PROVINCIAL CONSULTATION ON CAREGIVING AMONG ETHNOCULTURAL MINORITY AND ENGLISH-SPEAKING COMMUNITIES

SUMMARY

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CONSULTATION CONTEXT

In October 2020, the Quebec government adopted Bill 56, a law aimed at recognizing and supporting caregivers (PPA). This law led to the adoption of the national policy and the government action plan for caregivers (PAG-PPA). Designed for a five-year period (2021-2026), this PAG-PPA includes 61 measures distributed across four key areas.

A caregiver is defined as follows:

> *"Any person who provides support to one or more members of their entourage who have a temporary or permanent physical, psychological, psychosocial, or other disability, regardless of their age or living environment, with whom they share an emotional or family bond, or not. The support provided may be continuous or occasional, short- or long-term, and is offered on a non-professional basis, freely, knowingly, and revocably, with the aim, in particular, of promoting the recovery of the person being helped and maintaining or improving their quality of life at home or in other living environments. It can take various forms, such as transportation, assistance with personal care and household tasks (chores), emotional support, or coordination of care and services. It may also have financial repercussions for the caregiver or limit their ability to care for their own physical and mental health or fulfill other social and family responsibilities". (Article 2 of the LPPA, MSSS, 2021, p.4)*

The PAG-PPA also provided for the establishment of a team of 27 specialized caregiving coordinators: one to support caregivers in each CISSS or CIUSSS in the province, three for caregivers belonging to First Nations and Inuit communities, and one for caregivers from ethnocultural minority and English-speaking communities.

To support the activities of the latter and to consider the diverse realities of caregiving within ethnocultural minority and English-speaking communities, a follow-up committee was established. This committee, aiming to be as representative as possible of the various communities, brings together 18 members from different backgrounds, including individuals directly concerned, as well as members from the RSSS and the community sector.

The primary role of this committee is to share and discuss the realities and specificities of caregivers from ethnocultural minority and English-speaking groups (PAGEMA). Under the guidance of this committee and in collaboration with several partners, a provincial consultation was conducted in February 2023 to better define the challenges and needs of PAGEMA caregivers and the organizations that support them.

This consultation was carried out in two parts:

- A survey to outline the services provided by community organizations to PAGEMA caregivers;
- A virtual consultation to further explore the needs and challenges experienced by these two groups.

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PROFILE OF ORGANIZATIONS PROVIDING CAREGIVING SERVICES

Initially, a survey was conducted among organizations supporting PAGEMA individuals to identify the types of caregiving services they provide and to better define the clientele they serve. A total of 31 organizations completed the survey out of the 300 that were invited to participate.

These organizations operate in seven regions of the province: Montréal, Montérégie, Lanaudière, Capitale-Nationale, Estrie, and Gaspésie. Among them, ten specifically provide services to the English-speaking population, while 21 serve individuals from ethnocultural communities.

PROFILE OF THE CLIENTELE SERVED

Age	Number of Organizations
All Ages	16
65 and over	7
55 and over	2
35 and over	1
18 and over	2
Others Recently immigrated individuals	5
Issues	**Number of Organizations**
All issues combined (ID-ASD-PD, mental health, loss of autonomy, etc.)	16
Loss of autonomy	1
Mental health issues	1
Autism spectrum disorders	1
No response	6

TYPE OF SUPPORT PROVIDED BY ORGANIZATIONS

Services	Number of organizations providing these services*
Information, referral, and training	20
Identification and assessment	15
Support with administrative procedures	11
Transportation	10
Psychosocial services	9
Tax credits	6
Emergency assistance	5
Bereavement support	4
Respite and caregiving	3
Allowances	3
Support for daily tasks	3
Monitoring and supervision	2
Advocacy and influence on public policies	1
Caregiving workshops, lending library, and telephone assistance	2

* Note: Respondents could indicate all types of services provided by their organization.

RESULTS OF THE CONSULTATION MEETING

The second part of the provincial consultation aimed to discuss the issues and needs of PAGEMA individuals in Québec. The meeting brought together 85 participants.

Among these individuals,

- 18 are from English-speaking communities, including two who identify as caregivers,
- 40 belong to ethnocultural communities, including two who identify as caregivers,
- 27 works in the health and social services network (RSSS).

They are distributed across 11 regions of the province: Montréal, Montérégie, Lanaudière, Laurentides, Laval, Estrie, Capitale-Nationale, Abitibi-Témiscamingue, Gaspésie–Îles-de-la-Madeleine, Saguenay–Lac-Saint-Jean, and Mauricie–Centre-du-Québec.

