



PUBLIC CONSULTATION ON FEDERAL ACCESSIBILITY LEGISLATION

**Input from Canadians who have Speech,
Language and Communication Disabilities**



**Communication
Disabilities Access
Canada**

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Report prepared for the Federal Government's national consultation on accessibility legislation.

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Hear Us Roar!



“Accessibility to goods and services for people who have speech and language disabilities has been off the radar for far too long!

Finally, we have been given this opportunity to tell you about the communication barriers we face on a daily basis and what we want to see in the emerging federal accessibility legislation.

*Over **2,200** Canadians with speech and language disabilities contributed to this report.*

*This isn't about being nice to us – this is about human rights, equality and inclusion – because.... **it's 2017!**”*

Anne Abbott

COMMUNICATION DISABILITIES ACCESS CANADA

Communication Disabilities Access Canada (CDAC) is a national, non-profit organization with charitable status. Established in 2001, CDAC promotes accessibility, inclusion and social justice for people of all ages who have speech, language and communication disabilities (SLCDs) that are not due primarily to hearing loss. Communication disabilities include cerebral palsy, intellectual disabilities, autism spectrum disorders, learning disability, acquired brain injury, speech disorders, aphasia, stuttering, Amyotrophic Lateral Sclerosis, Huntington's disease, head and neck cancers, Multiple Sclerosis, Parkinson's Disease and other disabilities.

CDAC provides information and resources to four main groups of people:

- a)** People with compromised communication skills due to speech, language and communication disabilities (SLCDs)
- b)** Public, non-profit and private community organizations, businesses and services
- c)** Government policy makers and accessibility legislators
- d)** Essential service sectors for people with SLCDs

CDAC engages people with SLCDs as paid consultants, as well as qualified professionals with backgrounds in speech-language pathology, augmentative and alternative communication, human rights and accessibility legislation, social work and disability services.

CDAC is a unique organization in Canada in that it employs a social and human rights based model to address communication accessibility for people with SLCDs. While CDAC recognizes the need for clinical communication services and funding for communication devices, it focuses on eliminating the barriers, prejudices and exclusions that people with SLCDs experience when accessing goods, services and opportunities in their communities.

This project builds on CDAC's past projects relating to communication access for people with SLCDs. In 2009 - 2012, CDAC conducted a national research project to define the communication access needs of Canadians with SLCDs. In 2013, CDAC operated the Canada-wide, Communication Access Now project to increase awareness of the communication access needs of people with SLCDs. Since 2007, CDAC has worked with Department of Justice Canada to advance access to justice for this population. CDAC is active on local, regional, provincial, national and international levels, to increase awareness of communication access gaps and needs.

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EXECUTIVE SUMMARY

This report is in response to the Government of Canada's request for information on what should be included in a national accessibility law. It summarizes input from people who have speech, language and communication disabilities (SLCDs), their family members, clinical service providers and advocates.

To facilitate input from this sector, CDAC provided:

- accessible website information
- online and print surveys focusing on communication access barriers and recommendations
- picture and blissymbol vocabulary to facilitate contributions to the survey for people with SLCDs who require these supports

CDAC distributed the resources and survey to organizations that support people who have SLCDs. These organizations connected with speech-language pathologists, augmentative and alternative communication clinicians, educators, occupational therapists and others and crossed a number of sectors including healthcare, rehabilitation, disability, education, private communication services, professional associations and non-profit organizations.

The project solicited input from 2,205 participants from all provinces and territories across Canada.

Key Findings:

- People with SLCDs represent a distinct disability cohort that has unique accessibility requirements that are different from the accessibility needs of people who have mobility, sensory, intellectual, mental health, or learning disabilities.
- Communication access refers to ways that federal service providers can facilitate communication so that everyone, including people with SLCDs can communicate effectively when using their services. Communication access applies to all public services and opportunities including consumer services, information and communications, employment, public consultations, justice, healthcare, emergency and other services.

- Effective communication is a two-way process that involves being able to convey intended messages to another person and understanding what a person is communicating.
- People with SLCDs experience significant communication barriers when accessing government services in face-to-face interactions, telephone services, public consultations, and when accessing information and communications.
- Most of the barriers experienced by people with SLCDs can be addressed through inclusive accessibility legislation and education of federal service providers.
- Federal services where communication is critical such healthcare, justice, emergency and education require specific communication access policies and practices to ensure that people with SLCDs can effectively, accurately and authentically communicate within these contexts.

While this project focused on identifying and reducing communication access barriers to federal government services, 96% of surveyed participants, highlighted the need for increased provincial speech-language pathology, audiology, augmentative and alternative communication services and funding for communication devices. Participants stressed that many people with SLCDs cannot begin to use federal services unless they have the means and skills to communicate. Participants expressed hope that the federal government's new accessibility legislation will provide a strong and collaborative platform to work with provincial governments to increase communication services and device funding so that all Canadians with SLCDs can have equal access to goods and services.



**“Over 440K Canadians
have communication
disabilities.”**

*“We do not all have hearing impairments or
intellectual disabilities.*

*As the result of a stroke, I have aphasia that
affects my ability to communicate.”*

– Bill Scott

INTRODUCTION

In the Fall of 2016, the Government of Canada began a process of soliciting input from the disability community about what should be included in a national accessibility law.

That legislation will tell people who work in federal government services how to make their services accessible to people with disabilities. The Government's public consultation process aimed to collect information from people with disabilities about the accessibility barriers they may experience when using federal government services and recommendations to eliminate these barriers.

Communication Disabilities Access Canada (CDAC) is supporting the Government of Canada's public consultation process by engaging people with speech, language and communication disabilities (SLCDs) to provide their input. This includes people who have a wide range of disabilities that impact on their ability to speak, and/or understand spoken language such as cerebral palsy, intellectual disabilities, autism spectrum disorders, learning disability, acquired brain injury, speech disorders, aphasia, stuttering, Amyotrophic Lateral Sclerosis, Huntington's disease, head and neck cancers, Multiple Sclerosis, Parkinson's Disease and other disabilities.

The project focused on the communication accessibility needs of people with SLCDs when accessing government services. It did not address the needs of people who have significant hearing loss, or who are deaf or deafblind, as other organizations are addressing these issues.

A distinct approach is required in order to solicit from people with SLCDs to the federal consultation process, because:

- 1.** They may not have the communication accessibility supports they require to communicate at these public consultations
- 2.** They do not see their accessibility requirements reflected in accessibility discussions that tend to focus on mobility, sensory, intellectual, mental health, and learning disabilities
- 3.** They may not be aware that they have communication accessibility rights when using services
- 4.** They may not receive information about these engagements in accessible ways

This report summarizes the process of engaging people with SLCDs, their family members and their communication support services and shares key findings about communication barriers and accessibility recommendations for people with SLCDs.

All responses contributed by participants have been shared in a separate document with the Minister of Sport and Persons with Disabilities.

It should be noted that CDAC represents people with a diverse range of SLCDs, and takes an inclusive approach to describing communication access rather than focusing on specific types of communication disabilities. CDAC recognizes that people with SLCDs are unique and have individual communication access requirements. The purpose of this research was to identify a common ground that could be applied to all people with SLCDs and lead to a process where individual communication access accommodations can be identified and addressed.



**“There can be no
service without
communication.”**

*“Service providers need to know how to
communicate with us when we use their services.”*

– Tien Hoang

TERMINOLOGY

Communication: A two-way process that involves understanding what a person is communicating and having that person understand messages conveyed to them in face-to-face, group or telephone interactions, reading and writing.

Speech, Language and Communication Disability (SLCD):

A disability that impacts on one or more areas of a person's ability to speak; understand what others are saying; read or write.

Communication Access: In this report, communication access refers to what federal service providers can do to make their services accessible for people with SLCDs.

Communication Barrier: Any obstacle that prevents the effective exchange of ideas, thoughts and questions in face-to-face, group or telephone interactions, and via reading and writing.

Communication Accommodations and Supports:

Communication behaviours, assistance and resources that enhance the exchange of ideas, thoughts and questions in face-to-face, group, and telephone interactions, and via reading and writing.

Federal Service Provider: A person who works in the federal government and provides services to the general public either in face-to-face interactions, at a public consultation or meeting, over the telephone or through information conveyed and received via the internet, printed materials, and e-communications.

Clinical Service Provider: A speech-language pathologist, audiologist, augmentative and alternative communication clinician, educator, occupational therapist and others who provide clinical communication services to people who have SLCDs.

