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Access to Justice in English Project

Senior Care Services in English in Quebec

Executive Summary of Final Report
and
Recommendations to the
Ministry of Health and Social Services

March 31, 2023

ACCESS TO JUSTICE IN ENGLISH

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Introduction

QCGN's Access to Justice in English Project ("the AJEQ Project") identifies and researches areas where the English-speaking community are experiencing difficulty accessing their rights, with a strong focus on community access to public services. It leverages information as a strategic resource to understand and improve access to justice in English in Quebec.

The second issue studied by the Project was **access to health care services for seniors in English through Quebec's SAPA program (*Soutien à l'autonomie des personnes âgées*)**. The issue was selected on the basis of prior research conducted by the AJEQ Project, including a population survey of 1,601 English-speaking Quebecers conducted by Quorus Consulting Group in September 2021, which revealed that hospitals and CLSC care were among the most widely accessed provincial government services by English-speaking Quebecers, and that more than one in three English-speaking Quebecers who had accessed these services in the past two years found it difficult to do so in English. The issue of senior care was under close scrutiny at the time the issue was selected, in the wake of the COVID-19 pandemic and the subsequent coroner's inquiry into pandemic-related deaths at seniors' residences across Quebec.

The Access to Justice project acknowledges that the pandemic posed a unique set of circumstances that extended beyond language, and that other pressures on the health care system in general and on senior care services in particular can result in limited services for all Quebec seniors, regardless of language preference. At the same time, our research has found that a combination of policy, organizational, budgetary, and demographic circumstances has resulted in multiple concrete challenges to accessing care services in English, which may well be exacerbated in years to come.

Our methodology included a thorough investigation of the issue along four main lines of inquiry: the relevant policy and legal framework; the internal organization and administration of services; how English-speaking seniors and their caregivers navigate the SAPA program's assorted senior care services from at-home care to placement in long-term care; and firsthand population experience obtained through quantitative and qualitative research.

This investigation uncovered several **systemic barriers to English-speaking seniors accessing SAPA services in English**, in CLSCs, long-term care facilities, and other health care institutions across Quebec. We then validated these findings through a targeted outreach to 45 organizations and users' committees between August and November 2022, yielding some 16 informational interviews.

The present document contains an **executive summary of our top findings**, informed by our research and validation process. This is followed by **13 recommendations** presented by QCGN's AJEQ Project to the Ministry of Health and Social Services (MSSS) for further consideration.

Methodology

Our findings are based on a mixed methodology combining the following strands of research:

- A review of the existing framework of law and policy pertaining to provincial health care services and official language minority rights;

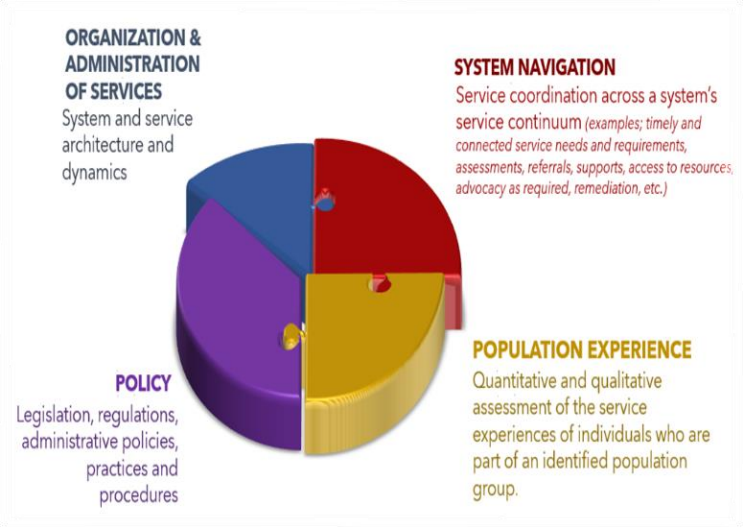
- An external legal opinion submitted by Ménard Martin Avocats on June 13, 2022;

- An analysis of available literature focusing on the organizational, administrative, and systemic practices of Quebec's MSSS and health care institutions (this may be found in the full research report);

- Primary research on population experience of senior care services, including:

    - a series of 16 qualitative interviews conducted by the AJEQ Project team of community-based organizations and CI(U)SSS users' committees across various regions of Quebec that provide assistance to seniors and their families; and

    - a quantitative and qualitative survey of N=923 English-speaking Quebecers, including n=633 seniors aged 60+ and n=290 caregivers to a senior aged 60+, conducted by Léger from November 29, 2022 to January 17, 2023.



These findings served to complete the four dimensions of the information strategy that governs the structure of the final report: Policy, Organization & Administration of Services, System Navigation, Population Experience (see Fig. 1, above).

