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

Final Report

Kettly Pinchinat Jean-Charles

SHERPA UNIVERSITY INSTITUTE

Integrated Health
and Social Services
University Network
for West-Central Montreal
Québec

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We would like to thank all the ethnocultural and English-speaking organizations, as well as the caregivers who participated in this consultation. Our gratitude also extends to the members of the follow-up committee, the caregiving coordinators from CISSS and CIUSSS who were not part of the committee, and the partners of the SHERPA University Institute who contributed to the completion of this consultation and report.

LIST OF ABBREVIATIONS AND ACRONYMS

ACCÉSSS	Alliance of Cultural Communities for Equality in Health and Social Services
CCOMTL	CIUSSS-Centre-Ouest-de-l'Île-de-Montréal
CHSSN	Community Health and Social Services Network
CISSS	Centre intégré de santé et de services sociaux - Integrated Health and Social Services Center
CIUSSS	Centre intégré universitaire de santé et de services sociaux - Integrated University Health and Social Services Center
DI-TSA-DP	Déficience intellectuelle, troubles du spectre de l'autisme, déficience physique - Intellectual Disability, Autism Spectrum Disorders, Physical Disability
IU SHERPA	Institut universitaire SHERPA - SHERPA University Institute
LPPA	Act to Recognize and Support Caregivers
MIFI	Ministry of Immigration, Francisation, and Integration
MSSS	Ministry of Health and Social Services
PAG	Government Action Plan
GAP-CG	Government Action Plan for Caregivers
CG	Caregiver
PAGEMA	Caregivers from Ethnocultural Minority or English-Speaking Groups - Proches aidant·es issu·es de groupes ethnoculturels minoritaires ou de langue anglaise
PRAIDA	Regional Program for the Reception and Integration of Asylum Seekers
RSSS	Health and Social Services Network

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1. CONTEXT

The Act to Recognize and Support Caregivers (LPPA) (Revised Statutes of Quebec (RLRQ), chapter R-1.1), adopted and sanctioned by the National Assembly in October 2020, illustrates the government's strong commitment to supporting caregivers (CGs) in their role, in order to ensure their health, well-being, and quality of life. This law is structured around the national policy for caregivers and the resulting government action plan. The Government Action Plan for Caregivers (GAP-CG) spans a five-year period (2021–2026) and includes 61 measures distributed across four key areas. These measures enable the government to address the many aspects of caregiving within Quebec society. Thus, the definition of a "caregiver" provided by the Ministry of Health and Social Services aims to be as inclusive as possible, encompassing the diverse realities of the caregiver–care recipient relationship:

> "*Any person who provides support to one or more people in their circle who have a temporary or permanent disability of a physical, psychological, psychosocial, or other nature, regardless of their age or living environment, with whom they share an emotional or familial bond — or not. The support provided may be continuous or occasional, short-term or long-term, and is offered on a non-professional, voluntary, informed, and revocable basis, with the goal of promoting the care recipient's recovery, maintaining, and improving their quality of life at home or in other living environments. This support can take many forms, such as transportation, assistance with personal care and household tasks, emotional support, or coordinating care and services. It may also have financial impacts on the caregiver or limit their ability to take care of their own physical and mental health or fulfill other social and family responsibilities.*" (Article 2 of the LPPA, MSSS, 2021, p. 4)

1.1 BETTER UNDERSTANDING THE ISSUES AND NEEDS OF CAREGIVING WITHIN ETHNOCULTURAL MINORITY AND ENGLISH-SPEAKING COMMUNITIES

The GAP-CG identifies the need to work collectively to promote the integration of actions within communities while recognizing the specific needs and issues that arise from them. Caregiving is experienced in different ways depending on a person's living environment or their belonging to one or more groups considered as minorities. These groups may require tailored support based on their language or culture. Measure 5 of the action plan proposes the creation of regional caregiving coordination positions. Through this measure, 27 individuals were appointed as specialized caregiving coordinators across Quebec's regions. One of them will act as a liaison for caregivers from ethnocultural and English-speaking communities, while three others will work with First Nations and Inuit (FNI) communities (MSSS, 2021). This report is part of the ongoing efforts to better understand the diverse realities of caregiving within ethnocultural and English-speaking communities.