Augmentative and Alternative Communication (AAC):

Communication methods that people with SLCDs may use to express their messages such as gestures, pictures, symbols, letter boards, and communication devices. AAC services are provided by specialized teams of speech-language pathologists, assistive technologists, occupational therapists and educators.

Communication Device: Devices that people use to select, type or speak out their messages or aids that help people hear what they or others are saying (i.e. voice amplification devices or hearing aids). Communication devices include tablets and smart phones as well as specialized devices that are programmed with customized vocabulary for an individual with reduced literacy and /or people who use switches or eye gaze to select items that they want to communicate.

Communication Assistant: A person, authorized by an individual with SLCD, to assist them communicating with another person, reading, understanding written materials, and communicating over the telephone. A communication assistant can be a family member, or a support person familiar with how a person communicates. Not all people with SLCDs require or want a communication assistant.

Communication Intermediary: A speech-language pathologist, working in a neutral role, trained by CDAC, who supports people with SLCDs when communicating in police, legal and justice situations or other contexts where communication is critical.

BACKGROUND

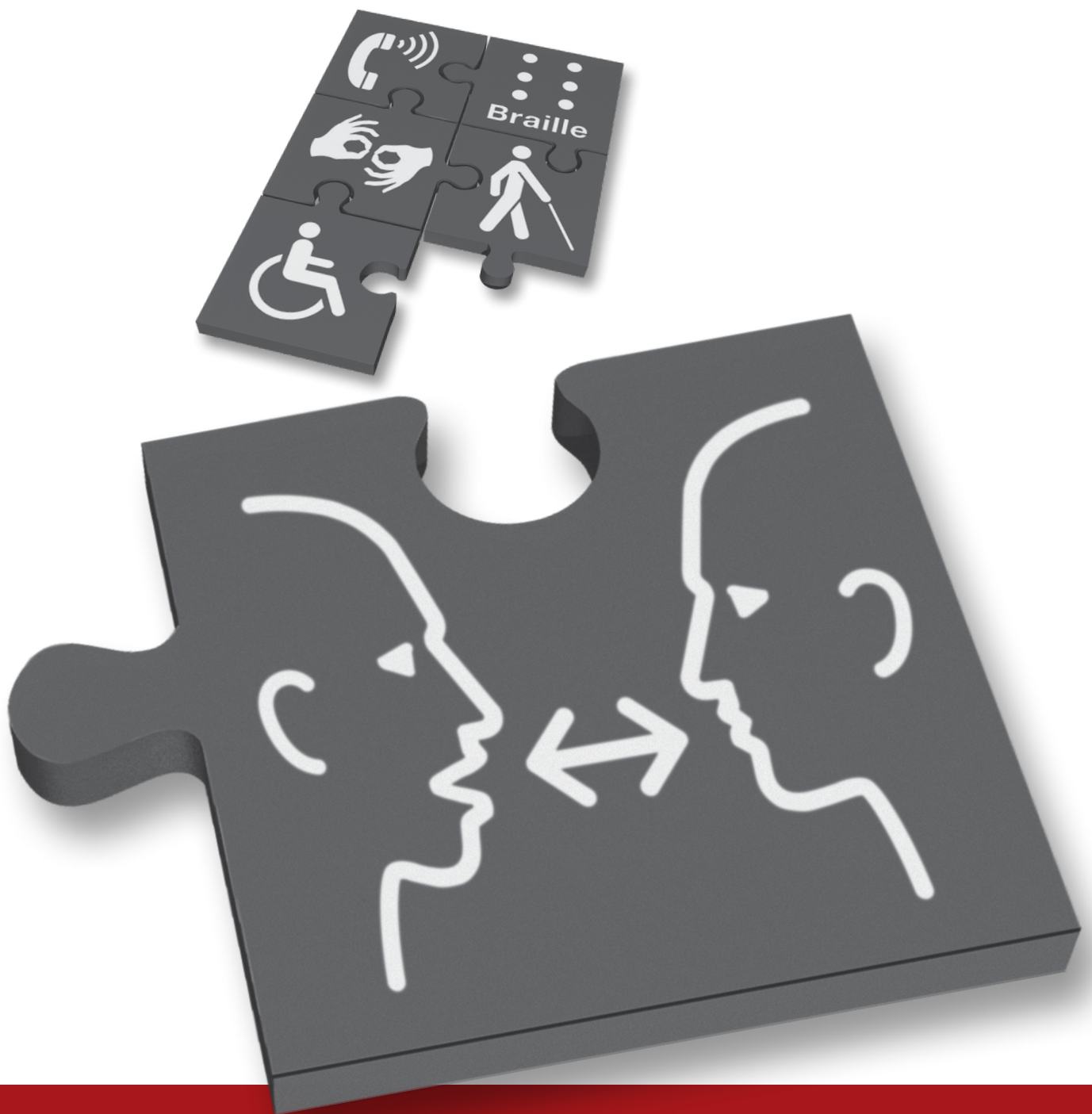
There are approximately 440,000 Canadians who have significant SLCDs. It should be noted that SLCDs refers to many different types of disabilities that have an impact on an individual's ability to communicate. Some are life-long disabilities, such as cerebral palsy, autism spectrum disorder, Down syndrome, a learning disability, or a cognitive disability. Others are acquired disabilities such as traumatic brain injury, aphasia after a stroke, dementia, Amyotrophic Lateral Sclerosis (or ALS), Parkinson's disease, Multiple Sclerosis. Having a SLCD can affect one or more communication areas such as a person's ability to speak, understand what others are saying, read and/or write. See Appendix A for information about SLCDs.

People with speech disabilities may have slurred or unclear speech; or they may have no speech and communicate using gestures, pictures, letter boards, communication devices or assistance from a person who knows them well. They may use a voice amplifier if they have a weak voice. People with language disabilities may have difficulty hearing what people are saying or they may hear but have difficulty processing or understanding what another person is saying. For example, people who have aphasia after a stroke or accident may have difficulty in understanding others, and in speaking, reading and writing. People who have intellectual disabilities from birth or who acquire dementia or Alzheimer's disease later, may have problems remembering, learning, understanding, or problem-solving, making communication challenging.

In addition to having communication challenges, many people have multiple disabilities. For example, people who have cerebral palsy, may be unable to speak, walk or physically manipulate objects. People who have autism may experience challenges learning and using language, as well as interacting with other people.

While some SLCDs are easily observable (e.g. person who cannot speak and uses a device to communicate), others may have no physical symptoms. For example, a minor stroke or a learning disability can have a profound impact on a person's ability to comprehend spoken language or express their own messages.

People with SLCDs may require clinical supports from speech-language pathologists, audiologists or augmentative and alternative communication clinicians. These provincial services assist people to use strategies and communication methods, aids and devices that may help them when interacting with people in different settings. In addition to these services, many people with SLCDs may require funding for communication devices.



This is the communication access symbol. It shows two people communicating with each other. It's about interaction, communicating, looking, listening and respecting each other.

COMMUNICATION ACCESS FOR PEOPLE WITH SLCDs

Effective communication, the foundation for all good services, is a two-way process that involves understanding what a person is communicating and having that person understand messages conveyed to them. Effective communication occurs in face-to-face interactions with other people in one-to-one or group situations, communicating over the telephone, reading and understanding print, internet and e-communications, writing messages, signing documents, taking notes and completing forms.

Federal service providers may need to do things differently when communicating with a person who has a SLCD, because the way they communicate may be unfamiliar to the federal service provider; their speech may be hard to understand; they may communicate at a slow rate or they may have difficulty understanding what the federal service provider is saying.

For people with SLCDs, effective communication access to services means having federal service providers who know about:

- Communicating with people who have speech that is difficult to understand or who use a picture, symbol, letter board, communication device or a communication assistant
- Supporting people who have difficulty processing spoken language to understand what others are saying
- Giving people the time, opportunities and conditions people need to communicate
- Negotiating specific individual communication access accommodations and supports
- Making public consultations accessible
- Making reading materials, internet and e-communications accessible
- Making forms accessible and negotiating alternate signatures
- Engaging a communication assistant when required

It is important to note that many people with SLCDs use customized communication picture or letter boards and devices. Unfortunately, not everyone who needs a communication system has access to clinical services or funding to get these supports. Apart from emergency situations, and the provision of simple low-tech solutions such as pen and paper, federal service providers are not expected to provide an individual with a communication device. However, federal service providers need to have strategies in place to guide them in how to optimize their interactions with people who do not have effective ways to communicate with them.

