

Part 1: Framing Communication Accessibility in the Canadian Context

Report from the Inclusive Design Research Centre

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# Executive summary

Communication access within the Accessible Canada Act refers to what the federal service must do to ensure that a person can effectively communicate and use their service. Communication Access includes responsive environments, aids, devices, strategies, and human support (Collier, 2020). Statistics Canada (McDiarmid, 2021) research shows that 61.5% of people with disabilities in their study encountered communication barriers when accessing federal services. For people with communication disabilities, the rates would be even higher and the need for communication access within federal organizations and businesses is urgent.

Addressing this issue is the central focus of a series of reports by the [Communication Access within the Accessible Canada Act](https://idrc.ocadu.ca/commacc/) Project (Communication Access Project). This framing report is one of three reports of the Communication Access Project. The project is led by [Inclusive Design Research Centre](https://idrc.ocadu.ca/) (IDRC) at [OCAD University](https://idrc.ocadu.ca/commacc/) with input and support from [Communication Disabilities Access Canada](https://www.cdacanada.com/).

The framing report is informed by three information areas:

1. an advisory panel,
2. environmental scans and
3. guided interviews with subject matter experts.

By our estimate 4.1 – 4.8 million Canadians have a communication disability (See Communication disability prevalence in Canada below for details on how this estimate was calculated). Communication disability, however, does not have to lead to experiences of communication barriers. In systems that have appropriate designs, supports, policies and procedures, communication barriers can be prevented or addressed when they occur.

Communication access means that “policies and practices within service entities to ensure that people understand what is said or written and can communicate what they want to convey in face-to-face and telephone interactions, teleconferencing, online learning, meetings, conferences, public consultations, reading (print, websites and digital), and writing (forms, signatures, surveys and notetaking)” (CDAC, n.d., c). Depending on type of service and whether the service is critical and has serious consequences, people may need different types of communication access approaches and supports in:

* Face-to-face interactions
* Telephone or alternate to telephone interactions,
* Online learning, meetings,
* Conferences, public consultations
* Reading (print, websites and digital)
* Writing (forms, signatures, surveys and note taking).

There is no one size fits all approach, and no one approach that will fit any one individual all of the time.

We see that the impact of communication barriers is severe and threatens the very rights and quality of life that should be supported by federal services and businesses: protected rights, justice and health, financial and housing security. As inclusive researchers, we understand that impact is more important than numbers and notions of central tendency — one person excluded from services is one too many. But since numbers are needed to bring context to the gravity of the barriers faced, we embarked on learning how many people in Canada live with a communication disability (see Table 1, p. 16.)

We found, through our calculations, that 4.1 to 4.8 million Canadians experience communication disability.

Our research shows that 4.1 to 4.8 million Canadians are living with a communication disability and that they face multiple barriers when interacting with federal services and businesses.

Reliable and consistent prevalence and incidences rates of communication disability are needed to support the understanding and inclusion of individuals faced with communication barriers in federal government service contexts and to plan ways to support communication access for those individuals.

# About this report

Communication access within the Accessible Canada Act refers to what the federal service must do to ensure that a person can effectively communicate and use their service. Communication Access includes responsive environments, aids, devices, strategies, and human support (Collier, 2020). However, research by Statistics Canada with adults who had accessed federal services over a two-year period (McDiarmid, 2021) found that,

When interacting with federally regulated organizations or businesses, 61.5% of those with disabilities, difficulties or long-term conditions experienced a communication-related barrier. The proportion of people experiencing a communication barrier was similar across age groups and by gender. The only difference was among those aged 65 years and older, where men (66.5%) were more likely than women to report a barrier (60.1%).

Participants in the survey were identified from the 2017 Canadian Survey on Disability. When communication barriers related to vision and hearing are eliminated, the reports of barriers are still alarmingly high:

72.7% for those with a cognitive difficulty … 69.0% for those with a mental health-related difficulty, 64.5% among those with physical difficulties and 65.0% among those who indicated they had some other type of health problem or long-term condition. Those with multiple difficulties or long-term conditions (66.6%) were more likely to report a communication barrier compared to those with only one difficulty or long-term condition (37.9%). Among those with multiple difficulties or long-term conditions, men (68.8%) were once again more likely to report a communication barrier compared to women (64.9%).

The need for communication access within federal organizations and businesses is urgent. Addressing this issue is the central focus of a series of report by the [Communication Access within the Accessible Canada Act](https://idrc.ocadu.ca/commacc/) Project (Communication Access Project). This framing report is one of three reports of the Communication Access Project. The project is led by [Inclusive Design Research Centre](https://idrc.ocadu.ca/) (IDRC) at [OCAD University](https://idrc.ocadu.ca/commacc/) with input and support from [Communication Disabilities Access Canada](https://www.cdacanada.com/). This project builds on CDAC’s extensive work and resources over the past 20 years in promoting communication access for people with speech, language and communication disabilities within the ACA and provincial accessibility legislation. IDRC recognizes that it was CDAC efforts that resulted in “communication” being added as one of the priority areas to be addressed in the ACA. Funding for the project was provided by [Accessibility Standards Canada](https://accessible.canada.ca/).