To include and consider a wide range of experiences and perspectives on this complex and multifaceted issue, *a caregiving advisory committee for ethnocultural minority and English-speaking groups was established*.

The committee is composed of 17 members from diverse backgrounds, representing various aspects of the issues surrounding caregiving within ethnocultural minority and English-speaking communities:

- The manager of the University Institute for Ethnocultural Communities (SHERPA UI), under the Directorate of Academic Affairs and Research Ethics at the Integrated University Health and Social Services Center (CIUSSS) of the Centre-Ouest-de-l'Île-de-Montréal (CCOMTL);
- The provincial coordinator specializing in caregiving for ethnocultural minority and English-speaking communities — assigned to SHERPA UI;
- A member of the Caregiving Observatory;
- The eight regional coordinators specializing in caregiving, representing the following regions: Montréal, Montérégie, Laval, Outaouais, Capitale-Nationale, Lanaudière, Laurentides, and Estrie;
- The head of the intercultural approach committee in Laval;
- The provincial advisor for ethnocultural and English-speaking communities at L'Appui;
- The national coordinator specializing in combating elder abuse within English-speaking and cultural communities;
- A member of the Alliance of Cultural Communities for Equality in Health and Social Services (ACCÉSSS);
- A member of the Regional Program for the Reception and Integration of Asylum Seekers (PRAIDA);
- A member of the Community Health and Social Services Network (CHSSN)
- A member of the CCOMTL's Intellectual Disability, Autism Spectrum Disorder and Physical Disability (ID-ASD-PD) Program Access Desk

The primary mandate of this committee is to monitor the implementation of the GAP-CG concerning the realities and specific needs of caregivers from ethnocultural minority and English-speaking groups (PAGEMA) across the province.

The objectives of this consultation were to:

- Promote caregiving within ethnocultural and English-speaking populations to encourage their involvement;
- Understand the key issues and needs that arise in caregiving for PAGEMA individuals;
- Collaborate with community organizations that support PAGEMA individuals;
- Explore potential solutions based on the data collected, in partnership with these organizations.

As part of this mandate, a provincial consultation with organizations serving these communities was conducted in February 2023, in collaboration with caregiving coordinators, partners from the health and social services network (RSSS), and the Ministry of Health and Social Services (MSSS).

2. BRIEF OVERVIEW OF ORGANIZATIONS SERVING PAGEMA INDIVIDUALS

This section presents the results of the survey conducted among organizations serving individuals from ethnocultural and English-speaking communities. The survey aimed to provide a brief overview of the caregiving services offered by the participating organizations. It included a section to identify the organization, and two questions focused on the main caregiving services provided and the profile of the clientele served. The questions are detailed in Appendix 6.1 of the report[1].

UAn introductory and invitation email was sent by CISSS and CIUSSS coordinators to 300 organizations, primarily identified through a list from the Ministry of Immigration, Francisation, and Integration (MIFI) and another list of organizations affiliated with CHSSN. The survey response collection took place over four weeks, shortly before the consultation.

In total, 31 organizations completed the survey, representing the following regions: Montréal, Montérégie, Laurentides, Lanaudière, Capitale-Nationale, Estrie, and Gaspésie. Among them, ten primarily provided services to the English-speaking population, while 21 specifically targeted individuals from ethnocultural communities.

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[1] The questions in this survey are inspired by the work conducted by the Center for Research and Expertise in Social Gerontology (CREGÉS) in 2020, published in the report "*Between Services, Best Practices, and Measures: A Perspective on Support for Caregivers. Final Report. Overview of Services and Support Measures for Caregivers*."

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
Respite Care	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.

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	6
Recently immigrated individuals, individuals in low-income situations	5
Issues	**Number of Organizations**
Loss of autonomy	1
Mental health issues	1
Autism spectrum disorders	1
All issues combined (ID-ASD-PD, mental health, loss of autonomy, etc.)	16
No response	6

Note: Respondents could identify other sociodemographic characteristics of their clientele..