See Appendix A for disabilities that may impact on speech, language and communication.



Communication Access is about face-to-face interactions, communicating over the telephone, at meetings and public events and reading and writing.

PART 1: ENGAGEMENT PROCESS

To engage people with SLCDs in the federal government's public consultation process, CDAC developed accessible resources and surveys that addressed the needs of this population.

These included:

Accessible information on CDAC website

The website pages provide a slide show that is accessible in audio and with a transcript. The slide show highlights the importance of engagement of people with SLCDs, clinical service providers, and advocates in the federal accessibility legislation. The website is available at <http://www.cdacanada.com/projects/federal-accessibility-legislation/>

Survey about communication access barriers and accommodations

CDAC developed a plain language survey about communication access barriers and recommendations that was based on a research project conducted by CDAC in 2010. In that study, CDAC surveyed 200 Canadians with SLCDs and asked them to define the common elements of communication access for people with SLCDs. Findings from that study helped to shape the questions in this survey in terms of access in face-to-face interactions, over the telephone, at meetings, and in reading and writing. It is important to note that many people found the survey questions helped to guide them in thinking about what access to services means for people with SLCDs. The plain language survey was made available for people to complete online, in print, and via email. It used a simple yes / no / I don't know question format that has been found to be effective in eliciting responses from people with a range of different SLCDs. Participants were also provided the option to add their own comments. The survey was available to be completed from October 15, 2016 until January 1, 2017 and can be downloaded from <http://www.cdacanada.com/projects/federal-accessibility-legislation-survey>

Vocabulary Resources

Supplemental vocabularies of pictures and Blissymbols were developed to support people to contribute to the survey. Blissymbols is a semantic graphical language that is used by some individuals with severe speech and physical impairments. Many people with SLCDs who are not literate require pictures or Blissymbols to support them to understand written or spoken words or to express what they want to communicate. Family members and federal service providers were encouraged to use these resources, when appropriate to assist people with SLCDs to contribute their input to the survey. Vocabularies included a response card that people could

point to when answering questions, graphics about human rights legislation, communication access barriers, and communication contexts. The resources are available online at <http://www.cdacanada.com/projects/federal-accessibility-legislation>.

Information to federal service providers and organizations that support people with SLCDs

CDAC distributed the resources and survey to approximately **80 organizations in Canada** that support people who have SLCDs, including healthcare, rehabilitation, education, communication services, professional associations and non-profit organizations. Organizations, in turn, shared the survey with members who were asked to share it with people with SLCDs and family members. Speech-language pathologists and augmentative communication clinicians were also asked to adapt the survey to meet the needs of the people they support, as well as to facilitate group discussions and assist people in completing the survey. In addition, federal service providers were requested to complete the survey themselves to represent the needs of people with SLCDs who could not independently contribute to the process.

PARTICIPANTS

2,205 people contributed to the survey via:

- Online survey (English) - 1,856 (includes 125 group participants)
- Online survey (French) – 77
- Facilitated input via paper survey – 245
- Email survey - 27

Note 370 people with SLCDs were assisted to provide input to the survey.

All provinces and territories represented as follows:

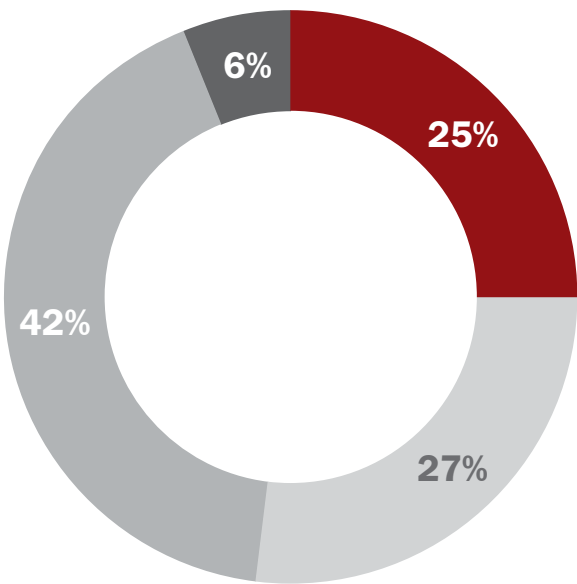
- | | |
|----------------------------|----------------------------------|
| • BC – 9.5% | • Quebec – 5.1 % |
| • Yukon / Territories – 1% | • New Brunswick – 1.7% |
| • Alberta – 10.5% | • Prince Edward Island – 0.6% |
| • Saskatchewan – 2.2% | • Nova Scotia – 2% |
| • Manitoba – 1.4% | • Newfoundland and Labrador – 1% |
| • Ontario – 65% | |

Respondent cohorts:

52% of respondents were people with SLCDs and family members. In addition, CDAC encouraged federal service providers and disability advocates to complete the survey.

Participant cohorts included:

- People with SLCDs
- Family Members
- Clinicians and Support Staff
- Disability Advocates



PART 2: FINDINGS: COMMUNICATION BARRIERS

In this section, we summarize responses about communication barriers to survey questions. Please refer to Appendix B for recurring themes and citations from participants.

LACK OF CLINICAL SERVICES AND COMMUNICATION DEVICES

“People cannot begin to communicate without clinical services and funding for devices. It is like saying people don’t need wheelchairs to get into buildings - a ramp isn’t enough. In many places across Canada, there are no communication services, especially for adults who have life long communication disabilities. In addition, there are very few provinces that provide funding for communication devices.”

The majority of participants (96%) took the opportunity to inform the federal government of the need for increased provincial speech-language pathology, audiology and augmentative and alternative communication services for people with SLCDs as well as funding for communication devices that people may need when using federal services. People with SLCDs need these clinical services and communication methods to communicate effectively when using federal services. Federal service providers need to know how to interact with people who have SLCDs and how to make their services accessible to them. For effective communication to happen, all components must be in place.

Access to appropriate clinical services and device funding varies widely across the country. Many Canadians with SLCDs, have little or no access to provincial speech-language pathology,

audiology and/or augmentative and alternative communication services. In some provinces there is no financial assistance for people with SLCDs to get communication devices, adapted telephones, and computers. Without these services and funding supports, many people with SLCDs do not have the communication strategies, skills and communication devices that they need to communicate in everyday life or to access federal, provincial and community services. Participants urge the federal government to find ways to work with provincial governments to ensure that people with SLCDs have what they need to communicate effectively when they use federal services.

DISRESPECTFUL ATTITUDES

“Everyday I leave the safety of my home and suffer pity and disgust from people. I overheard a woman in a mall talking about me. She said “He shouldn’t be let out on his own” – like I was an animal in a zoo.”

Participants (98%) want the new legislation to address issues relating to federal service providers’ attitude, ignorance, fear and discrimination about people with SLCDs. They report that federal service providers typically assume they are incompetent and unable to make their own decisions. Some service providers think that people with SLCDs cannot hear or understand spoken language. These experiences can lead to frustrating interactions with federal service providers where people with SLCDs feel disrespected, disempowered and humiliated.

Participants want the new legislation to mandate education for all federal service providers that interact with the public. They want federal service providers to know how to speak in a respectful way to a person who has a SLCD. This means federal service providers should not ignore people with SLCDs, underestimate their abilities, speak about them to the person with them or address them in a childish or loud manner.

RESTRICTION IN USE OF ALTERNATE COMMUNICATION METHODS

“When I try to communicate with some people, they insist on asking me Yes and No questions rather than letting me communicate my own ideas using my letter board. I know it takes a bit longer but I hate when people shut me up and control the conversation.”

The majority of participants (97%) want the new legislation to acknowledge that many people with SLCDs communicate in ways other than speech. They reported that people with SLCDs can experience barriers related to federal service providers who control a conversation by restricting the type of answers that a person with a SLCD can provide, such as only answering yes and no questions and not allowing the individual the opportunity to use their communication board or device. Participants reported situations where communication devices were “locked away” for safety in a hospital setting and unavailable for the person with SLCD to use. One participant was asked by a federal service provider to use a TTY over the telephone, although she does not have one, is not deaf, and chooses to use a person who knows her well to interpret her speech.