Research Highlights

This section provides a high-level summary of the knowledge obtained within each dimension of the information strategy that governs the structure of the final report.

Dimension 1: Policy

The relevant sources governing the policy and legal implications of accessing senior care services in English in Quebec are the:

- *Constitution Act*, *1867*;
- *Canada Health Act*;
- Canadian *Charter of Rights and Freedoms* and Quebec's *Charter of Human Rights and Freedoms*;
- *Act respecting health services and social services* (*AHSSS*);
- *Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies* (*AMHSSN*);
- *Charter of the French Language* (*CFL*), including amendments thereto through the *Act respecting French, the official and common language of Québec* (Bill 96);
- Relevant policies of Quebec's Ministry of Health and Social Services (MSSS), including the:
    - *Guide pour l'élaboration du programme d'accès aux services de santé et aux services sociaux en langue anglaise* (*Guide*);
    - *Politique relative à l'emploi et à la qualité de la langue française*;
    - *Orientations ministérielles concernant la pratique de l'interprétariat*;
    - *Politique d'hébergement et de soins et services de longue durée*;
    - *Politique de soutien à domicile*;
    - *Orientations ministérielles sur les services offerts aux personnes âgées en perte d'autonomie*;
    - *Politique nationale pour les personnes proches aidantes*; and
- International human rights treaties, such as the *International Covenant on Civil and Political Rights*.

Language is a prohibited ground of discrimination under the right to equality of section 10 of Quebec's *Charter*.

Section 15 of the *AHSSS* guarantees English-speaking persons the right to receive health care services in English in Quebec **where the human, material, and financial services are available**.

- The *CFL* provides that in designated health care institutions, all services must be provided in French and English, whereas in indicated health care institutions, only certain services outlined in the institution's Access Program must be provided in English.
    - In designated institutions, employers are allowed to require a reasonable level of English-language proficiency in their job postings.
    - Following Law 96's amendments to section 46 of the *CFL*, employers must now take all reasonable means to **avoid imposing a requirement of English-language proficiency** for personnel working in Quebec's health care institutions, and must justify such a requirement to the MSSS whenever imposed.

In its 2006 and 2018 editions, the *Guide* does not ensure that health care services provided in English in public institutions that were transferred to third-party service providers (which do not have the legal status of a designated bilingual[1] or indicated institution) would continue to be offered in English.

- This problem was exacerbated following the 2015 health care reform and the enactment of the *AMHSSN*, where many once bilingual services were transferred to third-party agencies that operate beyond the regulatory scope of Access Programs and no longer offer these services in English.

MSSS language policy provides that health care personnel must first address patients in French, but **can continue communicating in English upon the patient's request**.

- Currently, documents (including pamphlets, booklets, and brochures) can only be translated into English with MSSS authorization and where requested for individual health care users.
- On websites of health care institutions, content must be "majoritarily in French". Portions of the website translated into English must be on a separate part of the site. Also, translation of a webpage into English does not permit translation of documents linked on that webpage into English.

MSSS language policy provides that **any person facing a language barrier must have access to an interpreter whenever possible**, if the barrier would compromise the quality of the health care service being provided or the health of the patient. However, in-depth interviews conducted with community and health care system stakeholders revealed low to no access to professional interpreters for English-speaking seniors in a hospital setting, leaving seniors to rely on more bilingual family members or a member of staff who happens to speak English, if one is available. One CIUSSS Users' Committee clarified that interpretation services were for patients who speak a language other than French or English, though this is not made clear in MSSS language policy.

An English-speaking user may **file a complaint with the Complaints Commissioner** of the health institution **if they are not satisfied with the services rendered and received**. Any user who is unable to obtain services in English under an Access Program could file a complaint against the institution, a staff member, or a health care professional. This being said, several stakeholders interviewed spoke of seniors' reluctance, regardless of language preference, to file such a complaint for fear of negative repercussions on their ability to access care services in future. Thus, the authors hypothesize that a low number of formal complaints by English-speaking seniors is not indicative of a lack of barriers to accessing senior care services in English.

- Were a complaint to be filed, the Commissioner would determine whether the situation resulted in the failure to respect the rights of one or more users. If so, the Commissioner could issue recommendations to the institution's board of directors.
- If the institution's Complaints Commissioner were to reject the user's complaint, the patient would then have the right to file a complaint with the Ombudsman. The Ombudsman has authority over all ministries and public organizations, allowing it to intervene on aspects of the complaint that go beyond respect of users' rights.

[1] For the purpose of this report, bilingual means services offered in French and English.

Dimension 2: Organization and Administration of Services

The MSSS organizes its services into 22 Integrated (University) Health and Social Service Centres – CI(U)SSs – that govern and administer health care services across Quebec. Each CISSS or CIUSSS holds jurisdiction over a particular geographic territory.