The goal of Communication Access Project is to inform development of communication access standards and regulations under the [Accessible Canada Act](https://parl.ca/DocumentViewer/en/42-1/bill/C-81/royal-assent). The Accessible Canada Act specifically lists communication as an area where barriers will be identified, removed and prevented. In an amendment, after lobbying for clarity by CDAC, communication was further defined as including sign languages and not including information and communication technologies and broadcasting — both of with are regulated in other legislation. For clarity, we follow the CDAC proposed definition of communication: “a two-way, interactive process in which people give and receive information, using a range of communication methods in face-to-face interactions, over the telephone, online and via reading and writing” (Collier, 2019). Communication Access Project research addresses gaps in understanding of the accessibility needs of people with communication disabilities and how to meet diverse communication accessibility needs especially within federally regulated contexts. Communication For this project, the scope of communication disability is limited to speech, language, and communication disabilities due to life-long or acquired cognitive and/or neurological disabilities. Communication needs that require sign-language interpreters for those experiencing deafness or hearing loss are not part of this project.

This framing report is the first deliverable of the project; its purpose is to:

1. describe personal communication supports for Canadians requiring access to federal goods and services and
2. define the communication disability population in Canada in terms of prevalence.

Although the scope of Canadian federally regulated goods and services is quite large, in the tradition of [inclusive design thinking](https://idrc.ocadu.ca/ideas/inclusive-design-the-bell-curve-the-starburst-and-the-virtuous-tornado/) which prioritizes extreme or edge cases, we focus on communication access within critical contexts such as public health, policing, justice, public safety and border services. This approach enables us to learn from and address situations in which those already vulnerable from disabling communication environments and systems are most at risk for further trauma.

# Information sources

The framing report is informed by three information areas:

1. an advisory panel,
2. environmental scans and
3. guided interviews with subject matter experts.

At the start of the project, an advisory group of stakeholders who have lived experience of communication disability and representatives of disability organizations from across Canada was formed. We continued to grow the advisory group (currently at eleven members) in the first year of the project to better represent intersecting identities and perspectives. The advisory group advises on methods, data sources, document drafts and reports, and helped identify people with relevant experience that could be approached for a guided interview.

An environmental scan was conducted to learn about communication access in federally regulated contexts. The scope of the scan is international with a focus on literature related to Canadian government services (federal, provincial, territorial) and non-government organizations (NGOs). A second scan was conducted to gather information about incidence and prevalence rates of disabilities related to communication disability as well as incidence of communication disability within those groups. Source material reviewed in the scans included:

* federal and provincial service protocols, guides, and disclaimers regarding supports for people with disabilities
* national and international NGOs’ surveys, papers, and reports
* communication disability organization publications, online training and resources
* academic journals on communication disabilities and neurological disorders

We conducted five unstructured interviews to learn from professionals in the field about approaches for communication access, ways of communicating including no verbal or alternative and augmentative communication (AAC) and access approaches historically and currently and how communication access is being accommodated in critical government services including policing and justice systems.

Interview participants included:

* experts having lived experience of communication barriers,
* practicing communication intermediaries in the justice system,
* communication access scholars,
* leaders of non-government communication disability organizations, and
* federal government employees

We synthesized our learning from these information sources to provide this framing of communication disability and supports in Canada.

Communication is an interactive, two-way process that includes both understanding and being understood. Communication involves a range of communication methods in face-to-face interactions, over the telephone, online and via reading and writing (CDAC, n.d., b)

# Communication and communication disabilities

At first consideration, communication may seem like a basic concept without a lot of complexity. Even with further thought, the notion of communication may appear straightforward. It may be viewed as:

* the exchange of thoughts, ideas, and information
* both understanding and being understood (CDAC, n.d., a, b)
* the production of a message and the comprehension of meaning

But these simple explanations of communication have many facets: the ways we communicate, the conditions in which we communicate, the many functions that are part of communication (e.g., muscles, memory, other cognitive processes) and the many ways that communication differences may manifest. This complexity may be why prevalence rates of communication disability are difficult to find. By our estimate 4.1-4.8 million Canadians have a communication disability (See Communication disability prevalence in Canada below for details on how this estimate was calculated). Communication disability, however, does not have to lead to experiences of communication barriers. In systems that have appropriate designs, supports, policies and procedures, communication barriers can be prevented or addressed when they occur. Understanding communication and communication disability is the first step in moving towards more inclusively designed systems. Communication access means that “policies and practices within service entities to ensure that people understand what is said or written and can communicate what they want to convey in face-to-face and telephone interactions, teleconferencing, online learning, meetings, conferences, public consultations, reading (print, websites and digital), and writing (forms, signatures, surveys and notetaking)” (CDAC, n.d., c).

## Ways of communicating

Language is comprised of socially shared rules including meaning (semantics) and how base parts (e.g., symbols, gestures, words, etc.) are put together (syntax). **Language is different than speech** and can be in a variety of forms (systems) including spoken (speech), written, and pictograph (Burkhart, 2015); language can also be conveyed using gestures, body language, drawings, and symbols. Language systems can be supported by communication devices, both digital and analog or human supports such as a communication assistant or intermediary (CDAC, n.d.).

Communication may require a combination of systems, for example, written and pictograph, speech, and gestures. Supporting communication access means changing the general understanding of communication and being more flexible in determining how fast or synchronous it should be as well as how it is accomplished require. A communication exchange may require flexible practices in time, how meaning is expressed, and devices used. Perceptions of how communications are generated also require flexibility; for example, alternate ways of communication or the use of devices and supports does not mean someone is being coached in their decision-making or swayed one way or another (Howrey, 2022).

