



Communication Disabilities Access Canada

# PROJECT REPORT

August 31, 2021

**Communication Supports in Revealing and  
Exercising Legal Capacity and Decision-Making**

UNCRPD Projects: Stream 2: Legal Capacity and  
Supported Decision-Making

Project # 016515959

Barbara Collier Reg.CASLPO, F.ISAAC  
Executive Director  
Communication Disabilities Access Canada

[www.cdacanada.com](http://www.cdacanada.com)

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Name of Organization: Communication Disabilities Access Canada (CDAC)

Contact: Barbara Collier, Executive Director  
Email: Barbaracollier.cdac@gmail.com  
Tel.: 416 550 9532

## Contents

|  |    |
|--|----|
| Executive Summary.....   | 4  |
| Part 1: Background Information.....  | 7  |
| 1.1. Article 12: Equal Recognition before the Law. ....                              | 7  |
| 1.2. People who have speech, language and/or cognitive disabilities (SLCDs).....     | 7  |
| 1.3. Communication Methods.....  | 9  |
| 1.4. Communication Barriers in Exercising Capacity, Choice and Decision-Making ..... | 9  |
| 1.5. Communication Access Legislation .....  | 10 |
| 1.6. Relevance of Article 12 for People with SLCDs.....                              | 10 |
| 1.7. Guiding Principles .....  | 11 |
| Part 2: The Project.....   | 13 |
| 2.1 Goal and Objectives.....   | 13 |
| 2.2 Project Activities and Outcomes.....   | 13 |
| 2.2.1 Team Members .....   | 13 |
| 2.2.2 Advisory Meetings .....  | 13 |
| 2.2.3 Online Resources.....  | 14 |
| 2.2.4 Solicit Input .....  | 15 |
| 2.2.5 Translation.....   | 15 |
| 2.2.6 Field Test .....   | 15 |
| 2.2.7 Distribution .....   | 15 |
| 2.2.8 Evaluation.....  | 16 |
| 2.2.9 Presentations .....  | 18 |
| Part 3: Sector Recommendations.....  | 19 |
| 3.1 Capacity Assessors and Adjudicators.....   | 19 |
| 3.2 Healthcare Providers .....   | 20 |
| 3.3 Legal and Justice Professionals .....  | 20 |
| 3.4 Human Rights Agencies .....  | 21 |
| 3.5 Speech-Language Pathologists and Augmentative Communication Clinicians .....     | 21 |
| 3.6 Accessibility Policy Makers.....   | 22 |
| 3.7 People who have SLCDs .....  | 22 |
| 3.8 Support Persons.....   | 23 |
| 3.9 Disability organizations .....   | 23 |
| Appendix A: Glossary of Terms .....  | 26 |

## Executive Summary

This project addresses Article 12 in the United Nations Convention on the Rights of Persons with Disabilities (CPRD). Recognition that people with disabilities enjoy legal capacity on an equal basis is at the core of Article 12. Article 12 states that people must have access to the supports they need to exercise their legal capacity.

In the List of Issues Prior to Reporting 2019, (LOIPR), the UN Committee on the Rights of Persons with Disabilities, requested information on measures taken by Canada to ensure a “consistent framework for recognizing legal capacity, to enable access to support needed for its exercise and to withdraw the reservation of the State party to article 12 (4) of the Convention.”

This project describes the supports that people who have speech, language and/or cognitive disabilities (SLCDs) may require to reveal and exercise their capacity to make and communicate choices, preferences and decisions that affect them. As per CDAC’s mandate, the project does not address the needs of people who are Deaf or have significant hearing loss as other disability organizations address these needs. We refer readers to the glossary at the end of this report for terminology and definitions used within this report.

The project describes a unique framework and resources that includes communication practices, tools and human supports to enable people with diverse SLCDs to maximally and authentically communicate their opinions, whether they make decisions independently, with support from others or whether they rely on others to make decisions on their behalf, based on their known will and preferences. The concept of authentic communication as generated by the individual, with and without supports, is at core of our resources.