Among the three advisory committees overseen by the MSSS is the Provincial Access Committee for Health and Social Services in English (*Comité provincial pour la prestation des services de santé et des services sociaux en langue anglaise*). This committee:

- Oversees 16 Regional Access Committees
- Draft Access Programs to list range of services that can be accessed in English within a given CI(U)SSS jurisdiction (government approval of updated Access Programs has been delayed for several years)
- Ensures that services listed in these Access Programs are being provided in English
- Monitors for any discrepancies between the services listed and those provided in English
- Recommends ways to improve access to listed services in English
- The MSSS's **SAPA Program (*Soutien à l'autonomie des personnes âgées*)** is administered regionally. Each CISSS or CIUSSS has its own SAPA program director and its own budget for the program, which consists of two broad types of services:

  1. At-Home Care Services (*Services de soutien à domicile*)

  - For seniors with declining physical or cognitive autonomy
  - Provided through local CLSCs or other third-party (including private) agencies
  - Includes: medical and nursing care; nutrition services; personal assistance services (hygiene care, help with feeding or dressing, mobilization); domestic help (housekeeping, meal preparation, shopping and other errands, laundry); general readaptation services (physiotherapy, occupational therapy, speech therapy, audiology)

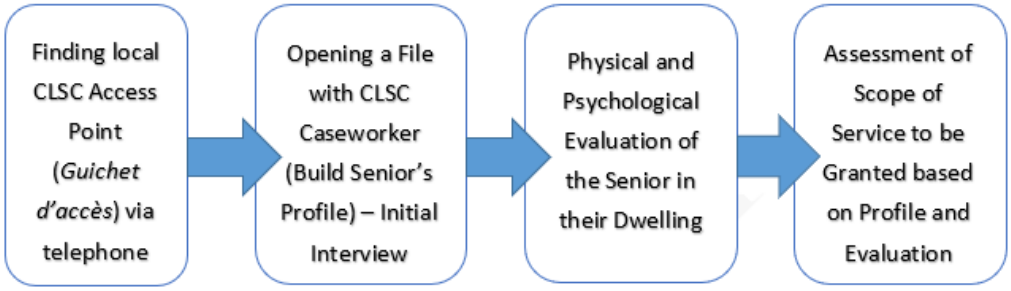
  2. Long-term Placement Services (*Services d'hébergement de longue durée*)

  - For seniors unable to live autonomously due to irreversible physical or cognitive decline
  - Offered temporarily or permanently in long-term care facilities such as CHSLDs (*Centres d'hébergement de soins de longue durée*), RIs (*Ressources intermédiaires*), and RTFs (*Ressources de type familial*)
  - Includes: admission and intake services; round-the-clock medical and nursing care; personal assistance services (laundry, bathroom assistance, hygiene care, help with feeding or dressing, mobilization); rehabilitation services (physiotherapy, occupational and respiratory therapy); dental services; recreational and leisure activities; palliative care

Dimension 3: System Navigation

A senior and their caregiver's journey through accessing care services through the SAPA program will largely depend on the type(s) of care services they require.

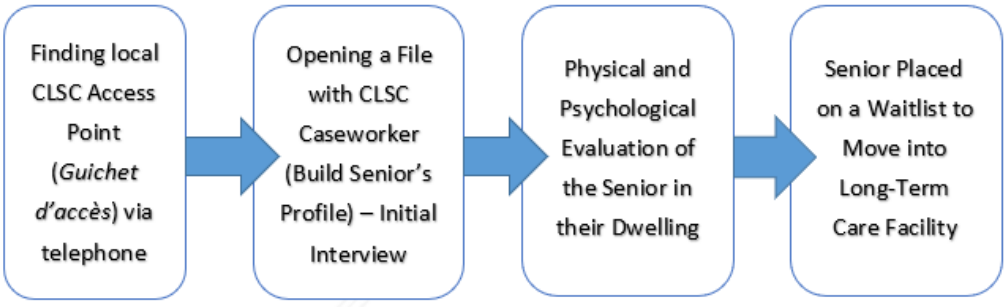
Seniors with declining autonomy in need of at-home care services must follow a series of steps in order to access the services they need. The general pathway is illustrated in the diagram below:



Flow Map for Requesting and Obtaining At-Home Care Services through a CLSC

- To obtain at-home care services, a senior or their caregiver will need to open a patient file at a local CLSC through its Guichet d'accès (access point).
- Contact information for a particular access point will vary depending on the CI(U)SSS jurisdiction under which the given CLSC falls. Most CI(U)SSS websites list telephone numbers for the local CLSC access points. In certain territories, access points must be contacted through Info-Santé, by dialling 811 and selection option 3 (*Guichet d'accès à la première ligne*).
- Following a round of questions to build the senior patient's health profile, a CLSC professional will be dispatched to the senior's residence to perform a physical and cognitive evaluation, which will complement the initial data collected when their file was first opened.
- Following the evaluation, the CSLC authorities to determine the level of care need for the senior, and how it will translate to the scope of service offered within the context of material and human resources available.