Participants want the new legislation to include education for all federal service providers that interact with the public on how and why people with SLCDs communicate using ways other than speech. They want federal service providers to know that they should provide opportunities for a person to use the communication method(s) of their choice in a given situation. This may include speech, gestures, writing, communication display, a device, or a communication assistant.

LACK OF INFORMATION AND GUIDELINES

“If federal service providers do not follow a person’s communication instructions, then the interaction will not be successful. Communication will not have taken place. Communication only occurs when a message has been transmitted by one party and received by the other. If the federal service provider does not follow the communication directions, then only one party is participating in the communication process.”

Ninety-seven percent of participants reported that the new accessibility legislation must ensure that federal service providers have policies, practices and resources to ensure they know how to communicate with people with SLCDs. Without this information, people with SLCDs cannot communicate effectively with them when using services. They want federal service providers to know that they should ask the person with a SLCD what they should do when communicating with them and how they should make their services accessible. The person with a SLCD may want them to repeat what they say so that they are sure they understand their message, or say the item out loud that they are pointing to. If appropriate, the person may also have instructions on how to assist them to understand what is being said, such as writing down what is said or showing pictures.

Participants want the new legislation to include education for all federal service providers that interact with the public on how to communicate with a person who has a SLCD, and how to negotiate their communication access requirements.

INSUFFICIENT TIME TO COMMUNICATE

“People who have SLCDs often state that being rushed is highly stressful and causes them to shut down completely. They feel the federal service provider does not have time and, therefore, there is no point in trying to communicate. As a result, they feel as if what they have to say is not valued and this diminishes their self-confidence.”

Participants (98%) want federal service providers to give extra time as an accessibility accommodation when communicating with a person who has a SLCD. They stressed that communicating takes longer for a person with SLCD. This may include being patient, giving the person longer service time or extending an appointment time in face-to-face interactions or providing a dedicated telephone line and service for people with SLCDs.

LACK OF STRATEGIES TO DEAL WITH COMMUNICATION BREAKDOWNS

“People who pretend to understand are disrespectful. They should ask for clarification and repetition or try to improve listening conditions to understand the message projected.”

Participants (99%) want federal service providers to make reasonable efforts to understand messages from a person with a communication disability. This means that they should know what to do if they cannot understand what a person is communicating, such as asking the person to repeat or to communicate a message in another way; moving to a quiet area to focus on a person’s message, or finding out if the person has someone who can assist. In the event that an individual with SLCD does not have an effective means to communicate when using services, the federal service provider should have strategies to support the individual in these situations.

Participants want the new legislation to include education for all federal service providers that interact with the public on how to handle communication breakdowns when providing services to people with SLCDs.

CHALLENGES WITH TELEPHONE SERVICES

“People who stutter often have the phone hung up on them because they have trouble starting their message. People who have motor speech disorders may not be taken seriously because, in some cases, they sound drunk. Those who use an AAC device may not be taken seriously because the voice output sounds computerized.”

Participants (96%) want people who provide services over the telephone to know how to communicate with people who have SLCDs. Strategies may include not hanging up on people, knowing what to do if they don't understand what the person is communicating, handling routine calls, using an authorized communication assistant, as well as ways to use alternatives to the phone such as email, text, Skype, and message relay services.

Many government federal service providers use telephone communication as a means of providing services to the public. People with SLCDs report that communicating over the telephone with federal service providers poses one of their most serious barriers. They find it difficult to communicate over the telephone because federal service providers are not trained in ways to facilitate their communication. In addition, they cannot access automated services and report that they often cannot understand federal service providers who speak quickly or unclearly. Participants report that people with SLCDs are not always permitted to use a person that they have authorized to assist a federal service provider in understanding what they are communicating over the telephone.

Participants want the new federal accessibility legislation to include policies and procedures for communicating with a person with SLCD over the telephone, such as providing a dedicated direct telephone line for people with SLCDs, giving options for email, text or Skype conversations, and having procedures to use an authorized communication assistant.

PUBLIC CONSULTATION FORUMS

“People with communication disorders are rarely represented in public forums, because typical oral communication is the way to participate in those forums. This means that they are often forgotten when decisions are made. Access to trained communication assistants would solve this.”

Participants (96%) want government public consultations, forums and committees to be accessible to people with SLCDs. This means providing a trained communication assistant to support people with SLCDs who request this support to communicate at these events. In the same way that people who are Deaf can request sign language interpreters, people with SLCDs should be able to request trained communication assistance if they need support communicating at these event. In addition, they want moderators of forums and committee meetings to know how to accommodate a person with a SLCD to ensure that they can effectively contribute at these events.

Participants want the new legislation to include mandatory education for all federal service providers who organize and host public consultations, forums and committees. In addition, they want the government to develop rosters of trained communication assistants that can be engaged to assist people who may require assistance communicating at these events.

READING MATERIALS

“There are huge barriers in obtaining information from federal service providers. Health information, government information, banking information etc. is not presented in a communication friendly manner.”

Participants (96%) want federal service providers to provide text, print, and digital information in ways that people who have SLCDs can access, read, and understand. They cited barriers for people with reduced literacy skills or life experience, or reduced ability to process written language due to an acquired brain injury. Others cited barriers related to physical disabilities that affect a person’s ability to handle paper, and physically navigate a website. Participants noted that many people with SLCDs do not have computers and internet access, and consequently, do not receive important information and cannot use e-communications to access federal services. In addition, many family members of people with SLCDs report that they also have difficulty getting information from government services either because they cannot access these services or the information they receive is not always useful or easy to understand.

Participants want the new legislation to include mandatory education on making information accessible for people with SLCDs for all federal service providers that prepare, and transmit information to the public. This includes guidelines for using plain language content, alternate formats, enhanced graphic support, best practice layout and design, and accessible electronic access.

WRITING ACTIVITIES

“I want forms in electronic format that I can use with my typing program which gives me word prediction and spell checking. I also need to be able to save forms and come back to them because I get tired when typing.”

Participants (96%) want federal service providers to provide paper and electronic forms and surveys in ways people with SLCDs can use.

People with SLCDs who have reduced literacy or physical disabilities, may have difficulty reading, understanding, and completing government forms, as well as taking notes at meetings and events. Participants report that most government forms are difficult to understand, and navigate. Many people with SLCDs want forms that they can use with their assistive technology such as the option to use spell checkers and word prediction. In addition, they want to be able to take breaks when completing an online, digital form. They want the option to email a form or complete a hard copy. They may require picture and symbol vocabulary to understand and communicate their responses. Many people with SLCDs require forms with simplified language, increased font size and white space, and picture enhancement where appropriate. A significant number of people with SLCDs report that they require human assistance to complete a form.

Participants want the new legislation to include mandatory education on making forms and surveys accessible for people with SLCDs for all federal service providers that solicit written information and input from the public.

CONSENT AND SIGNATURES

“Any alternate signature should be the one that is used regularly by that particular individual. It may be necessary that signatures are witnessed if it is something easily copied such as an X.”

According to 89% of participants, federal service providers should ensure people with SLCDs can give informed consent and approval when signing legal documents. This includes ensuring that they understand the decision to be made, have opportunities to ask questions, appreciate the consequences of decisions, and can effectively communicate their decision. For some people with SLCDs who have difficulty writing, this includes negotiating procedures for alternate signatures such as electronic signatures, having a person sign on their behalf, using a stamp, or an X.

Participants acknowledge that many people with SLCDs who also have motor disabilities, should be able to use alternate signature formats to sign documents. Many people with SLCDs report challenges signing documents because federal service providers question their cognitive capacity to make decisions.

Participants want the new federal legislation to include the need for specific policies and procedures that allow people with SLCDs to sign documents in alternate ways, as well as to protect their signatures.

CRITICAL COMMUNICATION SITUATIONS

“Long overdue! We want essential services to have policies and procedures to ensure we can communicate in these settings. We are nervous about the doctor assisted dying laws in Canada because right now we can’t communicate with healthcare providers about our most basic needs.”

Participants (97%) want federal service providers working in essential services such as healthcare, emergency, and justice services to have policies, procedures and practices in place so that people with SLCDs can effectively communicate in these situations. This includes ensuring people have the appropriate communication methods and assistance that they may need to support them communicating in these settings.