The resources developed through this project contribute a perspective to interpreting Article 12 for people who require supports in one or more areas of understanding information, retaining information, problem-solving and/or expressing choices and decisions. The resource defines communication as the foundation for all decision-making and applies a broad lens that includes any supports a person may need to authentically communicate choices, opinions and decisions that matter to them.

The project resources were developed by a multi-disciplinary team that included input from people with communication disabilities, human rights lawyers, speech-language pathologists, communication intermediaries, augmentative communication clinicians, social workers, healthcare providers and direct services providers in residential services. The team developed several key concepts which were used to guide the development of the resources and webinars. Integral to these concepts was the central role of formal and informal communication supports to reveal and to exercise maximum capacity in all decision-making situations, regardless of a person’s perceived capacity.

The project met and exceeded all its objectives. It developed a robust resource and recorded webinars which are available at no cost to users on the CDAC website and learning management system. These resources and webinars have been shared nationally and

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internationally via emails, webinars and social media to hundreds of organizations within the disability community, human rights agencies, consent and capacity boards, public guardians and trustees, legal professionals, elder abuse legal services, communication clinicians and people with communication disabilities.

The following comments provided by relevant sector representatives reflect the impact, scope and reach of this project and its resources:

*CRPD Article 12 ensures the right to equal recognition before the law, or legal capacity. The provision outlines how legal capacity can be ensured. The key to the process is putting appropriate safeguards in place, and no safeguard is more important than clear and open communication free of conflict of interest. CDAC's resources take this high-level concept enshrined by the CRPD and really flesh them out at the ground level. I've reviewed some of the resource modules and it's clear that the information and concepts examined will be extremely helpful for both people with communication disabilities and those seeking to support them. It's exactly the sort of resource that we would have imagined nearly 20 years ago when we commenced the work of drafting the Convention.*

Steve Estey, former advisor to the Canadian Government during the drafting of the CRPD  
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*This resource clearly describes what healthcare providers need to do when interacting with patients who have disabilities that affect their communication. Personally, I am of the view that it both augments and compliments the work of our committee in developing effective accessibility standards in healthcare in Ontario.*

Sandi Bell, Chair, Health Care Standards Development Committee for Ontario

*Much of this information will assist with ensuring applications have the supports they require to communicate with their lawyer/the Board. It also assists us in looking more critically at the capacity assessments themselves and the manner in which they were conducted.*

Lora Patton, Consent and Capacity Board

*Our policy colleagues will take into account communication disabilities and accommodating people with communication disabilities as they look to review disability resources currently available on our website over the coming months. We are looking for opportunities to integrate the issues raised in our work monitoring the CRPD.*

Carleen McGuinty, Canadian Human Rights Commission

*These resources allow for a better understanding from the perspective of the person with a disability. The information provided helps to better prepare if dealing with communication and/or cognitive disabilities. We have provided links to the recorded webinar and resources for capacity assessors in Ontario.*

Shelley Toland, Office of Public Guardian and Trustees

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*These resources are important, extremely well-done, respectful, reflect the important perspectives of people with disabilities and, most importantly are very needed. They do not exist anywhere else in the world.*

Sarah Blackstone United States Society for Augmentative and Alternative Communication

*CDAC's "Communication Supports in Exercising Capacity, Choice and Autonomy" are a helpful set of resources for lawyers, adjudicators, judges and legal sector workers. CDAC's tools raise awareness about barriers experienced by people with communication disabilities and how these barriers can interfere with people's rights to make decisions and choices. The tools provide information that will assist lawyers to navigate complex and challenging legal issues concerning their clients' decision-making rights. They offer much needed practical suggestions, supports and strategies that lawyers and the legal sector can use to facilitate communication with people with communication disabilities.*

Kerri Joffe, Staff Lawyer, ARCH Disability Law Centre

*Speech-Language & Audiology Canada (SAC), the national professional association representing speech-language pathologists, audiologists and communication health assistants - values the resources developed by CDAC. SAC has shared and promoted these resources to our membership and our international partners.*