Seniors with declining autonomy in need of long-term placement services in facilities such as CHSLDs or RIs must also take specific steps to access the care services they need. The general pathway is illustrated in the diagram below:

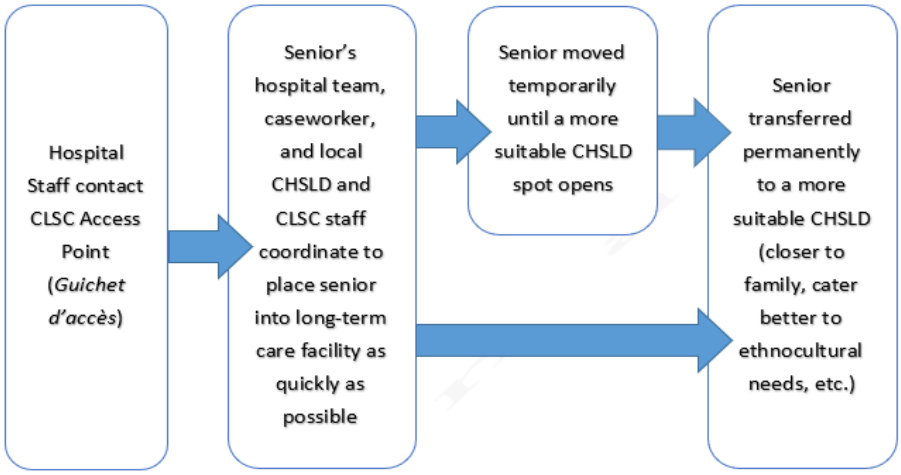


Flow Map for Requesting and Obtaining Placement in a CHSLD and RI for a Non-Hospitalized Senior

- The procedure is similar to that of seniors in need of at-home care services, with the exception of the end result: placement on a waitlist for the next available space.

- The senior's position on the waiting list will be adjusted depending on the senior's changing health status and available spaces in long-term care facilities in the senior's "area of residence" (some can be placed fairly far from their residence).

For seniors with declining autonomy who have been hospitalized due to a medial emergency and need urgent placement in long-term care, the two-branched pathway is illustrated in the diagram below:



Flow Map for Requesting and Obtaining Placement in a CHSLD for a Hospitalized, Permanently Debilitated Senior

- If a senior is hospitalized and, upon discharge, will need round-the-clock care, either permanently or until their convalescence is complete, the hospital administrative staff will make arrangements to have the senior placed into long-term care.
- When permanent placement is required, either: (1) the senior will be placed in a long-term care facility with the closest available open space, then later transferred to a more suitable facility (such as closer to their original place of residence or their family) once a space opens up; or (2) the senior will be discharged from the hospital directly into the long-term care facility best suited to their particular needs (including proximity to their place of residence or that of their family).

Throughout these critical navigation points, **English-speaking seniors or their English-speaking caregivers may face particular challenges** in trying to access and use at-home care or placement care services:

(1) Of the 22 webpages listing contact information for the CLSC Access Points in each of the 22 CI(U)SSS, only 3 are available in English;
(2) While an English-speaking senior's case file is being opened during the initial conversation with a CLSC caseworker (typically a social worker), communication problems can arise if the caseworker opening the file does not speak or understand English;
(3) Similar communication problems can arise during the physical and cognitive evaluation of the English-speaking senior in their place of residence if the CLSC health care professional does not speak or understand English;
(4) If bilingual personnel are not available in CLSCs and long-term care facilities, this could impede English-speaking seniors from communicating and establishing relationships of trust with staff who provide them care. The high turnover of medical and nursing staff who care for seniors at home or

in long-term facilities can prevent English-speaking seniors from having consistent care from bilingual professionals.

While some English-speaking seniors may be able to rely on bilingual caregivers to assist in overcoming language barriers, not every English-speaking senior has such support.

The abovementioned obstacles can ultimately lead to miscommunications and misunderstandings that jeopardize the health of English-speaking seniors, inadvertently contributing to social isolation and their further psychological or cognitive decline.

While a limitation of material and human resources currently plagues the entirety of Quebec's health care network, the project's research concludes that these problems can become exacerbated for the province's official-language minority.