Many people with SLCDs report that healthcare providers often defer decisions about their health to family members and support staff. There are no communication access protocols in place to ensure that people with SLCDs have the communication accommodations and supports they need to communicate within these settings and specifically within the medical assistance in dying context. Within justice services, people with SLCDs may require communication assistance from an impartial, qualified communication intermediary. Within emergency situations, first responders need training and access to emergency picture boards to assist people with SLCDs in communicating with them. Although some of these essential services fall under provincial government mandate, participants hope that the government can play a leadership role by addressing them on a federal level.

Participants want the new legislation to mandate federal essential services to have specific communication policies, procedures and practices to ensure people with SLCDs have the communication access accommodations and supports they need when communicating in these situations.

SIGNIFICANT FEDERAL GOVERNMENT SERVICES

While all government divisions and ministries need to be accessible for people with SLCDs, the following services have been highlighted as particularly significant and in need of improved communication access for people with SLCDs.

Participants want the new legislation to include specific policies, procedures, training, guidelines, and resources for these government programs.

Service Canada

“When I visited Service Canada in person, after a long wait the representative asked me to phone their line, because “only the people on the phone line can answer these questions, even though we’re all Service Canada.” I told the representative that I can’t use a phone, at which point she spoke much more loudly and more slowly. Now everyone in the packed waiting room could hear all my personal information, plus I felt stupid. I’m not hard of hearing and I’m not stupid. I just can’t reach Service Canada by phone.”

People with SLCDs need to negotiate federal benefits such as employment insurance, disability benefits, registered disability savings plans, education and training benefits, family benefits, pension plans, fuel exemptions and other benefits. Many of these services are only available via telephone, which makes them challenging to access for people with SLCDs.

Justice Canada Supreme Court of Canada

“Why do some people get communication support and we don’t? Justice services should provide trained communication intermediaries to support victims, witnesses and accused who have SLCDs to communicate in courts. Other countries have these services, why not Canada?”

People with SLCDs need to negotiate federal benefits such as employment insurance, disability benefits, registered disability savings plans, education and training benefits, family benefits, pension plans, fuel exemptions and other benefits. Many of these services are only available via telephone, which makes them challenging to access for people with SLCDs.

Canada Revenue Agency

“I called CRA and because I use a letter board, I asked my attendant to read out what I was spelling. The agent would not accept that and kept telling me to use a TTY. I told her I wasn’t deaf and didn’t have or need one. Still, she wouldn’t accept someone helping me.”

People with SLCDs require access to information in ways they can understand and use as well as access to a person who can communicate effectively with them over the telephone or via another mode of communication.

Emergency and Public Safety

“The first responders didn’t have a clue how to communicate with me. It was like they had never met a person with SLCD before.”

First responders, such as the police, and para-medics need information about how to communicate with people with SLCDs in emergency and disaster situations.

Immigration, Refugees and Citizenship

“My husband has aphasia and applied to become a Canadian citizen. He was called for an interview and I explained he would need assistance to understand the questions and communicate his answers. We were told that he could have a sign language interpreter. I explained he wasn’t Deaf. There was no information about how I could get a qualified person to assist. I spoke to our speech language pathologist and to my MPP. Finally we managed to get an exemption for my husband. But there needs to be a process that addresses the needs of people with SLCDs.”

There are currently no procedures to provide qualified communication assistants for people with SLCDs who may need communication assistance to take the citizenship interview and participate in the process.

Healthcare

“I struggle to communicate with healthcare providers at the best of times. I am particularly concerned about how I might negotiate medical assistance in dying if I can’t communicate with these people about anything.”

There are currently no communication access protocols in place to ensure that patients with SLCDs have the communication accommodations and supports they need to communicate within healthcare settings and specifically within the medical assistance in dying context.

Elections Canada

“It’s impossible to deck out every polling station with every possible accessible piece of technology. Most of us need things to be customized. It would be much better if we had the option for online voting or to bring someone we trust with us.”

People with SLCDs, who have difficulty reading or marking a ballot require specific accessibility accommodations when voting. These accommodations may include human assistance, or internet access voting.

Seniors

“I have seen countless people in the community and in long term care with significant communication disorders who never receive therapy or devices to support their communication. It results in significant depression a lot of the time because they are no longer able to participate in the community or with friends and family as they used to and have no means for improving their situation. It leads to social withdrawal and can be dangerous for those who are left on their own in an emergency situation.”

Many seniors have acquired SLCDs that occur more frequently in older adults such as stroke, Parkinson’s Disease, dementia and other conditions. In addition, people with life long SLCDs are living longer and their needs become increasingly complex as they age. Yet, there is a significant lack of communication support for this population. Federal resources and services for seniors should include principles and practices that support communication access to services.

Prisons

Research in the USA and UK has shown that up to 60% of inmates in prisons have SLCDs. There are currently no Canadian initiatives in place to research or address communication supports within these settings.

Canadian Radio-television and Telecommunications Commission (CRTC)

“I know people who have to live in long term care facilities simply because they don’t have an adapted telephone to call for help if they need it.”

The CRTC currently does not provide access to telecommunications for people with SLCDs in terms of accessible telephones, trained message relay services for people with SLCDs, speech-to-speech services, and video telephone services. Participants hope that the new legislation will obligate the CRTC to meaningfully assess the telecommunication needs of people with SLCDs and to begin to provide accessible telecommunication services for this population.

PART 3: RECOMMENDATIONS

OVERARCHING PRINCIPLES

The following information is intended to support the federal government in developing accessibility regulations that include the needs of people with SLCDs. It should complement general accessibility regulations that are required by all people with disabilities. It should be noted that many people with SLCDs can have co-existing and multiple disabilities.

Accessibility legislation and regulations should:

- Recognize that people with SLCDs represent a distinct disability cohort that has unique accessibility requirements that are different from the accessibility needs of people who have mobility, sensory, intellectual, mental health, or learning disabilities by including the term communication disabilities in accessibility legislation. It should be noted that many people with SLDs can have co-existing and multiple disabilities.
- Acknowledge that communication access is as important as physical access and that people with SLCDs may require a range of communication accommodations and supports when using services. Most people with SLCDs can be effective communicators if they are provided with appropriate accommodations and supports.
- Describe communication as a two-way process of understanding others which occurs in face-to-face interactions, over the telephone, in groups or public consultations, and through reading and writing.
- Higher access standards are required for services where communication is critical such as healthcare, justice, safety, financial, and other services. These standards must go beyond the generic, basic communication access regulations and must reflect the unique requirements of these contexts.
- While there are generic, basic communication accessibility standards that are applicable to all people with communication disabilities, flexibility is always required to accommodate each person's individual accessibility requirements within a specific service context.
- Acknowledge that communication is an integral part of all service provision. Therefore it applies to all federal jurisdiction services and provincial/territorial services funded by the federal government that are provided to the public. Regulations should be integrated into all face-to-face services, telephone, public forums, and information services. It should not be isolated within a separate standard for Information and Communications.

- Understand that a good attitude is the foundation of all good communication. However, in addition to being respectful, a service provider is required to do additional things to make their services accessible for a person whose disability impacts on communication.
- Ensure all federal service providers who deal with the public have appropriate education, and guidelines to make their services communication accessible for people with SLCDs. These should be delivered by a qualified organization that includes people with different types of SLCDs, as well as communication professionals should address:
 - The nature of a wide range of speech, language and communication disabilities.
 - An inclusive, respectful, universal approach to interacting with people who have a wide range of SLCDs in face-to-face interactions, group situations, and telephone communications.
 - Techniques to negotiate individualized communication access accommodations with people who have different communication disabilities and profiles.
 - Procedures for communicating with people with SLCDs over the telephone, including a dedicated telephone line and service, options for using alternatives to the telephone, and using an authorized communication assistant.
 - Procedures to make public consultations accessible for people with SLCDs.
 - Guidelines to make print, internet, and e-communications accessible for people with SLCDs, including plain language, application of universal design and layout, alternate formats, accessible websites as well as accessible forms, and procedures to take notes and use alternate signature formats.
 - Policies and procedures to obtain informed consent and signatures on legal, health and financial documents.
 - Provide information, guidelines, and resources for people with SLCDs to support them in knowing and negotiating their communication accessibility rights and responsibilities, when accessing government services.
 - Develop specific communication protocols, procedures, and guidelines for essential services where communication is critical such as healthcare, justice, citizenship and immigration, public safety and Revenue Canada for people with SLCDs.