Meredith Wright, Director of Speech-Language Pathology and Communication Health Assistants

*These webinars are very important to raise awareness of the issues facing people with communication disabilities. The CDAC resources are invaluable for both people with disabilities and those who are working to support them.*

Kathy Howery, President. ISAAC Canada

## **Part 1: Background Information**

### **1.1. Article 12: Equal Recognition before the Law.**

In the Convention on the Rights of Persons with Disabilities (CRPD), Article 12 addresses Equal Recognition before the Law and calls on State Parties to:

- a) reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- b) recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- c) take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- d) ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will, and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
- e) take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their financial affairs, and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

This project focused on Article 12 (c) in that it addresses measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. Consequently, it also impacts on Article 12 (d) because the provision of communication supports is integral to safeguarding the rights of people with SLCDs to enjoy legal capacity on an equal basis to others in all aspects of life.

### **1.2. People who have speech, language and/or cognitive disabilities (SLCDs)**

In Canada, reliable data on the prevalence of disabilities that affect speech, language and/or cognitive disabilities are not readily available. Unlike other types of disabilities, such as physical, intellectual, or sensory, disability-related surveys have typically not included information gathering about neurological and cognitive disabilities that affect areas of communication such as comprehension of spoken and written language, retention, problem-solving and expressive communication. Communication disability is typically narrowly interpreted as hearing loss or deafness.

However, communication disabilities affect a diverse group of people of all ages. Many disabilities, such as developmental, physical and neurological have co-occurring communication disabilities. Examples include life-long disabilities, such as cerebral palsy,

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autism spectrum disorder, Down syndrome, learning disability, or 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, head and neck cancer, and acute conditions such as voice loss.

It is estimated that 1.3% of the population in the USA (equivalent to 490,648 in Canada) cannot reliably meet their daily communication needs using natural speech (Beukleman and Mirenda, 2013) and require ways other than speech to communicate, such as augmentative and alternative communication (AAC) via the use of communication boards and devices. This number is likely severely underestimated given the increases in the number of individuals requiring AAC due to the rising incidence of autism spectrum disorders; advances in medical interventions that have resulted in improved survival, albeit with a lifelong disability; increased life spans of individuals with communication disability and increased overall life expectancy.

The number is also limited as it does not include people who experience significant communication disabilities and who do not identify as requiring or wanting to use AAC and people who speak but have disabilities that affect comprehension, retention or problem solving.

People who have SLCDs 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 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.

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 such as when a person uses a device to communicate, others may be invisible. 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, especially in a stressful situation, or when complex language and abstract concepts are required.

[More information on disabilities that affect communication](#)



### **1.3. Communication Methods**

People who have SLCDs may communicate using speech, which may be slurred or unclear. They may use gestures, facial expressions, body language, mime, sign language, writing, pointing to pictures, symbols, letters on a board or a speech generating device. These communication methods are called augmentative and alternative communication (AAC). Most people with SLCDs use a combination of communication methods depending on their preferences, the person with whom they are communicating, the context as well as whether they have access to communication support services and AAC devices. Many people with SLCDs are independent communicators and others rely on people they trust and who know them well to assist with communication. Using a AAC method does not mean that a person has difficulty hearing or understanding what others are saying.

People who have profound intellectual disabilities may use non-symbolic or non-language ways of communicating, such as body language, vocalization, facial expressions, looking at or reaching for objects. They rely on people who know them well to “interpret” what they are communicating.

[More information about communication methods.](#)

### **1.4. Communication Barriers in Exercising Capacity, Choice and Decision-Making**

People who have SLCDs can experience a range of barriers in communication situations depending on the type of disability they have, the context of communication, the skills and the familiarity of the person with whom they are communicating, how their disability affects one or more areas of communication, their method(s) of communication, personality, communication abilities and needs, as well as their access to tools and human supports.

