifestyle monitoring technologies allowing for better supervision of older adults at risk of relocation. On a secured Web platform, professionals can see the person's activities (sleeping habits, outings, hygiene and meals) and adjust intervention plans by adding or removing services as required. The goal is to provide care and services in a timely and appropriate manner so as to maximize the system's resources and improve client satisfaction.

CONCLUSION

The use of technologies aimed at keeping older adults with disabilities in their homes requires informed decision-making with clear knowledge of the person's needs, living environment and views on technology and privacy. Technology has a huge potential to support the independence of older adults, but not at any cost. Scientific evidence in this area is not yet conclusive, but studies are under way to further clarify the consequences of using technology to help older adults stay in their homes. >

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Including older adults with disabilities in seniors' organizations: a practical guide

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▶ Watch the webinar recording

This workshop was designed to familiarize participants with the Guide pratique pour l'inclusion des personnes ayant des incapacités dans les organisations pour aînés (GIPIO)— the result of a research partnership between the Compagnie des jeunes retraités (CJR) and Dr. Émilie Raymond. The workshop facilitators: 1) described the main stages in developing the guide; 2) highlighted its main features; 3) applied its content to two scenarios; 4) offered suggestions on how it may be used in organizations serving older adults.

The CJR is an organization run by and for retirees, which fosters a sense of belonging and offers a wide range of leisure activities. It has over 2,000 members, including 300 volunteers who organize physical, cultural and social activities, as well as trips. The average age of CJR members has increased in recent years: it was over 70 years in 2019. The organization is currently facing the challenge of how to ensure the continued participation of ageing members who are likely to either have or develop functional limitations. Reaching this goal is not that simple: both social representations of disability and the physical environment can be barriers to inclusion.

MAIN STAGES IN DEVELOPING THE GUIDE

The challenge faced by the CJR was the impetus for a project aimed at supporting the participation of older adults with disabilities. The first step was to develop an inclusion policy (2013). A participatory action research project (RAP- VAD) was then launched with the goal of implementing and evaluating the organizational policy. During the first phase of the RAP-VAD (2014– 2015), 60 CJR members where asked about the exclusion of those with disabilities. They

were also asked to identify priority actions to address this problem. During the second phase (2015– 2016), four working groups were formed to develop inclusion measures and tools according to each priority. In the third phase (2016–2017), pilot projects were carried out to test these measures and tools in the context of five regular CJR activities (e.g., bridge games and fitness classes). The fourth phase (2017–2018) involved writing the guide based on the previous work. The completed guide was validated by key actors and fine-tuned to create a final version.[1]

CONTENTS OF THE GUIDE

The workshop conveyed four key messages about the GIPIO and its use. The guide:

1. offers a range of possible solutions, not a one-size-fits-all formula;

2. recommends an approach consisting of several stages that can be adapted to users' needs;

3. is not limited to measures specific to disabilities, but rather promotes the participation of all older adults;

4. offers tools that can be adapted to the realities of each setting.

The workshop facilitators then presented each section of the GIPIO. The first section sets out the parameters of an inclusive approach. It describes the theoretical foundations on which the guide is based, including notions of impairment, disability and handicaps, as well as exclusion, inclusion and participation. This section also includes a simplified version of the Human Development Model – Disability Creation Process (HDM-DCP) conceptual framework.[2]

The second section contains a set of measures allowing actors to develop inclusion guidelines and identify levers to make their organization more inclusive. Examples of elements used to develop an inclusion policy are a code of conduct and tools to conduct an organizational diagnosis with regard to the exclusion of older adults with disabilities.

The third section contains content and tools to help raise awareness around ageing and disability. It provides information on various conceptions of ageing and types of disabilities. It also offers tips on how to better interact with those who have disabilities, along with information on problems affecting older adults such as bullying, isolation and depression. Awareness tools on these topics ➲

GUIDE PRATIQUE
POUR L'INCLUSION
DES PERSONNES
AYANT DES
INCAPACITÉS DANS
LES ORGANISATIONS
POUR AÎNÉS
(GIPIO)
Table des matières

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than the others, who criticized her. This woman had a problem with her eyesight, in addition to having reduced mobility, which it made it more difficult for her to travel to the organization and to access the rooms.