We utilize a social model of disability which holds that disability is not a trait of the individual but instead is the result of design which fails to meet the needs of the individual; disability is a mismatch between what is available or offered and what is needed. For example, an individual who communicates using a symbol board will face barriers in a court room where speech is the only modality of communication if they do not have a trained communication intermediary or assistant to interpret their message. Considering differences in how communication may be achieved and having flexible approaches to support these differences will avoid mismatches between communication systems/expectations and individuals with communication disabilities/differences. This understanding of mismatch and ways of communicating is also important in designing the policies and processes for communication in a variety of contexts.

## Conditions that can affect communication

Conditions that may affect speech production and/or comprehension include cerebral palsy, autism spectrum disorder, Down Syndrome, learning disabilities (LDs), intellectual disability, fetal alcohol syndrome (FAS), traumatic brain injury (TBI), aphasia after a stroke, dementia, amyotrophic lateral sclerosis (ALS), Parkinson’s disease, and multiple sclerosis, among others[[1]](#footnote-1). The way communication disability manifests across and within these conditions varies greatly; it can impact expression, comprehension, reading, writing and may do so to varying degrees (mild to severe).

## Functional differences in communication disability

Individuals with communication disability are highly diverse in terms of experience of barriers and access needs. Neurological conditions can affect motor production of sound e.g., speech tone and inflection ([prosody](#_Prosody)). Cognitive conditions can affect attention, memory, language processing, information processing, reading (e.g., dyslexia), comprehension development (dysmaturity, complex sentences, retention), memory and recall, and mental stamina. Organization, problem solving, executive functioning (e.g., working memory), metacognition, reasoning, and social skills are also associated with cognitive conditions and can affect a communication process (AMH, n.d.; ALS, 2022; MS Society of Canada, n.d.; LDAC, 2022, ABI Research Lab, n.d., Sutton, 2020).

## How communication differences may manifest

An individual’s communication needs, and preferences can change in different contexts and for different reasons, from one day or week to the next. Communication and speech disorders may be comorbid with other conditions, they can be lifelong (since birth) or acquired (e.g., someone may have had speech before a disruptive event such as a TBI or stroke); and some disorders are progressive (e.g., dementia or Parkinson’s disease). Communication and speech can also be disrupted by emotional or psychological stress ([psychogenic aphonia](#_Psychogenic_Aphonia)) or temporary conditions such as medical procedures or injury.

# Communication access rights

Communication access is often framed as a right. The International Communication Project and it’s 20+ participating organizations from Canada and around the world explain that communication is a basic human right because it is central to how we enjoy many other human rights such as the right to take part in the government of the country (to vote, for example), the right to education, the right to participate in community life, and the right to work. Communication is intrinsic to our humanity as social beings — our relationships are built and maintained through communication, our education and work depend on communication, and our participation in justice systems, political, and civic life are all negotiated through communication (internationalcommunicationproject.com). CDAC (n.d.b) provides specific criteria for the right of people who have speech, language and/or cognitive disabilities to accessible and inclusive services:

* Being treated with respect and having their opinions taken seriously.
* Being given the accessibility accommodations and supports they request and/or need to effectively communicate in order to access services.
* Having access to a qualified Communication Intermediary or Speech-Language Pathologist when required for effective communication in critical communication contexts such as healthcare services, capacity and consent adjudications, police, legal and justice situations.

The word, “accommodations” is falling out of favour with the disability community because it is imbued with obligation and the sense of an individual or organization having to provide “extra.” For individuals with disabilities, the need is not for “extra” but for “equitable”; they do not seek or ask for anything more special than their human rights. In this report we use the term, “access approaches” or “approaches.”

### Communication contexts

Depending on type of service and whether the service is critical and has serious consequences, people may need different types of communication access approaches and supports in:

* Face-to-face interactions
* Telephone or alternate to telephone interactions,
* Online learning, meetings,
* Conferences, public consultations
* Reading (print, websites and digital)
* Writing (forms, signatures, surveys and note taking).

There is no one size fits all approach, and no one approach that will fit any one individual all of the time.

# Communication Access Barriers

Barriers to communication access span all aspects of federal services. These barriers are discussed in more detail in the second report from this project, *Scope of Communication Access Approaches and Supports in Federally Regulated Contexts.* A compounding factor in communication access is access to clinical services which can significantly impact a person’s ability to communicate. These services include Speech Language Pathology services, AAC services, aphasia services etc. Many of these services are provincially regulated, however, they are necessarily intertwined with experiences of communication access/barriers for federal services. We learned from our experts that most of these services have long waiting lists and fund different ranges of devices. Thus, the barriers can begin before an individual interacts with federal services: If you can’t get a communication service and/or device then you can’t begin to access services. The barriers to services become insurmountable. This layering of barriers and interconnection between federal and provincial services are also detailed further in the Communication Access project report: *Scope of Communication Access Approaches and Supports in Federally Regulated Contexts.*

## Impact of communication barriers

Public services should enable autonomy, support human rights, and lift citizens out of housing, financial, and health insecurity. Canadian public services enable citizens to participate in society, enjoy intended benefits and have their rights protected. When a public service experience is inclusively designed it conveys, “you belong here, you are welcome here, we thought of you from the beginning.” For people with diverse communication access needs, most public services are *not* inclusively designed and fail to meet their communication needs. As a result, they have learned to expect barriers to access and challenging interactions; they know from experience that individuals with a communication disability are more likely to have reduced access to services, reduced quality of services, and discrimination with the risk of violation of their human rights (e.g., protection from abuse) (CDAC, n.d.d).