Overwhelmingly people with SLCDs report that professionals in healthcare, legal, financial and community services, underestimate their capacity to make and/or communicate choices and decisions that matter to them. They report that professionals who determine their capacity to make decisions about their life, often:

- Equate their inability to speak as an inability to make decisions and control what happens in their lives;
- Determine their capacity without providing them with the communication supports that they require;
- Make assumptions that they have a cognitive disability and require support to make decisions;
- Defer decisions to people they have not authorized to assist them or make decisions on their behalf;
- Lack clear policies, practices and safeguards to identify and provide the supports they need to effectively and authentically communicate about matters that affect them.

Erroneous judgements about an individual’s capacity can result in serious consequences in all aspects of life. This project solicited stories about capacity judgements from people with

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SLCDs. However, it should be noted that people with SLCDs are often reluctant to share their stories because unfamiliar people may misinterpret their request for support as a reflection of their capacity.

A team member illustrated this point by saying: *“It is much easier to discuss accessibility to a physical space than to discuss communication supports as the need for these supports are so often misinterpreted as the person having diminished cognition.”*

During this project, stories shared by six people with SLCDs included the following scenarios:

- [Making a will](#)
- [Losing inheritance](#)
- [Applying for supported housing](#)
- [Moving from long-term care facility to live in the community](#)
- [Depositing a cheque to a bank account](#)
- [Negotiating a healthcare service](#)

### **1.5. Communication Access Legislation**

In Canada, there are currently no comprehensive accessibility standards that describe the duty to accommodate the accessibility requirements of people with SLCDs at federal, provincial and territorial government levels. Accessibility standards that do exist tend to focus on a respectful attitude on the part of the person interacting with the individual who has an SLCD, on sign language interpreting services, and on information transfer via accessible websites, and alternate formats, such as plain language, Braille, and large print.

While the Accessible Canada Act (2019) recognizes communication, as distinct from information and communications technologies, standards relating to communication access for people with SLCDs have yet to be developed for face-to-face interactions, telephone or remote communication; meetings, conferences, public consultations; reading and writing.

Without robust safeguards to protect their right to effective communication accommodations and supports, people with SLCDs will remain vulnerable and excluded from accessing essential services. For example, at this time, there is currently no directive for federal courts and tribunals to provide qualified communication intermediaries to assist victims, witnesses and offenders who have communication disabilities communicating in these situations. Similarly, there are no directives and safeguards in place to provide supports that people require to reveal and exercise their capacity, choice and to make and communicate decisions in medical assistance in dying situations.

### **1.6. Relevance of Article 12 for People with SLCDs**

Article 12 in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that people with disabilities enjoy legal capacity on an equal basis to others and clarifies that this requires people have access to the supports they may need to exercise their capacity to make decisions that matter to them. For people who have disabilities that affect

their comprehension and expressive communication, Article 12 is about the supports they need to reveal and exercise their capacity to control what happens in their lives.

CDAC's interpretation of Article 12 recognizes that all people who have SLCDs, regardless of their perceived and real competency, have a right **to the supports they need to reveal and empower them to exercise their capacity to independently, or with assistance, make choices and decisions in all aspects of their lives.** People need these supports in all choice and decision-making situations regardless of whether they:

- make a decision independently
- make a decision with assistance from trusted people (supported decision-making)
- rely on someone who knows them well to make a decision on their behalf, based on their known will and preference.

While some people with SLCDs may require support to make decisions, others require communication supports, tailored to their unique communication needs, in one or more areas such as:

- understanding a spoken and/or written information
- retaining information about decisions to be made
- communicating their questions, opinions, choices, preferences and decisions
- problem-solving and making decisions
- completing and signing forms

### **1.7. Guiding Principles**

The key concepts that guided our project include:

- Communication is the foundation for both revealing and exercising capacity, choice and autonomy.
- Disabilities that affect understanding and being understood can mask an individual's capacity.
- Disabilities that may affect communication include life-long disabilities such as cerebral palsy, autism spectrum disorder, Down syndrome, a learning disability, or cognitive disability. Acquired disabilities that can affect communication include traumatic brain injury, aphasia after a stroke, dementia, Amyotrophic Lateral Sclerosis (or ALS), Parkinson's disease, Multiple Sclerosis and other neurological disabilities.
- Communication supports include practices, tools and assistance in one or more areas of understanding and retaining information, problem-solving, considering risks and options, expressing questions, concerns, opinions and decisions.
- Communication is authentic when it is generated by the individual, with or without communication supports.
- Without appropriate communication supports, people who have communication disabilities do not have the safeguards they need to control what happens in their lives.