The second scenario was a hiking/cross-country skiing activity held by a retiree association. The team of volunteers could not agree on how to deal with ageing members. Some thought they should encourage members "in poor health" to withdraw from the activity in order to avoid accidents and friction within the group, while others tried to find alternatives (e.g., suggesting other activities or organizations).

Based on these scenarios, participants identified several elements that contribute to the exclusion of older adults with disabilities: 1) a bullying dynamic; 2) problems associated with physical accessibility; 3) prejudices around ageing and disability; and 4) organizational structures and practices that are not compatible with the diversity of older adults' needs. They also discussed different avenues for action. They agreed that an essential measure would be to develop a code of ethics or code of conduct in collaboration with members, and to use these codes in conflict situations. They also noted the importance of ensuring universal accessibility with regard to both facilities ●

are also offered, including an educational workshop, a brochure, quizzes and videos. The last section shows how to adapt activities to the needs of older adults with disabilities and how to improve the general organization of activities. This section also includes measures to help participants feel more welcome. The tools include recommendations on holding open houses, a health self- assessment sheet, a planning notebook for activities, and satisfaction surveys. There

is also a mentorship protocol for participants and a checklist for creating a welcoming environment.[3]

PRACTICAL EXERCISE: TWO SCENARIOS

Participants were then invited to work on two scenarios showing typical situations of exclusion. The first scenario was a board game activity in a community centre. One participant was excluded from the group because she played more slowly

and equipment. Other ideas included diversifying the scope of activities and services based on a survey of members' interests, and creating sub- groups for the same activity in order to respect people's different rhythms and physical capabilities. They also noted that staff training is essential to avoid stigmatizing beliefs, attitudes and behaviours

PERSPECTIVES ON MOBILIZING KNOWLEDGE

The facilitators concluded their introduction to the GIPIO guide, noting that a training program is being developed in order to encourage its adoption. In addition, a digital platform will complete the contents of the guide. The on-site training program will allow the representatives of different settings to discuss their practices and apply the guide to the situations they encounter. Such measures are essential complements to the written guide in order to promote knowledge mobilization. The CJR'S experience confirms that it takes time to change practices. All actors need to be mobilized and efforts must be made to ensure that actions are chosen according the needs of each environment[4,5].

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Communicating with Deaf people: basic concepts for better service delivery

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This workshop provided participants with tools to improve their oral, written and sign language communications with deaf people. Adapting one's actions to the deaf community also involves correctly interpreting vocal intonations. The facilitators also discussed the use of visual material and technology to assist with communication. As a result of the workshop, participants will be able to communicate more effectively with deaf people.

TERMINOLOGY RELATED TO DEAF PEOPLE

Different terms are used to describe the diverse realities of people according to their hearing and methods of communication. Generally speaking, a person is said to have a loss of hearing when this loss is caused by ageing or illness. A hearing person is someone who has hearing, whether it is normal or not. A person who is hard of hearing is someone who has variable degrees of hearing loss and often uses a hearing aid. An oral interpreter is someone who mainly communicates orally, but does not know Quebec Sign Language (QSL). A person with an implant has received a cochlear implant. These are an option when hearing aids cannot sufficiently restore a person's hearing. Finally, a Deaf person is someone whose hearing loss is bilateral, ranging from severe to profound—a loss that occurred prior to the acquisition of language. A Deaf person communicates using QSL and is part of a Deaf culture. It is a mistake to refer to these individuals as "deaf mutes," because their vocal chords function. The use of a capital "D" signifies the identity and pride of those in this community. Deaf people see themselves as an ethnic minority group with shared values—not as individuals with a handicap.