We have known for many years that exclusion and lack of access perpetuates vulnerability. Council of Canadians with Disabilities reports that the result of exclusion is the perpetuation of poverty of not only for people with disabilities but also for their families. (Council of Canadians with Disabilities, n.d.).

The impacts from communication barriers are many. Communication Disability Access Canada has identified over 39 forms of communication barriers and shared on their web site the different ways that the impacts of these barriers are felt form a variety of perspectives ([www.cdacanada.com/resources/communication-disabilities/communication-barriers/)](http://www.cdacanada.com/resources/communication-disabilities/communication-barriers/)). These barriers and others were sourced from the over 1000 Canadians with communication disability and are reported in Appendix B of the CDAC report, Public Consultation on Federal Accessibility Legislation: input from Canadians who have Speech, Language and Communication Disabilities (Collier et al, 2018). Fundamentally, these impacts all result in reduced access, reduced quality, reduced autonomy, and reduced safety.

Our interview participants further confirm the harmful effects of communication barriers:

Anne Abbot uses a communication assistant and shared the de-humanizing experiences and refusal of service that they have experienced in public service interactions:

Banks and hospitals, they treat me like I don’t have a brain. Worse on the phone, banks don’t understand communication assistance and refuse to help me.

Their communication assistant added their account of communication access failures:

Whether the setting is a bank or a hospital, the staff members’ questions are usually direct to me. There hasn’t been a staff member present who would know how to use a communication board.

Not surprisingly, communications barriers are frustrating for individuals unable to access services or information. Caitlin Buchel, a practicing [communication intermediary](#_Communication_Intermediaries:), shared that in critical contexts “frustration can be perceived as aggression.” Layered on top of this misperception can be other misperceptions; for example, slurred speech and slower processing can be “perceived as intoxication.” When individuals with a communication disability are assumed to be incompetent or impaired it can have devastating effects for an individual. Already fraught situations such as those encountered in the justice and policing systems or with services like border, revenue, immigration, and health can become more fraught when communication barriers give rise to and foster attitudinal barriers.

Buchel also told us that because a condition such as traumatic brain injury (TBI) can result in a variety of neurological and mood disorders and disruptions it can make communication challenging and interactions with the justice system unpredictable and sometimes dangerous. For example, syntax and odd phrasing that may occur in a courtroom can easily confuse an individual with cognitive impairments, neurological disorders, and communication disabilities. The confusion can throw the communication processes off course and lead to rulings that are not aligned with facts of the situation being discussed but rather reflective of present behaviours due to a condition.

A study in Ontario revealed that individuals aged 18 to 28 years of age who had sustained a TBI were about 2.5 times more likely to be incarcerated than those who had not sustained a TBI (McIsaac et al, 2016). This is a group that is particularly likely to find itself within the justice system, so preparations and access approaches for individuals with TBI are important to ensure that they are able to equitably participate in justice proceedings. It is very likely that the risk of incarceration once involved in the justice system is exacerbated by communication access barriers ￼ For example,

It can often be difficult for police, lawyers and other persons working in the legal system or for persons working in systems interacting with the legal system to identify that a person has a cognitive impairment. This can result in a number of barriers to access to justice resulting in such persons being denied the legal rights to which they are entitled. (Communication Access Justice, n.d.)

Strong federal regulation that sets expectations and outcomes for communication access can mitigate the sometimes-horrific impacts of communication barriers on Canadians. The benefit of federal regulation has already been demonstrated by the Canadian Radio and Telecommunication Commission (CRTC) which is a federal regulatory body. The CRTC’s [Broadcasting and Telecom Regulatory Policy](https://crtc.gc.ca/eng/archive/2009/2009-430.htm) has led to continuous improvements of the accessibility of telecommunications and broadcasting services for persons who are Deaf or hard of hearing.

# Communication access approaches and supports

[Access approaches](#_Access_approaches) and supports are as complex, diverse, and variable as communication disabilities themselves. This section outlines the general landscape of the technology and approaches often used to support communication. The next report is focused on scoping and dives deeper into the access and use of different types of approaches and supports.

Access approaches are individual supports, adjustments, adaptations, and changes to approaches, formats, and environments based on an individual’s needs and preferences to enable equitable communication within a given context when sufficient access is not available. Communication access approaches and supports can be technology, people, or a combination of both as well as environmental changes such as a quiet place for communication and communication aids like communication boards. Individuals with communication disabilities may require access approaches during any point in a communication exchange. Most people who require communication assistance usually have someone they trust to assist. However, in critical situations such as police, legal and justice services, the service provider must provide a qualified communication intermediary to ensure accuracy of communication and to avoid a conflict of interest.

A common term for communication access support is AAC or Augmentative and Alternative Communication. AAC are tools, strategies, and devices that are used to support communication in all the ways an individual may communicate besides talking. The International Society for Augmentative and Alternative Communication (ISAAC) Canada defines AAC as the “various ways individuals who cannot speak may communicate their ideas” (ISAAC Canada, n.d.). This includes a variety of techniques and tools, including picture communication symbols, line drawings, Blissymbols, and tangible objects to aid communication. AAC may be digital devices such as synthesized voice and analog devices such as communication boards, flash cards, and hand drawing. A communication device can be dedicated (e.g., Tobii Dynavox) or non-dedicated (e.g., smartphone). Human supports can include [communication assistants](#_Communication_support_personnel:) and specialized support such as [Communication Intermediaries](#_Communication_Intermediaries:) who are trained to facilitate communication in critical justice contexts. They are also often a family member, friend or personal support worker or specialized support such a Speech Language Pathologist or AAC clinician. Dedicated communication aids are acquired through clinical AAC services.