Dimension 4: Population Experience

With Quebec's senior care services already overstretched, the Léger survey of seniors and caregivers commissioned for this report confirms existing studies that suggest demand is set to grow in the short to medium term. A majority of English-speaking caregivers (70%) think it likely that the senior they provide care for will request care services in their home within the next five years. While this makes them significantly more likely than seniors themselves to predict this need in the near term (potentially because they are answering on behalf of someone who may have more challenges than the seniors who answered the survey for themselves), three in ten English-speaking seniors aged 60 and over (29%) also think they are likely to request home care services within the next five years.

The survey reveals the following insights about home care services for seniors:

Low Awareness of Resources for Seniors

- Despite the "Programs and Services for Seniors" booklet being designed as an information resource for all Quebec seniors, awareness of it is extremely low among English-speaking Quebecers. Only 3% of seniors and 8% of caregivers polled had seen or read the booklet.
- Asked to identify the different types of care services provided at home by the CLSC, many seniors and caregivers were unaware of the full range of what is available to them. There are currently 13 care services offered to seniors in their homes through the CLSC. On average, seniors could identify four services on the list, while caregivers could only pick out 3.3 services. This underlines the necessity of better global access to information about home care services for seniors, both in French and in English.
- When awareness is low, seniors are less likely to access the services available to them. Many English-speaking seniors (43%) don't plan to request home care services in the next five years. Within this group, some say they won't ask because they don't know what services are available nearby (12%), or they think there aren't any services available in English (11%).

Negative Perceptions of Senior Care Services

- While most English-speaking seniors (85%) and caregivers (91%) have at least a fairly accurate idea of what care services and supports are available for seniors in their community, **very few rate their**

home care services as being easily available or of good quality. When it comes to care services offered in English, perceptions are even worse.

Positive Perceptions of Home Care Services in the Community (Excellent/Very Good)		
	Seniors	**Caregivers**
Availability overall	19%	26%
Availability of services in English	18%	24%
Quality overall	23%	34%
Quality of services in English	20%	27%

- These perceptions improve somewhat among those who are already accessing home care services through a CLSC. Nonetheless, only half of seniors (and less than half of caregivers) receiving home care services rate them highly on availability or quality.
- The perception that care services for seniors are rarely available in English can lead to some seniors and caregivers putting off requesting care services for longer than they should – potentially only starting the process when the need becomes acute. Among the 43% of English-speaking seniors and 14% of caregivers who say they are not likely to request senior care services in the next five years, 11% of seniors and 17% of caregivers say their reason for not doing so is because "there are no available services in English nearby."

Delays and Language Barriers Mar Experience of CLSC Home Care Services

A majority of seniors and caregivers say it is not always possible to receive care services in the senior's language of choice. Seven in ten (69%) seniors receiving home care services through their local CLSC report having received care services in French when they would have preferred those services to be in English, with about a quarter of seniors (24%) and caregivers (27%) saying this happens frequently. The survey also reveals several other areas in which language can be a barrier to seniors receiving a satisfactory level of care.

- While most (about six in ten) of those who have requested home care services through their local CLSC found the process easy, an important number of seniors (24%) and caregivers (39%) found the process difficult – suggesting a need for broader access to English services.
- Delays are a fact of life for all Quebec seniors trying to access care services at home through their local CLSC. Caregivers are more likely to report longer wait times for the senior after first making the request. Three in ten seniors (29%) and one in three caregivers (33%) report having to wait a month or more before gaining access to any care services, while roughly one in ten had to wait more than three months.
- These delays can often be language-based. When communicating with the CLSC or another public health care service on behalf of an English-speaking senior, three in ten caregivers (32%) have experienced a delay or a complication to the senior's services because of a language barrier.

Caregiver Experience

Caregivers remain reluctant to access services and supports available to them, despite most claiming to know what services exist. While language does not appear to be a barrier for most caregivers who do access support services for themselves, a majority say they struggle to navigate the health care system in French, and many encounter language-based delays.

- Only half (56%) of English-speaking caregivers feel comfortable navigating the health care system in French on behalf of the senior they're caring for. While this rises to 66% among caregivers to a senior already receiving home care services through a CLSC, it leaves many caregivers who are uncomfortable navigating the system in French despite the fact that the senior they care for must rely on them for organizing their health care needs and translating where necessary.
- Three in ten caregivers (32%) say that a language barrier has caused them to experience a delay or a complication to obtaining services for the senior they care for.
- Most caregivers (82%) claim to be aware of the services and supports available to them as caregivers. However, only 21% of caregivers have actually accessed these services – rising to 40% among those caring for a senior receiving home care services through a CLSC. Overall, 85% of caregivers who have accessed a form of dedicated caregiver support say they were able to do so in English, leaving 15% who were unable to do so.