QSL is the sign language used in Quebec. Sign language is not universal: it is different in France and the US, for example. QSL is a language in its own right and is studied by linguists. It has its own vocabulary, grammar and expressions, which are distinct from French. Also, in QSL a word is not equivalent to a sign. QSL is considered by Deaf people to be their mother tongue, whereas French is their second language.

COMMUNICATING WITH DEAF PEOPLE

How can we communicate with Deaf people? First of all, oral communication can be optimized by making it easier for the person to read your lips. To do so, you need to face the Deaf person and establish eye contact. You should speak naturally without exaggerating your articulation. Speak in short sentences, use simple words and be expressive to give visual clues. Using gestures and imitation—for example pointing at or even drawing the outline of an object—can be helpful.

Secondly, you need to adapt your written communications. Since French is the second language of a Deaf person, you need to check his or her level of understanding and write in a simplified manner: short, concrete sentences with a subject, verb and complement. Verbs should be in the present tense and active form whenever possible, since the past and future can be confusing. Respecting the chronological order of events and providing time indicators at the beginning of the sentence is essential. When it comes to word choice, opt for words with a single meaning. You should also be careful about using expressions from hearing cultures.

Third, the presence of an interpreter can be very helpful. An interpreter is a professional who translates messages from QSL to French and vice versa in a neutral manner, without offering opinions or comments. An interpreter may be used for all health problems and to make an appointment with a doctor or dentist.

Fourth, it is possible to use a communication support service. This service is offered by a special education technician who has studied auditory impairment rehabilitation. The technician can act as an intermediary between the Deaf and hearing person. Unlike an interpreter, a technician offers communication support and participates in the conversation. His or her role is to explain, repeat information and assist with steps to be taken following the exchange. For example, the technician can write up a checklist, prepare a person for a specific situation and offer ❯

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"Deaf people see themselves as an ethnic minority group with shared values—not as individuals with a handicap. "

emotional support. People might require communication support for a variety of reasons—for instance, if they have difficulty understanding (e.g., because of an intellectual impairment) or remembering the steps to be taken, if they wish to indicate that they have not understood, or if they feel a lot of anxiety.

Lastly, the development of new communication technologies can be of great assistance. One of the first technologies provided by telecommunication firms was the Message Relay Service, which allows a hearing person to speak directly with a Deaf person. However, since the transmission of messages between parties is very slow, MRS is not used as much today. Faxes, emails and text messages are other useful means of communication based on simplified French. Drawings and photos can also help to promote understanding. It is not a question of infantilizing the person, but rather of providing support. Glide and Skype allow for video communication, which is useful for SQL. While Skype allows for real-time video conversations, Glide only allows people to send video messages. The problem with these communication methods is that the platforms are not fully secure. Since 2011, telecommunications companies have offered the IP Relay Service, which allows a hearing person to speak on the phone to a Deaf person using a computer. This is a confidential service, with no additional fees, and it is available 24/7. Since 2016, the free Video Relay Service has also been available across Canada, 24/7.

Finally, there is Video Remote Interpreting, which allows a Deaf person and hearing person in the same location to have access to a live interpreter via video, even if the latter is in another location. It is also possible to have a multi-site conversation by adding participants in another location to the group. This pilot project has been tested in CLSCs and hospitals in Montreal, but is not yet available in Quebec City.

ADAPTING INTERVENTIONS

The Deaf community is small and it is easy to identify other users with limited information. Confidentiality is therefore of the utmost importance. In the context of service delivery, it is important to be cautious when interpreting vocal intonations. It is difficult for Deaf people to modulate their voice and they may not realize that they are making sounds as they express themselves. A loud voice does not necessarily mean the person is being aggressive. It is a good idea to use visual material (drawings, tables, calendars), as this makes the information ➤

concrete and facilitates visual and experiential learning, which Deaf people are accustomed to. It is important to make sure essential elements have been understood by providing examples and information, and continually adapting them to the person's level of understanding in French. Finally, it is always possible to try using mime and natural gestures to get the meaning across. Ideally, you should learn some QSL signs as well.