- Communication supports are safeguarding supports.
- People have different communication support needs because of the type and degree of disability they have; how they communicate; whether they have access to appropriate communication systems and human assistance as well as the context, the decision to be made and the skills of the person with whom they are communicating.
- Communication supports are integral in a supported decision-making arrangement. However, communication supports go beyond decision making as many people with SLCDs do not require support to make a decision.
- Communication support must always be applied within an intersectionality framework that recognizes an individual's overlapping identities and experiences including additional disabilities, ethnicity, creed, race, gender identity, sexual orientation, financial, linguistic, economic status, educational, and cultural identity.
- Communication supports must be in place before a person's capacity is determined and throughout the process of decision-making to ensure that their opinions and preferences are heard, acknowledged and negotiated.
- An understanding of the roles and responsibilities of a support person(s), including communication assistance, proxy/advocacy communication, and decision-making support is critical in recognizing authentic communication of the individual being supported.
- Organizations require policies, procedures, safeguards and documentation regarding the duty to accommodate the identification and provision of the communication support needs of people using their services.
- Formal speech-language pathology services are required in critical situations where:
  - the capacity assessor is not experienced or qualified to provide communication support
  - a person has a complex communication disability or no obvious way of communicating
  - a person's capacity to provide informed consent is questionable
  - if there is evidence of a conflict of interest, undue persuasion, or coercion from support person(s)
  - in critical communication contexts such as medical assistance in dying and justice settings.

Regardless of the underlying cause of a person's SLCD, this project describes a communication framework and a range of resources that can be customized to support an individual to reveal and exercise their capacity to make and communicate choices, preferences and decisions.

## **Part 2: The Project**

### **2.1 Goal and Objectives**

The goal of this project is to increase awareness of communication supports that people with speech, language and/or cognitive disabilities may require when exercising their legal capacity by developing and sharing information and resources about communication strategies, tools and resources that can be used to assist people to communicate their wishes, preferences and decisions.

### **2.2 Project Activities and Outcomes**

#### **2.2.1 Team Members**

Our team was comprised of twelve content developers with relevant and diverse expertise and experience to develop an online resource. Team members and representatives included:

- Barbara Collier (Project Manager and Primary Author of Resources)
- Glenda Watson Hyatt (Person with lived experience)
- Hazel Self (The Gage Transition to Independent Living)
- Megan Henze (Surrey Place Centre)
- Cindy DeGraff (Ontario Federation for Cerebral Palsy)
- Tracy Shepherd (Augmentative and Alternative Communication Services)
- Elyse Shumway (Speech-Language Pathology Services)
- Caitlin Buchel (Communication Access to Justice)
- Lana Kerzner (Human Rights Lawyer)
- Karen McClintock (Community Living Sarnia- Lambton County)
- Cathy Samuleson (North Yorkers Persons with Disabilities)
- Jo Watson, PhD. (Deakon University, Australia)
- Jason Jang (Webmaster)
- Glenda Watson Hyatt (Social Media Consultant)
- Laure Prechonett (Translator)

The diversity of the team allowed a broad scope of sharing of perspectives, experiences, and expertise as capacity impacts on every aspect of an individual's life. Canadian team members represented three provinces including British Columbia, Manitoba, and Ontario.