3. RESULTS OF THE CONSULTATION

The invitation to participate in the second phase of the consultation was sent to 300 organizations across the province that specifically serve people from ethnocultural and English-speaking communities. Organizations from the following regions participated in the consultations: Montréal, Montérégie, Lanaudière, Laurentides, Laval, Estrie, Capitale-Nationale, Abitibi-Témiscamingue, Gaspésie–Îles-de-la-Madeleine, Saguenay–Lac-Saint-Jean, and Mauricie–Centre-du-Québec. The event brought together a total of 85 participants, divided as follows: 18 people from English-speaking communities, including two who identified as caregivers (CG), 40 members of ethnocultural communities, including two who identified as caregivers, and 27 people working within the health and social services network (RSSS). The last group included specialized caregiving coordinators, development advisors from L'Appui, members of the IU SHERPA, and caregiving representatives from the MSSS.

Initially, a presentation of the GAP-CG was given. Seven bilingual workshops, in French and English, were then offered. Of these, five workshops targeted French-speaking ethnocultural communities, and two were tailored to English-speaking communities. The consultation focused on the issues and needs faced by PAGEMA individuals (Annex 6.2).

The selected themes reflect a consultation held in Laval in December 2022 on caregiving and the fight against mistreatment, involving organizations working within ethnocultural and English-speaking communities. This consultation brought together 27 members of organizations serving these two populations and five members of the RSSS, including two coordinators specialized in caregiving, two coordinators specialized in combating mistreatment, a provincial advisor from l'Appui, and a social worker from the region. The results of this initial regional consultation are included in the presentation of the discussions stemming from the provincial consultation below.

3.1 MAIN ISSUES RELATED TO CAREGIVING FOR ETHNOCULTURAL AND ENGLISH-SPEAKING COMMUNITIES

All participants in the consultation agreed that the experience of caregiving within communities considered as minorities can differ from that of the majority population. According to the feedback collected, this situation is mainly linked to difficulties in accessing caregiving services and resources. These difficulties arise from cultural, informational, financial, and geographical challenges.

3.1.1 Cultural Accessibility Issues

Some participants reported observing a lack of openness to difference and cultural diversity among certain service providers. This factor can negatively impact interactions between providers and service users. The lack of intercultural competencies may lead to misunderstandings of the issues experienced by PAGEMA individuals. These situations often push PAGEMA individuals to adapt the way they express their needs based on the beliefs and worldviews of providers from a culture different from their own.

Reported example:

> *“Healthcare workers are not well aware that caregivers from ethnocultural communities have a different conception of family, which leads to misunderstandings and frustrations on both sides. In remote areas, cultural accessibility is even more limited due to the low ratio of immigrants. It seems even harder for healthcare staff in these regions to adapt to a culture different from their own. It has been observed that staff do not listen enough to understand the caregiver”.*

Language barriers also pose a significant challenge for some PAGEMA individuals.

Participants noted that, at times, allophone caregivers need to be accompanied by a family member who speaks French to act as an interpreter. They also observed that this interpreting role often falls to younger family members who are more likely to master the language of their new home than their parents. For English-speaking caregivers, several difficulties were reported regarding service continuity in English. Some information gets lost due to the lack of translation services. Additionally, participants mentioned that the politeness factor common in anglophone culture can complicate matters. Many caregivers, lacking access to services in English, may pretend to understand to be polite — even when they do not.

Furthermore, respondents shared experiences where caregivers requested services in English but received negative responses. These negative experiences sometimes led them to give up on seeking help again. As a result, PAGEMA individuals may be less inclined to seek assistance from the health and social services system (RSSS), leading to negative consequences, such as an increased risk of developing health problems

Reported examples:

> *“When the person requests services, they are told: ‘You have enough services, you don’t need more...’ The response can be rude, and then the misunderstanding of the answer*

> *adds to the frustration“.*

> *“The professional starts interacting in English and ends in French, leaving the caregiver feeling lost”.*

Moreover, when asking for help, PAGEMA individuals might hesitate to request multiple types of services at once, despite their numerous needs. They would limit themselves to a single service out of fear of receiving nothing at all. This phenomenon makes them more vulnerable to burnout. According to respondents, other culture-specific aspects also create barriers to accessing services. In particular, participants explained that many PAGEMA individuals are deeply concerned about their loved ones' health, especially when it comes to elderly family members, and wish to keep them at home for as long as possible. This could lead to resistance to receiving any form of external help or a tendency to rely solely on their community, which in turn limits access to services and places a significant burden on caregivers.