Resources :

Service régional d'interprétariat de l'est du Québec
418 622-1037 or
1 800 268-1037
www.srieq.ca

Institut de réadaptation en déficience physique de Québec
AEO (intake, evaluation and orientation service)
418 529-9141 (ext. 2210)
Aeodeficience.sensorielle@irdpq.qc.ca

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Invisible disabilities: when eyesight and hearing deteriorate

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What is meant by "invisible disabilities"? Vision and hearing loss are considered invisible disabilities because they cannot be seen from the outside. Certain clues such as hearing aids, a cloudy eye or the use of a cane can point to vision or hearing loss, but they do not indicate the degree of loss.

DEFINITIONS OF SENSORY DISABILITIES

To ensure that all participants had the same terms of reference during the workshop, Valérie Martel, a specialist in orientation and mobility at the Institut de réadaptation en déficience physique de Québec (IRPDQ), provided three important definitions.

Visual impairment refers to a loss of visual acuity or visual field, even with the best available correction. Certain criteria must apply for a person to be officially considered visually impaired: grey zones may prevent the person from being assigned this status.

Hearing impairment is a partial or total inability to hear certain frequencies and to understand conversations in one's vicinity. This definition includes tinnitus.

Finally **deafblindness** is a unique condition where both hearing and vision are affected. Combined hearing and vision loss can be total or partial, creating a multitude of communication profiles. The two impairments create a new reality. Those who are hearing-impaired can no longer rely on their vision and blind people can no longer rely on their hearing.

IMPACTS OF SENSORY LOSS

Sensory loss appears in a gradual and sometimes insidious manner, which makes it seem normal to a degree. Those affected may not realize or perhaps think it is simply a normal part of ageing. Some people may be embarrassed to reveal their disabilities. In addition, vision and hearing loss cause fatigue and require additional effort, which may prevent a person from following a conversation, for example. A lot of effort is required to compensate for these losses. This can cause people to withdraw and become isolated, with all of the related consequences. This issue was not addressed in detail in the workshop, but social isolation is linked to a variety of problems among older adults.

SIMULATIONS OF SENSORY LOSS: PRESENTATION OF VIDEOS

During the workshop, Valérie Martel presented three videos showing a weather report, a restaurant outing and a conversation at a checkout counter. The videos were designed to simulate vision loss, hearing loss and a dual loss, allowing participants to put themselves in the place of someone with these impairments.

Video #1 Visual impairment. The first video allowed participants to understand how a person with a visual impairment sees. More specifically, it presented the vision of someone with macular degeneration. There was a partially opaque spot in the centre of the images, preventing viewers from making out important details. Auditory clues were necessary to fully understand the scenes, but certain details were lost, as in the following two cases.

Video #2 Hearing impairment.
The second video showed participants how a hearing-impaired person perceives sounds (speech, music, etc.). The video sound was altered, preventing people from easily understanding the scenes shown. They needed visual clues to follow the scenes, but even so, some of the jokes were difficult to understand.

Video #3 A dual impairment: deafblindness.
The last video put participants in the place of a person with a dual impairment—in other words, with both vision and hearing loss. The elements of the first two videos were brought together. There was a somewhat opaque spot in the centre of the images and the sound of video was altered. It was therefore virtually impossible for participants to follow and understand the scenes shown.

Following the presentation of the videos, participants were invited to comment on their experience and draw connections with the impacts discussed earlier. They confirmed that it was indeed "exhausting" and "tiring" to follow the videos, that it required significant effort and concentration. They understood more clearly how sensory loss can lead to isolation. People experiencing such loss may think it is better to just stay at home, because it is less exhausting.

"One should not think that people with a hearing aid necessarily hear well. It is important to be aware of their disability by reducing the ambient sound as much as possible and reading their lips, or by planning a group listening system (microphone and earphones), which allows people to receive quality sound directly (such systems are used for guided tours and in classrooms)."