Participants were assigned to seven workshops, five conducted in French and two in English. The discussions were recorded, then analyzed and categorized based on the two proposed themes. The results are detailed below.

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KEY CAREGIVING CHALLENGES FOR ETHNOCULTURAL AND ENGLISH-SPEAKING COMMUNITIES

Unanimously, the participants indicated that the caregiving experience within minority communities differs from that of the majority population in several ways. This difference is primarily rooted in barriers to accessing services and resources, which stem from cultural, informational, financial, and geographical accessibility challenges.

Cultural Accessibility Challenges

Participants noted a lack of openness to cultural differences and diversity among some service providers, which negatively affects their interactions with PAGEMA individuals. According to some, this lack of awareness of cultural differences can lead to misunderstandings of the challenges faced by caregivers. Additionally, due to language barriers, important information may be lost in the absence of translation or interpretation services.

Financial Accessibility Challenges

Difficulties in accessing stable, paid employment for many individuals from ethnocultural minority groups increase the financial insecurity already caused by caregiving responsibilities. Additionally, there is a lack of financial support to access services, particularly respite care. The assistance provided through the employment voucher program is often depleted solely due to this high demand. For organizations supporting PAGEMA individuals, obtaining adequate and recurring funding remains very challenging, which limits the scope of services they can offer.

Information Accessibility Challenges

Participants reported that PAGEMA individuals often feel excluded from decisions concerning their loved ones. They wish to be actively involved in decision-making and to share their experiential knowledge while respecting the expertise of healthcare professionals. They also struggle to access information about available services and to navigate the healthcare system (e.g., scheduling appointments, follow-ups, etc.). These challenges are even more pronounced for those who have recently immigrated to the country and for those who communicate in English.

Psychosocial Challenges

Isolation and difficulty in building a social network, especially for newly immigrated individuals, exacerbate several of the challenges mentioned and may even impact mental health issues. Furthermore, the taboos surrounding mental health within certain ethnocultural communities limit the willingness of PAGEMA individuals to seek help.

Geographical Accessibility Challenges

Outside major urban centers, the availability of services is more limited for PAGEMA individuals, who may face complex issues and isolation. Participants in the consultation noted that PAGEMA individuals are particularly affected by transportation difficulties within their communities in remote areas, which exacerbates their isolation and reduces their access to services.

KEY NEEDS IN CAREGIVING SUPPORT FOR ETHNOCULTURAL AND ENGLISH-SPEAKING COMMUNITIES

The needs identified by the participants during the consultation align with the challenges previously presented. These include needs related to cultural recognition, financial support, and access to information.

Needs for Information

To reduce burnout among PAGEMA individuals, multilingual communication and training tools would support the recognition and self-identification of caregivers within the health and social services network (RSSS) and help them navigate toward appropriate services. The implementation of key worker programs or peer navigators would be essential to guiding PAGEMA individuals through their service journey. Multilingual communication tools and training programs would facilitate access to information.

Psychosocial Needs

Access to psychosocial support for PAGEMA individuals should be made easier to help them overcome isolation. Information aimed at reducing the stigma surrounding mental health issues should be shared with PAGEMA individuals. Collaboration with religious leaders, who are key figures within many ethnocultural communities, has been identified as a strategy to address this need.

Needs for Cultural Recognition

Cultural diversity should be better acknowledged and integrated into the support services available to caregivers. Participants emphasized the need for service providers to receive enhanced training in intercultural communication and intervention. Additionally, many stressed the importance of ensuring service accessibility in individuals' native languages, either through interpreters or the translation of essential documents. Community organizations can play a key role in facilitating this process.

Financial Needs

It is important to support the reception and adaptation process of newly immigrated individuals to facilitate their access to employment, which would generally provide greater financial and social security for PAGEMA individuals.

The financial support available to organizations working with PAGEMA individuals—particularly for advocacy, guidance, community liaison, document translation, and interpretation—should also be increased. Representatives of these organizations highlight the need for better access to project funding opportunities that would enhance their financial resources.

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CONCLUSION

Caregiving within ethnocultural communities presents numerous challenges that require continuous and significant efforts from policymakers to enhance health equity. Future research is encouraged to better understand the realities and specific needs of PAGEMA individuals, which would help improve their access to the services and resources they require.

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