3.1.2 Information Accessibility Issues

Another aspect raised by consultation participants is the lack of trust that PAGEMA individuals have toward the healthcare system. They often feel excluded from intervention plans, and essential information about their loved ones is not always accessible to them, especially during the often brief visits with healthcare professionals. This has led to dissatisfaction and a feeling of lack of transparency from care providers.

Participants also reported that caregivers from recent immigrant backgrounds and those seeking asylum not only face difficulties accessing information but also navigating the services offered within the health and social services network (RSSS). The same applies to English-speaking caregivers who, according to participants, struggle to find the necessary information online. As one participant noted: “*Word of mouth is more accessible and available than information on the web.*”

On one hand, this limited knowledge of existing resources and how to access them reduces the likelihood that caregivers will even try to seek information. On the other hand, when they do try but cannot find what they need, they often feel guilty toward their loved ones. As a result, they tend to rely solely on their own resources, which can lead to caregiver burnout.

3.1.3 Financial Accessibility Issues

Many respondents highlighted that certain PAGEMA individuals, particularly asylum seekers, are not eligible for family allowances. Difficulties accessing employment and having their diplomas recognized result in long waiting times before they can enter the labor market. Their financial insecurity can worsen when they find themselves caring for a loved one.

Participants also reported that caregivers from both communities face significant challenges in finding home care providers to get some respite. Several factors contribute to this issue: a lack of specific funding for respite care, the exhaustion of employment-voucher services, and insufficient background checks. These factors create a lot of unpredictability in caregivers' lives and increase their stress levels — sometimes even leading to mental health issues for some individuals

Reported examples:

> *"The person may forget to provide the requested information because they are too stressed".*

> *"Some caregivers have to reduce their working hours, so why can't they be paid through the service employment voucher?"*

Participants also pointed out the lack of recurring funding and time for community organizations providing services to ethnocultural communities, which struggle to develop tailored activities or services.

3.1.4 Geographic Accessibility Issues

The diversity of services available from one region to another is highlighted by many respondents. In remote areas, the possibility of receiving culturally and linguistically appropriate services is even more limited than in larger cities (e.g., fewer French classes, less help for the most vulnerable, etc.). The lack of access to public transportation services in rural areas would also have a significant impact on PAGEMA individuals. These accessibility gaps would reinforce the desire for some people to move closer to larger cities to gain better access to certain services.

3.1.5 Psychosocial issues

Another issue identified by participants that exacerbates the vulnerability of PAGEMA individuals is the social isolation experienced by many of them. Newly arrived individuals may struggle to create support networks within their community. Similarly, English-speaking caregivers looking after an elderly loved one may sometimes find it difficult to participate in community programs that could help break their isolation. Furthermore, when faced with mental health issues, some PAGEMA individuals may be less likely to seek services due to the existing taboos around these issues within their communities.

3.2 MAIN CAREGIVING NEEDS FOR ETHNOCULTURAL AND ENGLISH-SPEAKING COMMUNITIES

The needs highlighted by participants reflect the accessibility challenges mentioned in the previous section. These needs have been grouped as follows: the need for cultural recognition, the need for financial support, and the need for access to information.

3.2.1 Need for Cultural Recognition

Participants agree that there is a significant need for cultural recognition among PAGEMA individuals. Some participants suggest that recognizing cultural diversity and the importance of cultural aspects should be better integrated into caregiving services. In this regard, participants recommend providing more support to RSSS establishments on best practices to promote communication between caregivers and people from ethnocultural minority communities. Cultural diversity is an essential factor to consider to strengthen communication and foster openness to others. Therefore, offering more training on intercultural interventions to RSSS professionals is recommended to raise awareness of the realities faced by PAGEMA individuals.