STRATEGIES FOR PROFESSIONALS AND CAREGIVERS TO PUT IN PLACE

Professionals and caregivers who assist people with a vision or hearing loss can implement certain strategies to facilitate communication. During the workshop, Valérie Martel identified several of these strategies. First, it is important to take one's time with the person in question, to speak more slowly and to hold their gaze. One should not necessarily speak louder or increase the type font, as this might not be helpful. It is important to ask the person what will be useful to them and to adapt communication

methods to their reality. Second, one should not think that people with a hearing aid necessarily hear well. It is important to be aware of their disability by reducing the ambient sound as much as possible and reading their lips, or by planning a group listening system (microphone and earphones), which allows people to receive quality sound directly (such systems are used for guided tours and in classrooms). This helps to promote communication and understanding and can even make interventions more relevant. Finally, it is important to avoid ignoring individuals with vision or hearing loss by only consulting their caregivers, for example. One should focus on including them in the conversation to find out how they feel about decisions that will affect them.

Those interested in learning more are invited to consult this practical guide on sensory exploration with older adults living with an intellectual disability. The guide is available on the website of the CIUSSS de la Capitale-Nationale.

The social participation of older adults with or without a mental health diagnosis: the Count Me In! program

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Summary by **Marie-Éve Vautrin-Nadeau**
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Following is a summary of the workshop led by Ginette Aubin and Julie Beauchamp who presented Count Me In!, a program co-constructed by CREGÉS and the VIES research partnership team (Vieillissements, exclusions sociales et solidarités) aimed at promoting the community participation of older adults, with or without a mental health diagnosis, who are experiencing psychosocial challenges.

What is social participation? How can we define it? What are its benefits? How can it be a source of opportunity and positive contact with others? These are the questions that Ginette Aubin and Julie Beauchamp posed at the start of the two workshop periods devoted to the Count Me In! program.

The conference was an opportunity to describe this program designed to address "issues related to the social exclusion and inclusion of seniors with mental health problems."[1] The facilitators stressed the importance of social participation, both for the target population and society in general. As indicated in the bilingual facilitation guide, which was passed around the room, "community participation should not rest entirely on the shoulders of individuals themselves. A collective effort is required to create favourable conditions for this."[2]

Count Me In! is based on a health promotion approach. The desired program outcome is not an absence of mental health problems, but rather the optimal community participation of individuals experiencing psychosocial difficulties, regardless of whether or not they have received a diagnosis. For the team that implemented the program, there were two main objectives: to give participants

the tools they needed by sharing knowledge, strategies and resources; and to facilitate the creation and accessibility of environments promoting community participation through collaboration and awareness-raising.[2]

How can the Count Me In! program be implemented? All health and social services professionals, community workers and peer support workers are invited to get involved. The facilitation guide was produced with this goal in mind, along with accompanying training videos (www.creges.com).

"Community participation should not rest entirely on the shoulders of individuals themselves. A collective effort is required to create favourable conditions for this."

COUNT ME IN! AT A GLANCE: THE FOUR PROGRAM SECTIONS

1. Individual interview
The individual interview, conducted prior to participation in the group workshop, is designed to help participants

identify their interest and set a personal goal with regard to their participation in the community.

2. Group workshop
The group workshop consists of a series of eight meetings (1.5 to 2 hours) on the following topics: social participation, identifying strengths, community resources, adaptation to ageing, financial management, communication, social networks and civic involvement. The activities in these meetings are both reflexive and interactive.

3. Visits to community organizations
One of the program objectives was to promote the use of community resources. Program leaders should therefore provide participants with information on available services and organize visits to organizations.

4. Media capsules
In this group activity, participants are invited to choose messages to include in media to be shared within the organization or community. The quotes reflect participants' experiences and opinions. ⊙

1. CIUSSS West-Central Montreal (2018). *Count Me In! Promoting Seniors' Mental Health and Community Participation. Workshop Manual.* Page 18.

2. CIUSSS West-Central Montreal (2018). *Count Me In! Promoting Seniors' Mental Health and Community Participation. Workshop Manual.* Page 11.

COUNT ME IN!