- Ensure all groups that receive funding from the federal government are accessible for people with SLCDs.
- Work with provincial government ministries to increase access to clinical speech-language pathology, audiology and augmentative and alternative communication services as well as adequate and secure funding for communication devices.
- Ensure people with SLCDs are represented and their communication access needs are accommodated at public consultations, accessibility reviews, advisory committees, commissions and monitoring procedures.

GENERIC RECOMMENDATIONS

The following recommendations have been provided by participants to make federal jurisdiction services and provincial/ territorial services funded by the federal government accessible for people with SLCDs.

Service providers who interact with the public

“People who don’t know me are afraid to start up a conversation. They don’t want to embarrass themselves and they talk to the person who may with me. There is such a need to educate people about those of us who have communication disabilities.”

Service providers who interact with the public should:

- Receive training in how to interact with people who have SLCDs as well as how to negotiate and accommodate communication accessibility requirements.

- Provide services in a manner that respects the dignity and autonomy of the person with a SLCD.
- Accept the person's chosen way to communicate, including unclear speech, picture, symbol, or letter board; a speech or text output device; or assistance from a communication support person.
- Follow instructions provided by the person with a SLCD on what they should do when communicating with them.
- Ask the individual what, if any communication accommodations and supports they may need to use the service.
- Make best efforts to accommodate the communication needs of the individual.
- Have access to a "go to person" with additional training in the event of communication breakdowns.
- Provide additional time for the person to communicate.
- Provide, if needed, a counter surface, at a level where a person can use a communication board or device and the service provider can see what the person is pointing to, typing or writing.
- Use a variety of question formats and avoid restricting a person's communication to answering yes and no questions, unless approved by the individual and the situation calls for this questioning style.
- Accept what an authorized support person communicates on behalf of an individual with a SLCD, if they choose to have someone assist them with communication.
- Ensure that both the person with a disability and the communication support person are permitted to enter the premises together and that the person with a disability is not prevented from having access to the communication support person while on the premises if he/she requests their assistance.
- Validate what the communication support person has communicated (if applicable) by asking the person with the SLCD if they agree with what the support person has said.

Telephone services

“They hang up on me. They think I am drunk because my speech is a bit slurred.”

Telephone service providers should:

- Offer a dedicated telephone line for people with SLCDs.
- Have policies and procedures to accept an authorized communication support person over the telephone.
- Receive training in specific strategies to communicate over the telephone with people who have communication disabilities.
- Provide alternative options to the telephone, such as text messaging, email and social media, video conferencing, and message relay services.

Public forums, meetings and committees

“If people can request and get sign language interpreters, we should be able to request and get people who are trained to assist us communicating at these events.”

Organizers of public forums, meetings, and committees should:

- Advertise the availability of communication accessibility accommodations and supports to people with SLCDs, prior to an event.
- Provide an agenda ahead of time.
- Provide communication assistants to support people communicating, if requested
- Use appropriate strategies to facilitate communication and participation of participants who have SLCDs.

Information and Communications services

“We need to get information in ways we can read and understand and forms that we can complete using our assistive devices.”

Information and Communications services should:

- Provide written information in several formats (e.g. electronic format and hard copy), including easy reading or plain language, enhanced text (e.g. pictures, large font), audio, and, if appropriate, human assistance.
- Ensure that websites comply with web content accessibility guidelines.
- Make accessible forms compatible with assistive writing or communication technology.
- Ensure that signage is clear, with recognizable graphics, and at a height and location that can be easily seen.
- Have procedures in place for alternate signatures, note-taking, recording services, and scribing.

Feedback and Complaint Process

“Don’t just give us a phone number – give us lots of options to complain and when we do complain - do something about it.”

- The feedback process must permit people with SLCDs to provide their feedback in person, by telephone, in writing, or by delivering an electronic text by email or with the assistance of a communication support person to the service provider and to the governing body in charge of compliance.
- The service provider should be obliged to respond to the complainant and copy their correspondence to an oversight body.

ESSENTIAL SERVICES RECOMMENDATIONS

In addition to generic communication access standards for all public services, there is a need for specific standards within services where communication is critical.

Healthcare Services

Service providers should have policies, procedures, training, and practices to:

- Identify patients with SLCDs and determine their need for specific communication accommodation and supports.
- Provide required communication accommodations and supports within a timely manner at all stages of healthcare services.
- Have a process in place that recognizes a patient's authorized communication support person.
- Document a patient's communication needs in medical files and share with pertinent healthcare staff.
- Provide patients with ways to communicate while hospitalized.
- Engage a speech-language pathologist to assist with communication if the person has no means of communicating, or if there is a question about the reliability of the communication process, as identified by either the medical practitioner or the patient.
- Train healthcare providers in best practice communication strategies to ensure patients comprehend what is being said and can effectively express their decisions in consent to treatment situations and end-of life directives.
- Provide communication accommodations and supports when there is a question about an individual's capacity to make healthcare decisions.
- Ensure that substitute and supportive decision makers consult and engage with patients within decision-making situations.

Justice Services

Members of the judiciary, police officers, duty counsel, defense lawyers, crown attorneys, court accessibility coordinators, tribunal members, lawyers, and paralegals should have policies, procedures, training and practices to:

- Identify victims, witnesses, and accused persons with SLCDs.
- Negotiate individual communication accommodations and supports.
- Engage the services of a qualified Communication Intermediary, at no cost to the person with a communication disability, to provide assistance with two-way communication between the victim, witness or accused person and justice professionals.

Emergency and Public Safety

“The emergency people just ignored me and ask a stranger who was standing beside me to consent to my treatment.”

Service providers should:

- Provide information for people with SLCDs about how to prepare for and communicate in an emergency, as well as evacuation plans.
- Receive training on how to communicate with a person with a SLCD in an emergency.

Canadian Radio-television and Telecommunications Commission

Service providers should:

- Ensure that telecommunications and broadcasting products and services are accessible for people with SLCDs
- Provide training for message relay operators to relay unclear speech or synthesized speech between a person with a SLCD and another person on the telephone.
- Provide video message services for people who use augmentative and alternative communication methods.

Employment

Service providers that work to increase employment opportunities for people with disabilities should:

- Have information about successful models of employment for people with SLCDs.
- Receive training on the range of communication accommodations and supports that people with SLCDs may require.
- Provide employment information, counseling, role models and support for people with SLCDs when seeking employment.

Financial Services

Service providers should:

- Have policies, procedures, and training to negotiate confidential financial matters, signatures, and authorizations with people who have SLCDs.

Elections Canada

Election officials should:

- Provide human assistance, picture based ballots as well as the option of human assistance or Internet access voting for people with SLCDs.

Citizenship

Service providers should:

- Provide the option to use qualified communication assistants if required by people with SLCDs at interview and swearing-in ceremonies.

CONCLUSION

To date, the communication accessibility requirements of people with SLCDs have not been well understood or adequately addressed in accessibility legislation at all levels of government. Yet, the consequences of ineffective communication for half a million Canadians can be significant and profound. This report is the first national study to source and document the barriers faced by people with SLCDs when using government services and their recommendations for making these services accessible to them. It provides a wealth of information upon which we can begin to build human rights legislation that meaningfully includes the accommodations and supports required by people who have SLCDs.

CDAC looks forward to working with the Government of Canada to ensure that people with SLCDs are involved in all stages of its emerging accessibility laws.

APPENDIX A

COMMUNICATION DISABILITIES

This information is provided here as a reference to support people in understanding how different disabilities can affect a person’s communication abilities. It is by no means a comprehensive list, and is not intended to replace professional assessments, diagnoses, and treatments by health care professionals.

Some of the disabilities affect a person’s ability to understand what others are saying, which involves listening, attention, memory, and processing abilities. Some disabilities affect how a person can communicate their message through speaking, pointing at pictures, writing, letter boards, or devices. People can also have dual and multiple disabilities that affect more than their communication skills. For example, some people may also have an intellectual disability, a physical and mobility disability, hearing loss, visual impairment, or a mental health disability.

It is important to note that everyone is unique and disabilities affect people in different ways.

Disability	Possible effects on communication
Cerebral Palsy	Cerebral palsy is a disorder that affects a person’s movements. Their speech might be slurred, unclear or they may have little or no speech and communicate using pictures, letters, symbols, or a communication device. The person may or may not have difficulty walking and physically manipulating things. Most people who have cerebral palsy have no difficulty understanding what people are saying and making their own decisions. However, some people who have cerebral palsy may also have an intellectual disability.