From the disability community perspective, any device whether a mobility device, service animal, or any form of AAC is an integral part of an individual’s identity; part of who a person is when fully participating in society. Maayan Ziv, activist and CEO of AccessNOW, who’s custom wheelchair was destroyed during airline travel explains that “her wheelchair is an extension of her body — when it's taken away, it strips her of her independence, mobility, health and comfort” (Balintec, 2022). AAC is just as important and connected as a mobility device is to the individuals that use them.

# Inclusive approaches

Equitable communication requires awareness of [ableism](#_Ableism) — the centring of the able body in the design of systems and within work culture. Ableism within a work and service environment can create further barriers to access. Overly generalized views of disabilities and a lack of nuanced understanding can lead to individuals avoiding interactions with people with communication disabilities and ultimately excluding them. Often avoidance is fear, fear of something they lack understanding of, such as behaviours, communication augmentation, and alternatives to speech (CDAC, n.d.).

Cultures that support inclusive practices will design with and continue to include the voices of those marginalized to better the systems that impact and exclude them. Our interview participants agree and suggest that there needs to be education in federal contexts to develop deeper understanding of communication differences and what the needs are for equity of communication, including access approaches and AAC. We learned that historically the thinking was synthesized voice would “solve” everything, which centres the “mouth talking” form of communication. And even then, there is a misrepresentation of how synthesized voice happens. Kathy Howery points out that “synthesized voice represented on TV / in media is highly edited to eliminate the time it actually takes to communicate through a device — it is not a one-to-one replacement for mouth speaking” (Howery, 2022).

John Ward, who works in federal government offices, talked about their work leading “sharing and learning circles about disability.” Through the Inclusion, Diversity, Equity, and Accessibility department in their federal office they develop trauma-informed presentations on dyslexia and neurodiversity and facilitate discussion on “how to have that within the workplace” (Ward, 2022). The inherently inclusive practice of Indigenous sharing and learning circles, when facilitated by trained employees[[2]](#footnote-2) with lived experience is a way of working toward more inclusive practices and a culture of knowing and understanding. We caution, however, that relying on employee resource groups or people who identify as having a disability to lead and educate others on accessibility can place undue burden on the individual. In cases where employees are asked to take on these roles, there should be a commensurate release from other work tasks or duties. It is also important that the employee not be “leaned on” to lead or teach colleagues, not everyone who represents a minority in the workplace is interested in this kind of role.

# Communication disability prevalence in Canada

As inclusive researchers, we understand that impact is more important than numbers and notions of central tendency — one person excluded from services is one too many. But since numbers are needed to bring context to the gravity of the barriers faced, we embarked on learning how many people in Canada live with a communication disability. Through our interviews and literature research we learned about the complexities of communication disabilities: they are vast, diverse, and intersect with other disabilities which often amplifies the communication disability.

To identify the number of people in Canada living with a communication disability we combed through research studies for data specific to identified conditions (see [Conditions that can affect communication](#_Conditions_that_can)) and their related communication disabilities.

Extracting communication disability rates, even in data-rich countries, is complex. Frequently communication disability is bundled with data collection about sensory difficulties. Communication disability also coexists with other disabilities and can be a primary or a secondary source of disability; as a result, communication disability may not be counted separately. (Wylie , 2013)

Statistics Canada, on behalf of the federal government, conducted a study in 2021 called the Survey on Accessibility in Federal Sector Organizations (SAFSO) that “asked participants about certain types of barriers and the degree to which they experienced them during their interactions with federally regulated organizations or businesses” (McDiarmid, 2021). While a priority area of the survey was communication barriers, the Canadian Survey on Disabilities, from which a sampling of participants was identified and invited to participate, does not include communication disabilities as one of its ten disability categories in its Disability Screen Questions (DSQ) (Collier, September 2020) which means that the survey findings cannot break the finding out by this disability area. We would expect that the already high levels of communication barriers reported by respondents in the SAFSO would be even higher for individuals with communication disability.

According to the SAFSO report, 73% of Canadians with disabilities, difficulties, or long-term conditions encountered an accessibility barrier while interacting with a federally regulated organization or business (note that SAFSOs research includes those experiencing deafness or hearing loss unlike our study that does not collect data of those experiencing deafness or hearing loss. See [About this report](#_About_this_report)). Communication barriers were reported by 61.5% of the survey participants and this increased by five percent when a participant had multiple difficulties or long-term conditions (McDiarmid, 2021).

Our communication disabilities research revealed that multiple disabilities or comorbidities within conditions is not unusual. For example, ASD and FASD commonly have co-occurring disabilities such as ADHD and LDs (learning disabilities such as executive functions) while FASD can also include intellectual disabilities (ID) and oppositional defiant disorder. We also learned that dementia is a co-occurring disability in the later stages of Parkinson’s for over 80% of individuals (Hely et al., 2008). These and other complex intersections of disabilities and demographics, such as the upper age group bulge in the Canadian population, increase the prevalence of communication disabilities. Co-morbidities also means that incidence rates and prevalence stats for different conditions may “count” an individual more than once. For this reason and other factors related to how our original sources represent prevalence and incidence, we provide a low and high estimate.