Access Barriers

Data drawn from the population survey are complemented by insights from a series of informational interviews the AJEQ Project conducted with 16 community organizations and users' committees, allowing us to identify four overarching barriers to accessing senior care services in English through the SAPA program. This section details the specifics of each.

Access Barrier 1: Lack of Information in English about Care Services

One of the most widely declared obstacles for English-speaking seniors and their caregivers is an overwhelming absence of information in English as to where, when, and how to access SAPA services (be it at-home or placement care).

As shown by the survey, few seniors or caregivers have seen the literature published by the Quebec government to inform seniors about care options. This means that most seniors and their families must do their own research to find out what care services are available. However, many seniors do not possess the reading and technical skills necessary to understand what health care services are available to them (let alone those available in English), and (as the survey also points out), nearly half of English-speaking caregivers have difficulty navigating this information in French.

Much of this information is available only online, buried deep in CI(U)SSS websites – of which only three out of 22 (approximately 14%) have basic information in English on who to contact to begin the request process. Seniors without an understanding of how to navigate the internet are forced to rely on immediate family or community volunteers to help them understand what services they may need.

Even in regions where seniors possess higher literacy rates and Internet skills, accessing the information in English can often prove overly difficult.

Several pamphlets, brochures, and booklets are only available online in French. Printed copies of these documents may sometimes be available in CLSCs, private clinics, hospitals, or other senior care organizations, but they are not readily or widely distributed to either French- or English-speaking seniors.

Many documents and forms that may need to be completed by an English-speaking senior or their caregiver may only be available in French. This can prove strenuous for English-speaking seniors (or their caregivers)

who do not have the French-language skills required to understand the nuances of the health information required in the forms, or the procedure of how the form(s) must be filled out and to whom it must be sent.

In efforts to help remedy the situation, several community organizations actively collaborate with their regional CI(U)SSS to translate relevant documents into English, which are then uploaded onto the CI(U)SSS website.

However, this initiative relies upon the proactive goodwill of non-governmental organizations to take it on themselves to translate these documents for their regional CI(U)SSS. **Some of these organizations may not possess sufficient resources to translate these documents.**

Certain informal channels exist to request that these documents be translated directly through the regional CI(U)SSS, but **the resultant translation delays can deter English-speaking seniors or their caregivers from contacting their regional health care authority or from receiving the services they need in a timely manner**. This is on top of existing delays experienced by all seniors due to a lack of resources for providing SAPA services across the network.

The Quebec government annually publishes a booklet titled ***Programs and Services for Seniors***, which outlines the general procedure, in English, for requesting at-home care services or long-term placement through an English-speaking senior's local CLSC.

However, population research shows that **only 3% of English-speaking seniors and 8% of English-speaking caregivers have seen or read the booklet**. Likewise, many community organizations interviewed by the project either said that they had never heard of it or that it is not readily available to anyone without Internet access. Attempts by the Access to Justice Project to speak with Quebec's Ministry of Employment and Social Solidarity (MTESS), which is understood to have disseminated the booklet, were unsuccessful.

While the booklet provides a helpful starting point for accessing SAPA services, **it does not provide a written outline for the process of requesting and accessing these services**, what English-speaking seniors or their caregivers may expect throughout the process, and how they can prepare for it.

Access Barrier 2: Lack of Interpreters & English-speaking Care Personnel

MSSS policy provides that translation services should be available in all of Quebec's health care institutions 24 hours a day, seven days a week, across all regions in the province. The government is further responsible for ensuring health care users are made aware of translation services.

However, the language of the policy itself severely restricts this recommendation. The need for translation services must be assessed on a case-by-case basis, taking into account the resources of each particular health care institution.

The loose language and implementation of this policy have ensured that for English-speaking seniors (and English-speaking Quebecers more generally), government-subsidized interpreters in health care institutions are little more than wishful thinking across Quebec. Every community organization and users' committee interviewed confirmed that, for the health care facilities in their regions, there were **no translators or translation services readily or even scarcely available to translate French-language communications into English**.

Further, there is evidence that regional CISSS and CIUSSS administrators are reading the policy to mean that interpretation services should only be made available to patients who do not speak French *or* English, effectively excluding English-speaking Quebecers from the opportunity to receive the services of an interpreter if needed. One CIUSSS users' committee confirmed as much to the project in an interview. While not a facility for providing services to seniors, the Montreal Children's Hospital website also makes it clear that interpretation services are for those who do not speak French or English. However, the MSSS policy on interpreters specifically mentions English-speaking Quebecers, recognizes that they are a group to whom language barriers are more likely to apply, and reiterates Article 15 of the AHSSS. Research for this project confirms 2016 research by the CHSSN, which found that formal interpretation services are very rarely used in English. While demand for interpretation services remains low, this is likely due to a lack of awareness that such services are available and can be requested. Ultimately, this provides justification for conducting a needs assessment and investing in additional interpretation resources where a proven need exists.