Disability	Possible effects on communication
Autism Spectrum Disorder	<p>Autism spectrum disorder (ASD) is a life-long neurological disorder that can affect the way a person communicates and relates to the people and world around them. ASD can affect behavior, social interactions, and one's ability to communicate verbally. ASD is a wide spectrum disorder, which means that while all people with ASD will experience certain difficulties, the degree to which each person on the spectrum experiences these challenges will be different.</p>
Fetal Alcohol Spectrum Disorder (FASD)	<p>Fetal Alcohol Spectrum Disorder (FASD) is a general term that describes the range of neurological and behavioural challenges that may affect a person if the person's birth mother drank alcohol while she was pregnant. Individuals with FASD may have difficulties with learning, memory, attention span, problem solving, speech, and hearing.</p>
Intellectual or Developmental Disability	<p>Intellectual or developmental disability is a disability that can be caused by any condition that impairs the development of the brain, before birth, during birth, or in childhood and adolescence. The condition may be caused by genetic or inherited factors such as Fragile X Syndrome, Down Syndrome or other chromosomal abnormality; problems during pregnancy such as maternal infection, or maternal alcohol ingestion; problems at birth, such as premature delivery or oxygen deprivation; childhood diseases or head injury. Developmental disabilities can be mild, moderate, severe, or profound. They are characterized by significant limitations in both intellectual functioning and in adaptive behavior. Intellectual functioning refers to learning, reasoning, problem-solving skills. Adaptive behavior is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives, such as communication, literacy, money, time, number concepts, self-direction, safety, ability to follow instructions and other areas. People with intellectual disabilities may require support to understand questions and communicate their messages.</p>

Disability	Possible effects on communication
Dual Disability or Multiple Disabilities	People can have co-existing conditions. For example, people with intellectual or developmental disabilities can also have motor, hearing, and visual impairments, or mental health illnesses.
Speech disorders	Speech disorders affect how a person pronounces words. There are different types of speech disorders. Apraxia affects how a person moves and sequences their lips and tongue when speaking. Dysarthria is a weakness of muscles and can result in slurred speech or no speech.
Stuttering	Stuttering affects the fluency of speech. It is characterized by disruptions in the production of speech sounds.
Aphasia	<p>Aphasia results from damage to the parts of the brain that contain language. Aphasia may cause difficulties in speaking, listening, reading, and writing, but does not affect intelligence.</p> <p>Aphasia is most often caused by stroke. However, any disease or damage to the parts of the brain that control language can cause aphasia. These include brain tumors, brain injury, and progressive neurological disorders.</p>
Amyotrophic Lateral Sclerosis (ALS)	ALS, sometimes called Lou Gehrig's disease, is a progressive brain disease that attacks the nerve cells that control muscles. ALS can result in a person having unclear or no speech. A person with ALS may use a communication device. ALS does not affect a person's intelligence, memory or the ability to understand what is being said.

Disability	Possible effects on communication
Dementia	Dementia is a group of symptoms related to memory loss and overall cognitive impairment. People with dementia may have difficulty processing what is being said to them, remembering, finding the words they want to say, attending to conversations and problem solving. There are different types of dementia, such as Alzheimer's Disease and Vascular Dementia.
Huntington's disease	Huntington's disease is an inherited disease that results in difficulty in movement, thinking, and behavior. Speech may be slurred or the person may have little or no speech. A person may need to use a communication display or device. Communication difficulties may also cause problems with memory, sequencing, and problem solving.
Brain Injury	There are different types of brain injuries. These injuries can be caused by a stroke, tumors, infection, and traumatic brain damage. Depending on the location and severity of the damage, communication functions that can be affected include speech, understanding of language, attention, memory, perception, reasoning, organizational skills, social interactions, insight, and problem solving, behavior, reading and writing.
Stroke	A stroke can cause paralysis or muscle weakness, loss of feeling, speech and language problems, memory and reasoning problems, swallowing difficulties, problems of vision and visual perception. Communication deficits may include difficulty in understanding or producing speech correctly such as in aphasia; slurred speech due to weak muscles and/or difficulty in programming oral muscles for speech production. Cognitive deficits may include difficulties in attention, awareness, orientation, memory, problem solving, and reasoning skills.
Selective Mutism	Selective Mutism usually happens during childhood. A child with selective mutism does not speak in certain situations.

Disability	Possible effects on communication
Head and Neck Cancers	Cancers that affect a person's mouth, larynx, esophagus, or throat can affect their ability to speak. Brain tumors can affect how a person can attend and process language.
Cleft lip and palate	Children can be born with a variety of cleft types and with variable severity. In cleft lip there is a separation of the sides of the upper lip. A cleft palate is an opening in the roof of the mouth in which the two sides of the palate did not join while your baby was developing in utero. Most clefts are surgically repaired. Speech may or may not be affected.
Hearing Loss	There are different types of hearing loss that can make it difficult or impossible for a person to hear what someone is saying and sometimes their own speech may not be easily understood. Many people wear hearing aids and want speakers to do things that make it easier for them to hear and understand what is being said. However, if a person is Deaf and uses sign language, they require sign language interpreting services, not the services of a Communication Intermediary.
Learning Disability	People with learning disabilities have challenges with reading, spelling, and/or writing. In addition, many people with learning disabilities have difficulty expressing their messages in a clear manner, understanding questions and following directions, reading and comprehending material.
Attention Deficit / Hyperactivity Disorder (ADHD)	There are different types of voice disorders that can result in a weak voice that makes it difficult for a person to speak loudly or be understood. Some disorders result in hoarseness, breathiness, quivering, jerkiness, or a rough sounding voice. Some people may be able to speak for a short period of time.

Disability	Possible effects on communication
Voice Disorders	There are different types of voice disorders that can result in a weak voice that makes it difficult for a person to speak loudly or be understood. Some disorders result in hoarseness, breathiness, quivering, jerkiness, or a rough sounding voice. Some people may be able to speak for a short period of time.
Multiple Sclerosis (MS)	MS is currently classified as an autoimmune disease of the central nervous system (brain, spinal cord). MS can cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment and mood changes. Speech may be weak and unclear.
Parkinson's Disease	Parkinson's disease (PD) is a neurodegenerative brain disorder. People with Parkinson's may have unclear, hoarse, quiet and monotonous speech. People may misinterpret an individual's mood due to reduced facial expressions, altered hand gestures or changes in postures.

APPENDIX B

RECURRING THEMES AND CITATIONS FROM SURVEY

A. Impact of Ineffective Communication

Impact of Ineffective Communication	Quotes
Social Isolation	Life without communication is like being a wall in a room full of people (You are lucky if people talk to you!) Life without communication causes people to feel disconnected from others, and like an inanimate object or a piece of furniture.
Loss of autonomy	People think that because I can't speak, I can't make my own decisions.
Reduce access to services	I want to change my will but I know the lawyer won't understand me and I don't want my family members to come with me to help them understand what I am saying.
Reduced quality of services	I couldn't communicate with the nurses and doctor when I was in hospital. They took away my communication device and locked it up for safe keeping.
Increase risk for abuse, crimes and violation of human rights	I tried to tell the police about how I was abused. They told me I would not be a credible witness because I could not speak.
Lack of consent	I had a medical procedure that I didn't consent to. They didn't give me a chance to use my letter board to get the information I needed.

Impact of Ineffective Communication	Quotes
Unemployment	I am struggling to get by on social assistance, not because I lack education, skills, talents, motivation, or technology to accommodate my disability. I am struggling on social assistance, because I could not find an employer, who saw beyond the assumptions, and mis-perceptions of my disability.
Compromised safety	The emergency people just ignored me and asked a stranger who was standing beside me to consent to my treatment.
Loss of dignity	Everyday I leave the safety of my home and suffer pity and disgust from people. I overheard a woman in a mall talking about me. She said “He shouldn’t be let out on his own” – like I was an animal in a zoo.
Loss of Independent Living	I know people who have to live in long term care facilities simply because they don’t have an adapted telephone to call for help if they need it.
Mental health issues	When a child can’t communicate and is on waiting lists for services, frustration develops and the child’s actions are seen as “behavior” when, really they may be the only child’s way of communicating.

B. Lack of Clinical Services and Device Funding

Impact of lack of services and device funding	Quotes
Communication is not seen as a priority	I think people with SLCDs feel less human and less important than people with other types of disabilities where there are more services and funding for assistive devices.