Promoting Senior's Mental Health and Community Participation

Workshop Manual
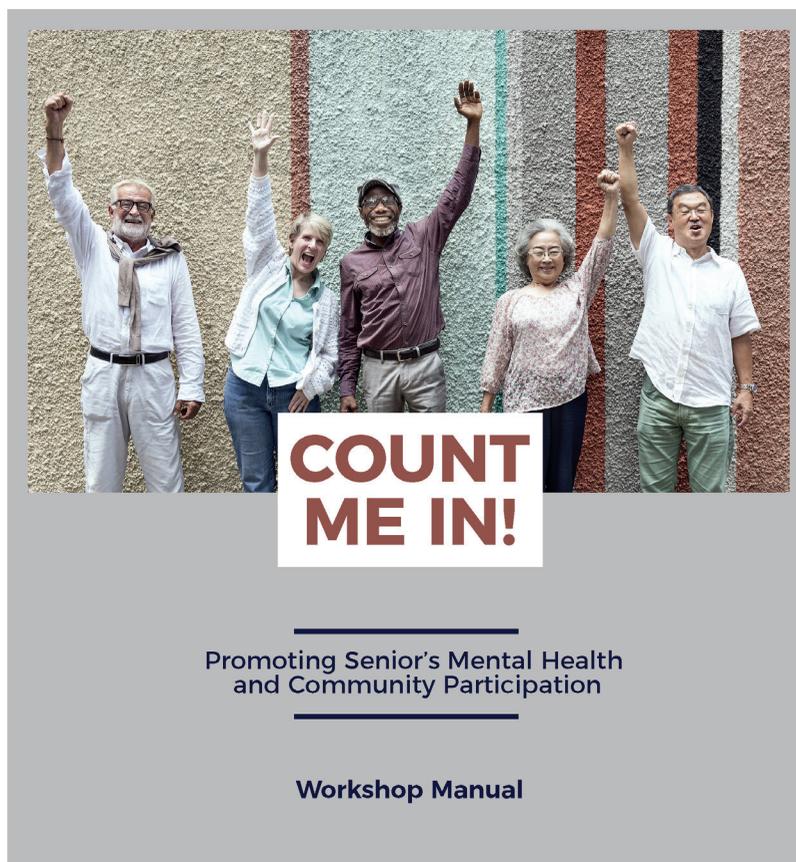
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Double ageing: the experiences of parents living with an adult with an intellectual disability

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Marie Boulanger-Lemieux and Denise Juneau
Mothers whose children have an intellectual disability

Summary by **Romane Couvrette**
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In this workshop, co-facilitators Élise Milot and Fanny Leblanc described the process of double ageing experienced by parents living with an adult child with an intellectual disability (ID). This new reality creates challenges that require an adaptation of services designed for this population. The discussion with individuals who have experiential knowledge in this area allowed participants to learn more about the challenges for both parents and ageing adults. The co-facilitators also stressed the need to plan for the future, an important step to facilitate transitions.

THE CHALLENGES OF AGEING FOR INDIVIDUALS WITH AN INTELLECTUAL DISABILITY AND THEIR PARENTS

Today, older adults with an intellectual disability (ID) are the first generation to survive their parents. In 70 years, their life expectancy has risen from 20 to 70 years.[1] As a result, these individuals form what is called an "emerging" population, creating a number of challenges in terms of services targeting this group. Although the life expectancy of older adults with an intellectual disability is significantly closer to that of the general population, their ageing process remains atypical. They can experience premature ageing, with symptoms appearing earlier than one would normally expect. "Older adults" are a social category determined by a temporal marker. In Quebec, the group is generally defined by eligibility for an old age pension—in other words, those who are 65 years of age.[2] The ageing of older adults with an intellectual disability might not match this typical ageing trajectory, which is mainly based on a person's chronological age and does not factor in life circumstances (e.g., illness, poverty, stress).[3]

One of the challenges of this new reality is the process of double ageing experienced ▶

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by the person with an ID and his or her parents. They sometimes live under the same roof and grow old together. It becomes more and more difficult for the parents of the adult with an ID to provide support. Sometimes parents aged 80 and over are the main caregivers of a middle-aged adult with an ID,[4] which is why it is so important to plan for the future.