Much of the translation efforts currently depend entirely on the highly variable English-language skills of health care professionals (such as doctors, nurses, orderlies, social workers, case workers, or administrative staff) or the caregiver of the English-speaking senior in question.

For English-speaking seniors without a caregiver or without a caregiver with adequate French-language skills, it can be difficult to find a health care worker on shift in a given institution with the necessary English-language skills to adequately understand the accent, phrasings and tone of the seniors. This can be a particularly difficult issue for Quebec's English-speaking immigrant communities.

Difficulty understanding medical instructions in French can cause several stresses and problems for seniors and their caregivers if neither can successfully act as their own interpreter:

(1) If an English-speaking senior or their caregiver calls a local CLSC to request at-home assistance for a senior with declining autonomy, a full assessment of the senior's health profile and needs may not be able to be properly ascertained if the CLSC cannot provide a caseworker on-duty who is able to communicate in English.
(2) An English-speaking senior who may need to be placed into a CHSLD immediately after hospitalization will need this transition explained to them, which can be difficult and overwhelming if not properly communicated in a language they can understand.
(3) Information as simple as appointment times and locations, or directions within a health care facility, can be misunderstood by an English-speaking senior or their caregiver if the administrative personnel with whom they interact can or will only speak to them in French.
(4) With respect to at-home care services, there is a high turnover of nurses and other personnel who help seniors in their homes. Aside from the difficulty of many seniors (regardless of language) to therefore build a rapport or relationship of trust and respect with a single, continuous at-home health care worker, the turnover means that English-speaking seniors may have a health worker who can speak English one week, but not the next.

Access Barrier 3: Reluctance of English-speaking Seniors to Seek Out Care Services

In CI(U)SSS territories where there is a sizeable English-speaking community but no bilingual institutions, **the availability of SAPA services in English (be it home care services or placement care) relies in large part on the will to enforce and uphold each regional institution's Access Program**. This issue can create an uneven level of service for English-speaking seniors and their caregivers based simply on where they live.

Organizations interviewed for this research have relayed instances where English-speaking seniors and their families have been forced to contemplate moving to different regions where there are more English-speakers and SAPA services are more readily available in English.

However, many English-speaking seniors live close to the poverty line, and their families cannot afford to relocate to an area of the province that may better serve their elderly family members. In cases where English-speaking seniors do have the means to move to another region to obtain services in English there, many seniors still refuse out of fear of being isolated from their loved ones.

For these reasons, many English-speaking seniors **with declining autonomy remain reluctant to seek out assistance**. This reluctance stems from pride and a desire to maintain self-reliance, which is common to all seniors regardless of language, as well as an unwillingness to attempt to navigate the convoluted channels to procure limited SAPA services.

This has resulted in instances where English-speaking seniors in need of at-home care have delayed requesting these services for far too long. With caregiver(s) unable to devote themselves full-time to the care of the senior, many seniors eventually suffer a serious injury that could have been avoided.

A lack of cultural competency can be a particular issue for English-speaking racialized and immigrant communities. For instance, one community organization reported that seniors within Montreal's English-speaking Black community who have accessed at-home care services through a CLSC often end up requesting that care providers stop visiting them, after efforts to communicate fall through. This may be due to difficulties in understanding a senior's dialect or simply not treating them with cultural sensitivity during interventions such as help with bathing or administering medication. Separately, a CIUSSS Users' Committee spoke to the project about a lack of trust in the public health care system among African and Caribbean communities, and the challenges this can present when attempting to build relationships with caregivers – particularly in a high-turnover environment.

As a result, these English-speaking seniors are hospitalized and often forced to take the next available spot in long-term care, often in facilities with limited or no English-language personnel or services.

Access Barrier 4: Hesitation over Filing Complaints or Raising Awareness of Lack of Health Services in English

A lack of data on SAPA services or senior care in English is further exacerbated by a fear of English-speaking seniors or their caregivers to file complaints. Declaring formal grievances would enable the Commissioner of Complaints or Ombudsman's office to collect data on instances where these seniors have experienced inequitable health care services on the basis of language, be it from lack of bilingual personnel or information, or hostility or discrimination based on the senior's first spoken language. There is a genuine fear amongst English-speaking seniors and their caregivers to "rock the boat" or "make waves".

This is arguably driven by the overstretched nature of senior care services in general. For seniors needing at-home care, waiting lists for care services can be lengthy (often three months or more). Nurses are only able to visit at most a few days a week, leaving caregivers with a sizeable duty of care for their senior. Waiting lists for placement in long-term care facilities average at two years for seniors with declining autonomy who may need permanent, full-time care, leaving the extra burden to fall on caregivers who may not be equipped (materially, financially, or physically) to take on these extra responsibilities.