According to the feedback collected, PA-

GEMA individuals have a strong need to feel heard by RSSS staff. In this context, increasing access to services in PAGEMA individuals' native languages, providing translation services, or enhancing existing services are solutions to prioritize. Some participants pointed out that these services could be offered by community organizations. Multilingual communication tools and multilingual training programs could be developed. Additionally, participants expressed the need to improve access to French language courses and interpretation services for allophone caregivers.

For English-speaking communities, services in English should be considered in respect of their rights (e.g., respite care in English, English-language documents, and staff who can greet them in English). According to respondents, when caregivers have to act as interpreters between RSSS staff and their loved ones, it adds to their responsibilities. The challenge is even greater for young caregivers who take on interpretation duties for their relatives. This additional responsibility deserves more support.

3.2.2 Needs for Information

In general, considering the various findings raised during this consultation, access to information should be improved to facilitate processes and increase CG knowledge of available services. Respondents believe that PAGEMA individuals should receive swift support to help them self-identify in this role, preventing burnout and guiding them to appropriate resources (e.g., healthcare, language classes, etc.). Given the specific challenges related to PAGEMA integration, they should receive more assistance with legal, administrative, and health procedures.

Additionally, they could benefit from greater support in information technologies to enhance their ability to navigate digital systems and access online information. According to respondents, there should be designated guides within the RSSS, acting as key contacts or peer navigators, to help PAGEMA individuals understand service pathways and navigate the healthcare system structure (e.g., CLSC, GMF). This system would also direct them to resources and organizations that offer services tailored to their needs, including services in their native language).

Reported example:

> *"Knowing that autism programs differ between childhood and adolescence, parents should be directed towards the programs best suited to the evolving needs of the people they care for. It is already difficult for non-immigrant majority CGs to navigate the system; it is even more challenging for CGs from ethnocultural minority backgrounds."*

Participants suggested that a detailed kit of health and social services should be provided to people with recent immigration experiences. Some participants indicated that this information should also be available in English. At the same time, screening strategies should be implemented when PAGEMA individuals are hard to reach. To achieve this, partnerships should be established with community organizations working with this population, consulting regional communities to better understand their realities and needs, and promoting resource sharing between regions. To reduce the sense of exclusion from the healthcare system felt by some PAGEMA individuals, participants proposed that the Ministry of Health and Social Services conduct information campaigns highlighting their commitment to addressing the needs of caregivers from ethnocultural and English-speaking communities.

3.2.3 Financial Needs

In terms of financial support, respondents expressed the expectation that PAGEMA individuals should be able to have paid employment to meet their needs. Structural changes to facilitate access to employment were highlighted as desirable forms of support, as well as the possibility for PAGEMA individuals to benefit directly from the "Chèque-emploi service" program when they need to reduce their working hours to care for their loved ones.

To help PAGEMA individuals better meet their financial needs, participants emphasized the importance of supporting their overall adaptation and integration. They recommended increasing support for community organizations that assist PAGEMA individuals, especially by developing more project funding opportunities. Participants pointed out that when these project calls happen during summer vacations, it becomes even harder for organizations — already struggling to stay afloat — to participate.

Additionally, participants stressed the need to increase financial support for community organizations that help newcomers integrate into the job market, advocate for rights, guide caregivers, connect them to their communities, and provide document translation or interpretation services.

3.2.4 Psychosocial Needs

The collected statements highlight the urgent need to address the social isolation experienced by PAGEMA individuals, to provide them with support and prevent them from facing numerous negative consequences related to caregiving. Mechanisms should be developed to identify PAGEMA individuals and quickly direct them to appropriate resources.

According to participants, it would be important to establish partnerships with more specialized community organizations (e.g., relevant religious communities for PAGEMA individuals) that have already built a relationship of trust with them.

Reported example:

> *"It would have been helpful to have religious leaders at the consultation table to relay the message and avoid contradictory messages".*

IIt is also necessary to offer psychosocial support to PAGEMA individuals who are grieving, in a post-caregiving situation, refugees, or experiencing family conflicts.

For PAGEMA individuals with mental health issues, the idea of creating dedicated spaces for sharing was suggested to help reduce the stigma around this issue and build their trust in healthcare professionals.