Impact of lack of services and device funding	Quotes
Lack of speech-language pathology services	Right now, seniors in long term care have almost no speech language services and the people staffing these facilities have no skills in communication
Lack of augmentative and alternative communication services	Long waiting lists for AAC services; lack of AAC services and of access to appropriate communication devices and lack of appropriate accommodation for AAC interfere with the early development of communication which impedes education, inclusion, relationships, participation and self esteem. Isolation, withdrawal and depression are common.
Lack of funding for communication devices	Our daughter has Rhett syndrome. She has lost her ability to speak and control her body. She is trapped in her own body, but with the help of technology and communication devices she has started to communicate with us daily. Manitoba is far behind in communication services. We have travelled to Ontario to learn how to use devices like the Eye Gaze system. My parents purchased a system for our home and a non-profit organization purchased one for her at school. Because she can't speak many people think she doesn't know anything...she is proving them all wrong!

C. Disrespectful Attitudes

Barrier	Description	Participant quote
Assumption of incompetence	Ignoring the person with SLCD, deferring questions to an accompanying person, speaking in ways that implies the person is incapable, has reduced cognitive abilities and is unable to make their own decisions.	My husband has aphasia because of his stroke; unfortunately, his difficulty in communicating is perceived as an intellectual issue.

Barrier	Description	Participant quote
Generalization of disabilities	Speaking loudly, slowly and in a childish manner to a person with SLCD.	I find people are usually very respectful - however, because our son is non-verbal they of course assume he is deaf....so we continually message for him as using his device is slow.....We always explain our son can hear you however he uses a computer/phone to speak (and that takes time - so unless in school or with friends and family using a communication device is still not something so many are familiar with - raising awareness continues to be a challenge in most communities.
Unfamiliarity	Avoiding interactions with the person for fear they may not understand their message.	The biggest barrier is ignorance. Many assumptions made about people with communication disabilities stem from a lack of education and exposure to the realities. Often when people think they are being helpful (e.g., speaking louder; filling in the person's word; speaking in short, simple sentences to an adult, etc.) they are well-intentioned, but their ignorance presents itself as patronizing, belittling condescension.
Ignorance	Not knowing the nature of communication disabilities and how it impacts people in different ways including one or more aspects of speech, understanding, reading and writing.	<p>People often talk about people in front of them as if they cannot understand.</p> <p>My husband has recently been diagnosed with ALS-- his speech has been severely compromised and continues to decline. He has been accused of drinking. People get frustrated with him, and rolling of eyes, etc. It is horrible to see him struggle.</p>

D. Lack of Information on how to communicate with people with SLCDs

Barrier	Description	Participant quote
Lack of communication skill	<p>Federal service providers need information on how to communicate with people who have different communication profiles and how to negotiate accessibility requirements for people with SLCDs.</p> <p>Tendency for federal service providers to “pretend” they understand a person’s message, to ignore what the person is communicating or to change the topic.</p>	<p>If federal service providers do not follow a person’s communication instructions, then the interaction will not be successful. Communication will not have taken place. Communication only occurs when a message has been transmitted by one party and received by the other. If the federal service provider does not follow the communication directions, then only one party is participating in the communication process. The transfer of the message will be incomplete. People who pretend to understand are disrespectful. They should ask clarification, repetition or try to improve listening conditions to understand the message projected.</p>
Insufficient time to communicate	<p>It takes longer to communicate when a person has processing difficulties or when they use an AAC method of communication, therefore they require extra time for communicating with federal service providers.</p>	<p>Using alternative communication is typically a much slower process than oral communication. Time is needed for the person to express himself.</p> <p>We need a way to ensure that federal service providers can provide extra time as an accessibility requirement for people with SLCDs</p>

E. Telephone Services

Barrier	Description	Participant quote
Inability to connect to government telephone services	Some government websites do not provide a telephone number or email address to connect. There can be long waiting times for an answer. People with SLCDs may rely on paid attendants to assist them to make these calls and there may be no answer within a work shift. This makes it impossible to connect.	I can't get an answer when I call Service Canada. I wish I could email them. I have to get someone to make the call for me because I can't push all the numbers to get through to the right person.
Agents lack information and skills to communicate with people who have SLCDs over the telephone	People with SLCDs report that agents often hang up on them because they think they are drunk or because they think there is no one on the phone when a person is typing or can't get their words out due to stuttering. Agents do not have training in how to communicate with persons who have SLCDs over the phone; what to do if they use an AAC device or if they don't understand their speech.	People who stutter often have the phone hung up on them because they have trouble starting their message. People who have motor speech disorders may not be taken seriously because, in some cases, they sound drunk. Those who use an AAC device may not be taken seriously because the voice output sounds computerized.
Lack of protocols and procedures for use of communication assistance over the telephone.	People with SLCD report they are not permitted to use a person that they have authorized to assist an agent in understanding what they are communicating over the telephone.	I needed to make a phone call to Revenue Canada. Because I spell out what I want to say on an alphabet board, I wanted someone to read out my message over the telephone. They would not let me use a communication assistant or explore ways to ensure that I had authorized this person to be my voice.

Barrier	Description	Participant quote
Lack of alternate communication options to the phone.	Many people with SLCDs want to use alternate ways to telephone communication such as email or skype or in person meetings	I can communicate independently through email, yet many federal service providers including my own doctor's office refuse to use email and force me to have someone call for me. They claim it is for privacy reasons yet email is much more private for me than having someone call on my behalf and learn about my health information.

F. Public Consultations, meetings and committees

Barrier	Description	Participant quote
No communication accommodations at events	Unlike people who are deaf who can request sign language interpreters, and people who are deafblind who can request intervenors, people with SLCDs are not offered trained communication assistants to support them to communicate in these situations.	I can't just show up at a meeting and expect that people will let me communicate using my letter board because there is nobody there who can assist me. There are no trained communication assistants at these events to help us communicate.
Lack of alternate options to contribute	People with SLCDs require a range of accessible ways to contribute and participate at public consultations and events, such as online, print, graphic, symbol enhanced information and questionnaires.	This survey is a much easier way for me to give my input because I can discuss it at my pace and get support from people to complete it.

Barrier	Description	Participant quote
Moderators at meetings	People with SLCDs may need to program their device or write what they want to communicate ahead of a meeting or event. They may need the moderator or chair of the meeting to instruct the participants about how to facilitate their involvement.	Even moderators think I can't contribute. They don't know how to give me a chance to communicate because they are worried that everyone else will get bored waiting for my message.
Communication supports (graphics and symbols)	People with SLCDs may need vocabulary in pictures or symbols to communicate about issues relating to topics being addressed.	People with aphasia needed the pictures to help them understand this survey.

G. Information and Communications

Barrier	Description	Participant quote
Reading and understanding written materials	People with SLCDs, who have reduced or impaired language and / or literacy skills, may require accommodations to read and understand written information that is in print, on a website, or in e-communications.	I can't just show up at a meeting and expect that people will let me communicate using my letter board because there is nobody there who can assist me. There are no trained communication assistants at these events to help us communicate.
Navigate websites and handle paper	People with SLCDs, who also have motoric disabilities, may require accommodations to access printed brochures and navigate websites and e-communications.	Because I use a switch to access web pages, I want pages that are easy to navigate and do not involve a lot of scrolling. When it's a paper copy I need someone to help turn the pages.

Barrier	Description	Participant quote
Alternate formats	People with SLCDs may want print material in large font or sent to them electronically so that they can read them using a screen reader on their computer.	It's easier for me to get document in electronic format so I can use my screen reader and also look up words I may not understand.
Alternate signatures	People with SLCDs, who also have motor disabilities, may have difficulty physically signing documents and require alternate signatures. Many people with SLCDs experience challenges signing documents because federal service providers question their cognitive capacity to make decisions.	Any alternate signature should be the one that is used regularly by that particular individual. It may be necessary that signatures are witnessed if it is something easily copied such as an X.
Note taking	People with SLCDs, who also have motor disabilities that affect their ability to write or type, may require accommodations to take notes at a committee meeting or public event.	In some situations, like a classroom or lecture I want someone to take notes for me or I want to record the session so I can listen to it again.
Forms	People with SLCDs, who also have motor disabilities that affect their ability to write or type, may require forms that they can complete using their communication device or computer. These forms should allow them to take frequent breaks.	I want forms in electronic format that I can use with my typing program which gives me word prediction and spell checking. I also need to be able to save forms and come back to them because I get tired when typing.



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