[Click here for bios on team members](#)

#### **2.2.2 Advisory Meetings**

CDAC hosted approximately ten meetings and/or e-connections with various partner groups throughout the project. Partner groups included: Canadian Association for Community Living, People First Canada, Canadian Chapter of the International Society for Augmentative and Alternative Communication, The Aphasia Institute, Ontario Federation for Cerebral Palsy,

Blissymbolics Communication Institute Canada, Gage Transition to Independent Living, Centre for Independent Living Toronto, Council of Canadians with Disabilities and Arch Legal Disability Centre.

### 2.2.3 Online Resources

CDAC developed a robust online resource that is comprised of over 100 separate items including text, webinars, captioned videos, audio slides, written transcripts. The following hyperlinks to resources are available:

- [Description of communication supports to reveal and exercise capacity, choice and autonomy](#)
- [Context of communication disabilities](#)
- [Experiences of people with communication disabilities](#)
- [Communication Support Questionnaire Form](#)
- [Overview presentation on key issues](#)
- [Animated overview of article 12 and communication support](#)
- [Guiding Questions for Service Providers](#)
- [Communications Support Chart](#)
- [Key Concepts and Belief Statements](#)
- Sector recommendations
  - [Capacity Assessors](#)
  - [Healthcare](#)
  - [Legal Professionals](#)
  - [Capacity Adjudicators](#)
  - [Human Rights Agencies](#)
  - [Communication Clinicians](#)
  - [Accessibility Policy Makers](#)
  - [People with communication disabilities](#)
  - [Support Persons](#)

- Webinars (slides, captioned videos, audio scripts and supplemental handouts)
- [Communication and Capacity: Context and Guiding Principles \(Barbara Collier\)](#)
  - [Communication Disabilities: Barriers and Impact on Choice and Control \(Barbara Collier\)](#)
  - [Legal Context for Exercising Capacity and Provision of Communication Supports \(Lana Kerzner\)](#)
  - [Communication Supports: Formal, Symbolic Communicators \(Barbara Collier\)](#)
  - [Communication Supports: Informal, Non-Symbolic Communicators \(Jo Watson\)](#)

The webinars address supports for people who have a range of disabilities and who communicate using body language, facial expression, objects, pictures, symbols and speech-generating devices. Guidelines include strategies, tools and assistance to interpret “non-verbal” behaviors, how to collectively validate interpretations, and how communication behaviors inform preferences in everyday situations such as what a person wants to do, how

they want to spend their time, and who they want to do things with. The webinars describe how these strategies can be used to maximize a person's autonomy and control in their daily lives and how they can inform support persons in more complex decision-making situations. For people who use objects, pictures and symbols, the webinars describe how visual supports can be used within a supported-decision making context in everyday life and critical situations, such as informed consent to treatment in a healthcare setting. For people who use letter boards and speech generating devices, there are resources that describe ways to facilitate communication with unfamiliar people, how to support people to use their augmentative communication systems to ask questions, communicate opinions and make decisions.

The webinars contain approximately 30 video clips that are captioned. Handouts and supplemental information accompany each webinar. In addition, written transcripts of audio are provided.

#### **2.2.4 Solicit Input**

Input was solicited from 12 project team members with diverse perspectives throughout the project. Sectors represented on the team included people with lived experience and their allies, professionals in the communication disability sector, healthcare, social services, and legal sectors. Team members provided input to the project's resource development, video clips, key concepts as well as facilitating the distribution of the final products.

#### **2.2.5 Translation**

All resources and webinars were translated into French.

[Click here for French online resources](#)

#### **2.2.6 Field Test**

Online resources were shared with all partner organizations. Feedback was requested via survey monkey. No changes were requested.

#### **2.2.7 Distribution**

- Emails
  - Information about the resource was distributed via over 100 email and social media posts on Twitter and Facebook to project partners, the Government of Canada, provincial and territorial governments that address accessibility issues and relevant stakeholders.
  - Emails about the resource were sent to over 100 national, provincial and local healthcare and financial organizations, and accessibility policy-makers.
  - Emails were sent to over 3,000 communication assistants and people registered on CDAC's learning management system.
  - Social media posts to organizations that connect with people who have SLCDs.