We found, through our calculations, that 4.1 to 4.8 million Canadians experience communication disability.

## Our numbers

The following table details our high and low estimates for incidence and prevalence of communication by related conditions.

|  |  |  |  |
| --- | --- | --- | --- |
| Associated Condition | Prevalence of condition (2022) | In-group prevalence and rate of CD (Low End) | In-group prevalence and rate of CD (High End) |
| Amyotrophic Lateral Sclerosis (ALS) | 3,000 | 2,400  80% | 2,850  95% |
| Autism Spectrum Disorder (ASD)[[3]](#footnote-3) | 1,099,030 | 1,099,030  100% | 1,099,030  100% |
| Cerebral Palsy | 84,345 | 9,634  11% | 10,082 12% |
| Dementia (including Alzheimer's) | 1,010,000 | 1,010,000  100% | 1,010,000  100% |
| Down Syndrome | 45,000 | 40,005  89% | 40,005  89% |
| Fetal Alcohol Syndrome Disorder (FASD)[[4]](#footnote-4) | 1,560,000 | 1,404,000  90% | 1,404,000  90% |
| Learning Disability (LD) | 3,900,000 | 364,000  9% | 557,700  14% |
| Multiple Sclerosis (MS) | 90,000 | 7,500  8% | 17,357  19% |
| Parkinson’s | 100,000 | 6,427  6% | 19,286  19% |
| Stroke | 741,800 | 133,524  18% | 331,691  45% |
| Traumatic Brain Injury (TBI) | 760,000 | 32,933  4% | 293,867  38% |
| Total | 9,308,830 | 4,109,453 | 4,785,868 |

Table 1: 2022 Prevalence rates in Canada of people with communication disabilities relevant to a condition

### How we arrived at our numbers

Because of the lack of specific data on communication disabilities, we used combinations of existing data to create prevalence ranges within conditions that have communication disabilities. We collated research studies from national statistics databases, journal articles, and disability advocacy group websites to come up with the estimated range of how many people in Canada live with communication disabilities. For each of the study’s identified conditions (see Conditions that can affect communication), we collected available prevalence figures from multiple studies for both conditions associated with communication disability as well as figures that directly related to communication disability. Our calculations utilized the current Canadian population of 39 million. Where we were unable to find rates within 5 years, we used incidence and prevalence calculations to project the updated number to the present day.

Prevalence is calculated by dividing the number of people having a particular condition or characteristic of interest by the total number of people in the sample. Prevalence is reported as a percentage (e.g., 5% or 5 people out of 100) or as the number of cases per 10,000 or 100,000. We primarily used point prevalence, which is the proportion of a population that has the characteristic at a specific point in time, in our calculations.

We used communication disability prevalence rates from our research (e.g., 8%-60% of individuals with stroke present with dysarthria) to produce both a low and high estimate. We began by converting the current point prevalence figure for a condition group in Canada into a decimal by dividing by 100,000 per person as a unit of measurement and multiplying by either the low or the high communication disability estimate (which is presented as a decimal). Then we multiplied this figure by 100,000 to convert back from a decimal to a new prevalence figure. We did this for multiple estimates in any given condition. For both the low and high estimates for in-group prevalence we took an average of the estimates of rates, and these are represented in the table above.

To capture the reality of published data (i.e., extreme variations in the prevalence numbers for some conditions) we presented the numbers for communication disability within each condition as a range from low end to high end (see Table 1, p. 16). It is important to note that we found data collection sources to be sporadically published in some groups. Surveillance data and cross-sectional studies typically include prevalence for the condition group but not the communicational disability(s). We had to review studies with smaller sample sizes and highly contextual circumstances. For example, the 2003 – 2004 Ontario Stroke Audit captured the incidence rate of aphasia from stroke patients admitted to emergency departments in Ontario (Dickey, 2010), or studies examining school-aged children for FASD-related behavior. Inferring rates from targeted populations can carry certain biases such as the rates of the condition being higher than in the general population (Flannigan, 2018).

Additionally, communication disabilities rarely exist in isolation and are often accompanied by additional intersecting disabilities — including moderate to severe physical or neurological disabilities — parsing out data specific to a communication disability can be difficult. This is echoed in a national study of neurological conditions in Canada, where its research methods section discusses wide variations in estimates being due to differences in methodology, populations studied, case ascertainment, or definitions used. Differences in incidence and prevalence may also be influenced by environmental, geographic, and genetic factors (Canada, 2014). Furthermore, these numbers and condition groups don’t account for temporary or episodic illnesses that can impair communication disability, which would increase our final figure.