At the same time, care and service providers should receive appropriate training to better understand the migration journey of PAGEMA individuals

4. PROPOSED SOLUTIONS AND CONCLUSION

This report outlines the main results from a province-wide consultation on the issues and needs of caregivers from ethnocultural and English-speaking communities. Based on the feedback collected, the following potential solutions have been identified:

1) All healthcare and social services network (RSSS) practitioners should be trained to better intervene in intercultural contexts. This training should be based on a reflective approach that supports them in their intervention practices with this clientele.

2) Services should be adapted to the language of PAGEMA individuals, considering interpretation for allophone caregivers and the translation of documents into English for English-speaking caregivers.

3) A support service provided by resource persons within the health and social services network (RSSS), such as a designated caseworker or peer navigators, should be promoted to help PAGEMA individuals find information, navigate the RSSS, and access the resources they need.

4) PAGEMA individuals should receive financial support to address financial insecurity, which makes them even more vulnerable to the negative consequences of caregiving.

5) Partnerships should be essential between the RSSS and community organizations working with PAGEMA individuals, as this would help to holistically identify the needs of these caregivers.

All in all, caregiving in a multicultural context raises many challenges that require constant and considerable effort. The action paths proposed during this consultation — such as training for professionals to work in intercultural contexts, improving access to information, developing tailored services, providing support through resource persons within the RSSS or the community, and increasing access to interpreting services — are promising avenues to explore.

Additionally, literature reviews compiling scientific and empirical studies on these issues are essential to better understand caregiving for PAGEMA individuals. The research project linked to Measure 30 of the GAP-CG will provide a deeper understanding of these realities and propose strategies to promote better access to services and resources for PAGEMA individuals, with the goal of improving their health and well-being.

5. REFERENCES

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Online

6. ANNEXES

6.1 SURVEY QUESTIONS ON CAREGIVING AMONG ETHNOCULTURAL AND ENGLISH-SPEAKING ORGANIZATIONS

1. Among these caregiving services defined by the Centre for Research and Expertise in Social Gerontology (CREGÉS)[1], which ones do you offer? (check with an X):

Services	**Name of the organization and responsible person**	**X**
Respite and Caregiving / Monitoring and supervision		
Psychosocial Services		
Information		
Training		
Respite Care		
Support for daily tasks		
Support with Administrative Procedures		
Psychological consultation services		
Support and self-help groups		
Bereavement support		
Tax Credits		
Allowances		
Cash for Care		
Transportation		
Others		
Autres		

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[1] Van Pevenage, Isabelle et Margaux Reiss (2020). Entre les services, les bonnes pratiques et les mesures : mise en perspective du soutien aux personnes proches aidantes. Montréal, Québec: Integrated Health and Social Services University Network for West-Central Montreal , Centre for Research and Expertise in Social Gerontology. 140 pages.

2. If you offer caregiving services, what is the profile of your clientele (check with an X)?

Clientele	**x**
Name of the organization and responsible person	
Seniors (65 years and older)	
Adults (19-64 years old)	
Young adults (18 years and older)	
Youth (18 years and younger)	
People with intellectual disabilities	
People with autism spectrum disorders	
People with physical disabilities	
People with mental health issues	
People with loss of autonomy	
People with substance use dependencies	
People in bereavement	
LGBTQ+ individuals	
Others (please specify)	

6.2 WORKSHOP FACILITATION GUIDE: PROVINCIAL CONSULTATION OF ORGANIZATIONS WORKING WITH ETHNOCULTURAL AND ENGLISH-SPEAKING COMMUNITIES - WORKSHOPS

Date: February 23, 2023

Time: 9 AM - 12 PM

Group Number:

Workshop Agenda

The discussions will last 40 minutes (20 min/question).

Facilitator:

1. Conduct a quick roundtable (each person's name and the organization they represent).
2. Send the notes to the responsible person at the end of the workshop.

Note-taker:

1. Write down responses in the designated spaces.
2. Present your notes in plenary for 3 minutes

1 - What are the main issues you identify regarding caregiving for ethnocultural and English-speaking communities?

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2 - What are the main needs you identify regarding caregiving for ethnocultural and English-speaking communities?

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