Planning involves ensuring a secure future for the person with an ID. Planning should be carried out when the family situation is stable with no apparent risk of a crisis. This will facilitate the transition to a new stage of life. However, planning for the future is still a relatively rare practice, since Quebec has not yet developed a policy on the topic.

Planning for the future can cause anxiety to some parents and adults with an ID. A lack of information about residential options and available services for older adults with an intellectual disability, as well as legal and financial considerations, can cause worry and stress. However, when no plans have been made, individuals with an ID may experience negative consequences in terms of their well-being and social participation following the death of their parents. They will be rapidly relocated, which could mean being uprooted from

the environments in which they socialize, leading to a loss of their social network. They might also have trouble adapting to a new living arrangement that is not suited to their needs and expectations, given the lack of options adapted to the reality of this group.

WHAT IS THE SITUATION OF FAMILIES EXPERIENCING DOUBLE AGEING?

Double ageing leads to a loss of energy and patience among the parents of an adults with a ID. The two mothers who attended this workshop noted that it can be difficult to continue supporting their child and keep up with other commitments (e.g., leisure activities, job, social outings, etc.). They noted the importance of having access to other resources so as to gradually reduce the support they provide to their child and avoid burnout. However, letting go leads to feelings of guilt, since it sometimes prevents the person with an ID from doing activities, due to a lack of transport, or even from obtaining services if the mothers do not follow up with practitioners.

The mothers also said that an adult with an ID may stay in the family home for a variety of reasons. Sometimes the person is obliged to continue living with his or her parents because

of health issues. In this situation the ageing parents and child do not always have the same aspirations for the future.

WHAT ARE YOUR CONCERNS ABOUT PLANNING FOR THE FUTURE?

As social worker Valérie Slythe noted, the ageing of the general population means that those in charge of residential resources are ageing as well. Some residential resources, where residents have been living more than 20 years, are closing their doors, which means residents have to be relocated. The number of residential options available for older adults with an intellectual disability, which were already minimal, are reduced even further. It is therefore crucial to prepare carefully for this transition.

For the parents of an adult with an ID, there is a lot of concern and worry about planning for the future. Some of the questions they may ask are: Who will support my child after I die? Where will he live? How will his brothers and sisters be involved in this transition and new life stage?

All of these questions are legitimate and point to the need for careful and structured planning. However, a challenge encountered by parents ▶

during this planning process is the lack of support. The mothers mentioned that they have to find solutions on their own for the future of their child. They referred to the residential project APPART'enance, a parents' initiative that will allow individuals with an intellectual disability to live in housing adapted to their needs, which will promote inclusion and social diversity.

Siblings may also have to deal with certain impairments as they age, or may be parents themselves and therefore less available to take care of a family member with an ID.

It is also complex for practitioners to support parents through this process. Those who attended the workshop said that work needs to be done with parents to ensure an accurate perception of the person's abilities. Some parents under- or overestimate the adult's abilities, planning a life that would not be entirely suitable for their child. It is challenging for workers to support parents in a process of letting go, encouraging them to gradually delegate their role as main support provider. It is a long-term process, which is why it is so important to start planning for the future as early as possible.

SOLUTIONS AND STRATEGIES

To conclude, the facilitators presented various possible solutions and strategies. It is essential to promote the self-determination of people with an ID so that they can take part in the discussion. Planning for the future in a way that is adapted to the needs and expectations of the person inevitably requires his or her active participation in the process. Finally, it is important to develop and adapt residential resources to the needs of older adults with an ID. To date, the demand is greater than available spots. In addition, no residential options are currently adapted to the dual reality of older adults with an ID.