During the process of aggregating results of communication disability prevalence, we had three key findings that informed how we expressed communication disability data in our identified groups:

1. Certain groups have acute outward expressions of communication disabilities (e.g., ALS, Parkinson’s, MS), which lend itself to a more consistent consensus on the rates of communication disability and therefore smaller range of prevalence. For example, Parkinson’s, of which there are approximately 45,000 individuals in Canada, the prevalence rate of communication disability is up to 98% of individuals within that group. When averaging out studies conducted on the expression of these communication disabilities, we came away with a figure of approximately 40,005 individuals.
2. Some neurological conditions (e.g., dementia, and ASD) have communication disabilities which aren't as distinguishable in the existing data. Communication disabilities are a prominent feature of these conditions thus we have used the prevalence number of these conditions as the prevalence number of communication disabilities for this analysis.
3. The incidence of communication disability in groups such as TBI and stroke have wider ranges of communication disability prevalence because of averaging out of the prevalence figures for specific communication disabilities. For example, the 760,000 people affected by TBI (updated from Statistics on Brain Injury, 2020), dysarthria occurs in 10 – 65% of patients (ASLHA, n.d.), while aphasia occurs in 2 – 32% of patients (Elboourne et. al., 2019). Based on these calculations, our average rate of communication disability in the TBI population, therefore, results in a range of 32,933 – 293,867.

# Conclusions and initial recommendations

We see that the impact of communication barriers is severe and threatens the very rights and quality of life that should be supported by federal services and businesses: protected rights, justice and health, financial and housing security. Our research shows that 4.1 to 4.8 million Canadians are living with a communication disability and that they face multiple barriers when interacting with federal services and businesses.

## Data collection recommendations

Reliable and consistent prevalence and incidences rates of communication disability are needed to support the understanding and inclusion of individuals faced with communication barriers in federal government service contexts and to plan ways to support communication access for those individuals. We recommend more specific communication disability national data collection, more comprehensive surveillance and monitoring (the Canadian Chronic Disease Surveillance System is an example of a collaborative network of provincial and territorial surveillance systems), and to include speech, language and communication disabilities as one of the disability types in the Disability Screen Questions (DSQ). A more comprehensive approach would include the complexity and diversity of communication disabilities and the barriers individuals face in critical contexts. Having more ways to collect data regionally and consistently can support robust data at the federal level. At the provincial and territorial level health registries and surveillance systems are not regularly available and are inconsistent in reporting across provinces and territories (the Canadian Chronic Disease Surveillance System is an example of a collaborative network of provincial and territorial surveillance systems). Based on feedback from our advisory panel, we recommend implementing inclusive design practices by integrating Indigenous perspectives and leadership at the discussion, design, and decision tables to build more inclusive approaches to communication disability data collection. Areas to address include: research protocols that align with indigenous perspectives and ways of knowing and language and labels that are inclusive of different backgrounds.

# Glossary

## AAC (Augmentative and Alternative Communication)

AAC refers to tools, strategies, and devices that are used to support communication in all the ways an individual may communicate besides talking. AAC includes both digital and analog devices, such as synthesized voice, communication boards, flash cards, and hand drawing; a communication device can be dedicated (e.g., Tobii Dynavox) or non-dedicated (e.g., smartphone).

## Ableism

Ableism is discrimination and social prejudice against people with disabilities or who are perceived to be disabled. (*Wikipedia*, 2023)

## Access approaches

Access approaches refers to parts of a design or systems or changes in existing designs or systems to make them more accessible and inclusive. Access approaches are design decisions that support accessibility and inclusion.

## Accommodations

Originally, accommodations referred to the changes that may be required to support a person with disabilities in accomplishing requirements or goals in a given situation. The word has fallen out of favour in the disability community as not properly express that access is a right. In this report we use the term access approaches.

## Aphasia

Aphasia is a brain disorder that affects communication (talking and understanding), as well as reading and writing. Aphasia usually happens after a stroke or head injury and can “mask a person’s inherent competence”. Symptoms can include incomplete sentences, word substitution, unrecognizable words, and not understanding a conversation or written material. (Aphasia Institute, n.d.)

## Apraxia of speech (AOS)

Apraxia is a brain disorder that can be acquired or present from birth. Acquired AOS can result from a stroke, head injury, or tumor and occur together with other conditions such as dysarthria and aphasia. Symptoms can include difficulty pronouncing words, inconsistent errors in speech, repeating words, errors in tone, stress, or rhythm (prosody). (NIDCD, 2017)

## Communication

Communication is an interactive, two-way process that involves both understanding and being understood. Communication occurs synchronously and asynchronously such as face-to-face interactions, communication over the telephone or an alternate to telephone, at meetings, case conferences, and online learning. Communication is required when accessing, reading, and understanding information, as well as when completing forms and signing documents. (Adapted from CDAC, n.d.e)

## Communication Disorder Assistant (CDA)

CDAs are support workers who work with speech-language pathologist (SLPs). They have a post-graduate CDA diploma or certificate, and, in most cases, prior work or volunteer experience in the field of communication disorders. (CDAAC, n.d.)

## Communication Intermediaries

Communication intermediaries (CIs) are registered speech-language pathologists (SLPs), trained to facilitate two-way communication between individuals with speech, language and/or cognitive-communication disabilities and justice professionals. Like language translators and interpreters, CIs act as neutral officers of the court. They provide the support needed for individuals with communication disabilities to have equitable access to legal, police, corrections, and justice services in Canada. (Communication Access to Justice*,* n.d.)

## Communication methods

Communication methods for people who have speech and language disabilities may include speech, vocalization, mouthing, body positioning, facial expressions, eye gaze, gestures, mime, sign language, adapted signs, writing, drawing, typing, selecting, or pointing to pictures, photographs, symbols, written words and letters on a board or device. People who are Deaf, deafened, or hard of hearing may use speechreading, lipreading, sign language and captioning in real time. (Adapted from CDAC, n.d.e)

## Communication support personnel

Communication support personnel are staff provided by attendant care facilities. They can generally provide non-medical assistance with activities of daily living in the home, such as dressing, bathing, eating, and helping with range of motion. (March of Dimes Canada, n.d.)