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- Organizations shared resources with their stakeholders and members.
- Customized webinars were provided for:
  - ISAAC Canada (Recorded for members)
  - ISAAC International (Recorded for members)
  - Canadian Human Rights Commission (3) (Recorded for members)
  - Arch Disability Law Centre
  - Ontario Public Guardian and Trustees (Recorded for members)
  - Consent and Capacity Board (Recorded for members)
  - Speech Audiology Canada (Recorded for members)
  - Stream 3 team (Neil Belanger, Steve Estey and Kerri Joffe)
- Communiqués
  - Nine communiqués were developed and shared in local and national newsletters and websites for the following sectors:
    - Human rights lawyers
    - Healthcare
    - Accessibility policy makers
    - Consent and capacity boards
    - Office for public guardians and trustees
    - Augmentative and alternative communication clinics
    - Speech Language Pathologists
    - People with SLCDs.
    - Developmental disability organizations.
- Social media postings
  - Over 100 messages were posted on Facebook and Twitter to all targeted groups, including people with communication disabilities, and allies, professionals in the communication disability sector, healthcare, financial and legal sectors.
  - Messages centered around driving people to (a) the project's main page, (b) specific sessions and/or slides, (c) the project's resources (e.g., communication support questionnaire), and (d) key recommendations.
  - Twitter monthly engagement rates average between 1.5% and 2.2%. Engagement rates for individual tweets have been as high as 4.5%-6.5% and higher, indicating the high quality of our tweets.
- Website
  - Overall usage of the CDAC website increased visits with daily average going from 80-100 to 140-160 since January 2021. This reflects an increase in accessing the resources related to communication supports and capacity.

### 2.2.8 Evaluation

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While we created a feedback survey on survey monkey, very few people responded. However, the following comments were contributed from pertinent sectors that used and distributed our resources.

*CRPD Article 12 ensures the right to equal recognition before the law, or legal capacity. The provision outlines how legal capacity can be ensured. The key to the process is putting appropriate safeguards in place, and no safeguard is more important than clear and open communication free of conflict of interest. CDAC's resources take this high-level concept enshrined by the CRPD and really flesh them out at the ground level. I've reviewed some of the resource modules and it's clear that the information and concepts examined will be extremely helpful for both people with communication disabilities and those seeking to support them. It's exactly the sort of resource that we would have imagined nearly 20 years ago when we commenced the work of drafting the Convention.*

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*This resource clearly describes what healthcare providers need to do when interacting with patients who have disabilities that affect their communication. Personally, I am of the view that it both augments and compliments the work of our committee in developing effective accessibility standards in healthcare in Ontario.*

Sandi Bell, Chair, Health Care Standards Development Committee for Ontario

*Much of this information will assist with ensuring applications have the supports they require to communicate with their lawyer/the Board. It also assists us in looking more critically at the capacity assessments themselves and the manner in which they were conducted.*

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Carleen McGuinty, Canadian Human Rights Commission

*These resources allow for a better understanding from the perspective of the person with a disability. The information provided helps to better prepare if dealing with communication and/or cognitive disabilities. We have provided links to the recorded webinar and resources for capacity assessors in Ontario.*

Shelley Toland, Office of Public Guardian and Trustees

*These resources are important, extremely well-done, respectful, reflect the important perspectives of people with disabilities and, most importantly are very needed. They do not exist anywhere else in the world.*

Sarah Blackstone United States Society for Augmentative and Alternative Communication

*CDAC's "Communication Supports in Exercising Capacity, Choice and Autonomy" are a helpful set of resources for lawyers, adjudicators, judges and legal sector workers. CDAC's tools raise awareness about barriers experienced by people with communication disabilities and how these barriers can interfere with people's rights to make decisions and choices. The tools provide information that will assist lawyers to navigate complex and challenging legal issues concerning their clients' decision making rights. They offer much needed practical suggestions, supports and strategies that lawyers and the legal sector can use to facilitate communication with people with communication disabilities.*