In Quebec's decentralized health care system where resources are allocated to individual CI(U)SSSs, many lack the financial resources needed to guarantee a continuous, satisfactory stream of SAPA services being delivered to seniors, regardless of language. The priority for these health care institutions is to simply provide the services. As an unfortunate and possibly inadvertent consequence, linguistic considerations and cultural sensitivity often fall by the wayside. Indeed, the survey points out that a majority (69%) of English-speaking seniors receiving home care services through their local CLSC have received service in French despite their linguistic preference, with one in four (24%) saying this happens frequently.

Even in situations where services in English should have been provided based on the regional or institutional Access Program, many English-speaking seniors and caregivers are hesitant to demand service in English or to complain if they do not receive it. According to community stakeholders interviewed for this report, most English-speaking seniors and caregivers are "simply grateful" to be receiving services at all in Quebec's underfunded and understaffed health care network. Many English-speaking seniors and their do not want to make the situation worse by drawing attention to their inability to receive services in English.

For instance, with at-home care, many English-speaking seniors and caregivers worry that if they demand an English-speaking nurse, the senior may be subject to hostile behaviour by a health care professional that could harm the senior's health or dignity.

Many caregivers with seniors in long-term care fear raising language-related concerns to the administrative staff or health care personnel of the facility out of fear that their senior may be mistreated by workers there.

Whether or not these worries are justified by data, the fear is real amongst English-speaking seniors and their caregivers, who feel helpless to ask for services in English where they may very well be entitled to them.

Recommendations to the MSSS

Based on the available data on these areas of unmet need, we have developed eight recommendations for ways in which the Ministry of Health and Social Services (MSSS) can take action to improve access SAPA program services in English in Quebec. We feel these actions are needed to ensure optimal compliance with the Government of Quebec's commitment, as set out in the *AHSSS*, *CFL*, and ministerial language policy, to provide equal availability and quality of health services to French- and English-speaking seniors in provincial health care institutions.

We recommend that:

1. A paper copy of the government booklet *Programs and Services for Seniors* be mailed to every Quebec resident upon their 60th birthday, in French and English, and that every new edition released thereafter be mailed to them as well in both these languages.

2. All CI(U)SSS webpages outlining information on At-Home Care Services (*Soutien à domicile*), Long-Term Care Services (*Services d'hébergement de longue durée*), and the Access Points contact numbers (*Guichets d'accès*) be translated into English.

3. All CI(U)SSSs hire certified translators to translate into English all documents and forms available for download on CI(U)SSS websites needed for accessing SAPA program services. These documents and forms must be available on the CI(U)SSS's respective English-language webpages or be listed alongside the original French-language versions.

4. Bilingual personnel be provided to English-speaking seniors or their caregivers within a reasonable time delay when opening a case file at their local CLSC, or when being evaluated within their residence for their physical and cognitive condition.

5. That each CI(U)SSS's SAPA director implement a staff recruitment program targeting racialized English-speaking communities, in order to build trust among seniors from these communities who are reluctant to access care services until their need becomes acute.

6. A policy-based plan be developed to establish how to connect English-speaking seniors and their caregivers with the closest health care institution with bilingual staff, especially outside of regions with designated healthcare institutions.

7. Health care institutions with no bilingual staff be required to hire bilingual doctors, nurses, and administrators in proportion to the English-speaking patient population of the region (in accordance with section 15 of the *AHSSS*, ministerial policy, and as a reasonable justification under section 46 of the *CFL*), and to report every two years on the number of bilingual staff in these categories.

8. CI(U)SSS authorities with limited access to SAPA program services or other senior care services in English provide English-speaking seniors and their caregivers subsidized transport accommodation when they need to travel to other regions with English-language health care services.

9. For CI(U)SSSs with past or current Access Programs, that a monitoring mechanism be put into place to collect and report data for the CI(U)SSS on the availability of health care services in English. This information must include services that have been transferred to third-party agencies and service providers.

10. In the event of any organizational restructuring, a mandate be given to conduct a re-evaluation to assess whether health and social services in English have been diminished or compromised.

11. All regional Access Programs be made available on each CI(U)SSS website on a distinct and easily retrievable page available in English.

12. The MSSS collaborate with regional community organizations so as to provide English-language information on how to obtain and navigate SAPA care services available to seniors, with the information being displayed in local CLSCs, pharmacies, doctors' offices, libraries, seniors' clubs, and other community organizations.

Finally,

13. **We invite the MSSS to explore tangible collaboration with QCGN, CHSSN and their partner organizations** to identify community groups possessing the capacity to complement the offer of English-language support needed to English-speaking seniors across all regions of Quebec.