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Being the caregiver of an older adult living with disabilities: preliminary results of a qualitative study

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▶ Watch the webinar recording

Canada's population is ageing[1] and the prevalence of disabilities increases with age.[2] To address difficulties caused by disabilities, a number of older adults need a caregiver. This is a person who provides unremunerated assistance to someone who has difficulties related to a disability or chronic condition, or who has age-related needs.[3] Caregivers are usually members of the immediate family, such as a spouse or children, but can also be other individuals, like friends.[4]

It is not always easy to be a caregiver, as several studies have demonstrated. Caregivers can experience psychological effects such as anxiety, fatigue, irritability[5] and increased depressive symptoms.[6] They can also experience physical[7] and financial[8] effects. The use of assistive devices can help lessen the burden for caregivers and reduce certain psychological symptoms such as anxiety.[9] However, there are barriers to using assistive devices, such as cost, and the perception that it will not produce improvement.[10]

To support the caregivers of older adults using assistive technology, a vast Canadian study was launched. As part of this project, assistive technologies were defined as assistive devices (e.g., manual wheelchairs, commode chairs), services (e.g., home care, adapted transport) or political support (e.g., funding for home care or the adaptation of homes). This study is the first component of the larger project. The specific objectives of the study were to explore: 1) the experience of care provided to older adults by caregivers, particularly activities and situations considered more demanding; 2) the ways in which assistive technologies are currently incorporated into care provided.

METHODOLOGY

To meet the objectives of this study, a qualitative approach based on semi-structured interviews was adopted. The caregivers of older adults, including former caregivers, were recruited for the study. Respondents had to be at least 19 years old and were either anglophone and francophone. There were two recruitment and data collection sites: Quebec City for the francophone caregivers and Vancouver for the anglophone caregivers.

The caregivers initially had to complete a sociodemographic questionnaire. They then had to take part in a semi-structured interview about their experiences as a caregiver, notably the activities they considered to be more burdensome or enjoyable, and the assistive technologies they used during these activities. A descriptive analysis (mean, standard deviation) was carried out for the sociodemographic questionnaire and a thematic content analysis was used for the semi-structured interview.

RESULTS

A total of 59 caregivers took part in the study—20 francophones and 39 anglophones. Their average age was 64±11 years. Most of the caregivers (68%) were women of whom just over half (56%) were married. Those receiving care were mainly the spouses/husbands (47%) or parents (34%) of the caregivers. They had age-related physical or cognitive disabilities, or a diagnosis such as Alzheimer's disease, a stroke, tetraplegia, muscular dystrophy and Parkison's disease. Three main themes emerged from the interviews: activities carried out by caregivers; difficulties encountered during these activities; and ways of coping with these difficulties.

1. Activities carried out by caregivers

The caregivers in the study provided assistance in all areas of their loved one's life: activities of daily living, instrumental activities of daily living, leisure, work and mobility. They also had other responsibilities such as indirect monitoring and direct supervision of their loved one's activities. They were involved in advocating for the rights and needs of their loved one as well as their own needs. It was not possible to identify an activity considered more burdensome than others by the majority of caregivers, since the situation for each one was unique.

2. Difficulties encountered during activities

The caregivers noted various daily challenges as they assumed their responsibilities. These challenges were related to their psychological state (e.g., worries, exhaustion) and physical state (e.g., pain, fatigue). In addition, they noted that they felt overwhelmed by everything they had to do, as well as by future situations they anticipated, and that they needed external assistance. The caregivers also identified activities they found enjoyable, such as outings or sharing meals.

3. Ways of coping with difficulties

The caregivers used two main strategies to assume their responsibilities and cope with ➤
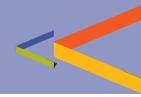
their various challenges: sharing the task with loved ones, friends or paid help, and using assistive technology. They reported that the assistive technologies helped to make certain tasks easier and led to renewed confidence. However, several barriers were also identified—notably the cost of assistive devices and difficulties in using them (e.g., learning curve, malfunctions, etc.).

CONCLUSION

This study allowed the team to better understand how complex it can be for caregivers to provide assistance to older adults with disabilities and to incorporate assistive technology. To complete this study, the first stage of the large project, the results should be compared to articles in the literature in order to identify areas of overlap and difference

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