In some cases, such as through services like [Direct Funding Ontario](https://www.dfontario.ca/), patients are considered employers, who are fully responsible for managing their own employees (attendants) within a budget developed on an individual basis. (Direct Funding, n.d.)

## Communication supports

Communication support is human support that an individual may or may not require. Support can be provided by a Communication Assistant and must be approved by the individual who requires support. person who knows the individual well, such as a family member or support worker and who has been authorized by the person to assist them with communication. In some situations, communication support may be formal and provided by a Speech-Language Pathologist. In justice situations, a Communication Intermediary may be required, which is Speech-Language Pathologist who is trained to work in these settings. (Adapted from CDAC, n.d.e)

## Dysarthria

Dysarthria affects the muscles used for speech production. Muscles may be weak or cannot be controlled. Symptoms include slow or slurred speech.

## Dysmaturity

Dysmaturity is a common characteristic of individuals diagnosed with [FASD](#_FASD), and it is not outwardly visible. Dysmaturity refers to “widely varying levels of maturity in different areas of development, such as expressive language and language comprehension, social and self-care skills, and awareness and regulation of emotions.” ([CAMH](https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/fetal-alcohol-spectrum-disorder), n.d.)

## Dyslexia

Dyslexia is neurobiological and is “characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities.” Other characteristics include reading comprehension. (International Dyslexia Association, n.d.)

## Echolalia

Echolalia is the unsolicited repetition of vocalizations made by another person (when repeated by the same person, it is called palilalia). In its profound form it is automatic and effortless. It is one of the echophenomena, closely related to echopraxia, the automatic repetition of movements made by another person; both are "subsets of imitative behavior" whereby sounds or actions are imitated "without explicit awareness". Echolalia may be an immediate reaction to a stimulus or may be delayed.

Echolalia occurs in many cases of autism spectrum disorder and Tourette syndrome. It may also occur in several other neurological conditions such as some forms of dementia or stroke-related aphasia. (*Wikipedia*, 2022)

## FASD (Fetal Alcohol Spectrum Disorder)

FASDs refer to a collection of diagnoses that represent a range of effects that can happen to a person including hyperactive behavior, difficulty with attention, poor memory, learning disabilities, speech and language delays, intellectual disability, and poor reasoning and judgment skills. (CDC, 2022; CAMH, n.d.)

## On-the-Job-trained (OJT)

Supportive personnel with a variety of educational backgrounds including high school diploma, college diploma and/or certificate (other than CDA), undergraduate degree or training as a speech language pathologist (SLP) or audiologist from a different country than Canada.

An OJT’s education or training may be concentrated in one area (e.g., B.A. in Linguistics) or may be geared toward a certain population (e.g., early childhood education (ECE) diploma). OJTs are not specifically trained in the field of communication disorders and support. (CDAAC, n.d.)

## Perseveration

Perseveration is when someone “gets stuck” on a topic or an idea. It is a term often associated with Autism, but it can also be a symptom of a brain injury, ADHD, and is sometimes present for people with Aphasia. People who perseverate often say the same thing or behave in the same way repeatedly. They can get also get stuck on their emotions, actions, and thoughts. (Morin, n.d.; *Wikipedia*, 2023)

## Prosody

Prosody is the patterns, rhythms, and intonations in spoken language.

## Personal communication boards

A communication board is a device that displays photos, symbols, or illustrations to help people with limited language skills express themselves. The user can gesture, point to, or blink at images to communicate with others.

Communication boards are one type of augmentative or alternative communication (AAC) device. They can be simple, handmade boards or computerized programs. They can be useful in schools, homes, healthcare environments, or any community setting. (Healthline, 2020)

## Preferred Communication Method

Refers to the person’s preference in using their communication methods in a specific situation. For example, in some situations, a person may prefer to use a letter board or answer yes and no questions rather than using their speech generating communication device. (CDAC, n.d.e)

## Psychogenic Aphonia

Psychogenic aphonia is loss of voice due to emotional or psychological stress.

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1. More examples and details are available at <https://www.cdacanada.com/resources/communication-disabilities/communication-disabilities/> [↑](#footnote-ref-1)
2. certified through the Four Directions University which is in partnership with the Knowledge Circle for Indigenous Inclusion (KCII), which is housed in the Canadian Heritage [↑](#footnote-ref-2)
3. We have identified that the predominant disabilities of ASD are communication disabilities, therefore, we have used the prevalence of this conditions as the prevalence of communication disabilities for this analysis. [↑](#footnote-ref-3)
4. Studies that reveal FASD prevalence focus on children and youth and don’t include incidences of FASD in later adult diagnosis. FASD is complex with many comorbid conditions that can affect a communication interaction. One study found that out of the five most prevalent comorbid conditions two of the more common functional barriers are language disorders: receptive and expressive (Popova et al., 2016). FASD research indicates screening and diagnosis is limited which leads to underrepresentation of prevalence. The low and high prevalence of CDs figures in the table are the same in this group because we calculated based on the estimate that up to 90% of the FASD population have comorbidities that affect communication. (Flannigan et al., 2020) [↑](#footnote-ref-4)