Kerri Joffe, Staff Lawyer, ARCH Disability Law Centre

*Speech-Language & Audiology Canada (SAC), the national professional association representing speech-language pathologists, audiologists and communication health assistants - values the resources developed by CDAC. SAC has shared and promoted these resources to our membership and our international partners.*

Meredith Wright, Director of Speech-Language Pathology and Communication Health Assistants

*These webinars are very important to raise awareness of the issues facing people with communication disabilities. The CDAC resources are invaluable for both people with disabilities and those who are working to support them.*

Kathy Howery, President. ISAAC Canada

### **2.2.9 Presentations**

Due to the global pandemic, conferences have been canceled. We redirected this activity to presenting customized webinars which are listed on page 17.

Outcome: Completed and met.

## Part 3: Sector Recommendations

The following points, in conjunction with applicable laws, rules and policies, should guide accommodation policies and practices for critical sectors when determining the capacity of an individual who has a SLCD and ensuring that people with SLCDs have the supports they need to reveal and exercise capacity in decision making situations.

### 3.1 Capacity Assessors and Adjudicators

- Mandatory training on communication supports for all capacity assessors on recognizing and accommodating the needs of people with speech, language, communication and/or cognitive disabilities
- Develop policies, procedures and documentation about how communication supports are identified and provided.
- Specific emphasis on:
  - Acknowledgment that an individual's way of communicating should not be grounds for determining their capacity to make decisions.
  - People who have disabilities that affect their SLC have a right to the supports they need to communicate and/or make decisions that matter to them regardless of whether they make decisions independently, with support from trusted people or rely on someone who knows them well to make decisions on their behalf, based on their known will and preferences.
  - An individual who has a SLCD may or may not require support to make a decision. If a supported decision-making arrangement is required, communication supports are integral to the process.
  - Communication supports include policies, practices, tools and assistance that an individual may require in one or more areas of understanding spoken and/or written information; retaining information; problem-solving, weighing up risks, consequences and making decisions; expressing questions opinions, preferences and decisions.
  - Communication supports must be in place before a person's capacity is determined and throughout the process of decision making to ensure their opinions and preferences are heard and acknowledged.
  - Alternate decision-making arrangements and guardianship should not be considered unless ALL effective communication and/or decision-making supports have been put in place.
  - Engagement of a Speech-Language Pathologist may be required to ensure that an individual has the communication supports they need throughout a hearing in the areas of:
    - Identifying and providing an individual's communication support needs for effective two-way communication
    - Determining and confirming an individual's understanding of critical information
    - Ensuring authenticity and accuracy of an individual's expressive communication

- Providing communication assistance if there is evidence of a conflict of interest, undue persuasion, or coercion from support person(s)

### 3.2 Healthcare Providers

- Ensure all front-line staff and healthcare providers have policies, procedures and training for effective communication with patients who have pre-existing and acquired speech, language, communication and/or cognitive disabilities.
- Specific emphasis on formal processes to:
  - Record a patient’s communication support needs.
  - Identify the person(s) that the patient authorizes to assist with communication, and/or decisions and ensure they have access to the support person at all times.
  - Ensure the patient has access to [communication tools](#) they use or need at all times.
  - Ensure best practices are used to support a patient in one or more areas of understanding, problem-solving, decision-making and/or expressive communication.
  - Elicit the patient’s questions, concerns, opinions and decisions.
  - Engage a Speech-Language Pathologist if:
    - Patient has no reliable way to communicate
    - Patient’s capacity is questionable
    - There is evidence of a conflict of interest, undue persuasion, or coercion from support person(s)
    - The authenticity of the individual’s communication is questionable
    - It is a high-risk situation, such as medical assistance in dying.
- Document how and when supports were provided and how decisions were made.

### 3.3 Legal and Justice Professionals

- Mandatory training for all legal and justice professionals on recognizing and accommodating the needs of people with SLCDs.
- Policies, procedures and documentation about how communication supports were identified and provided.
- Specific emphasis on:
  - Acknowledgment that an individual’s way of communicating should not be grounds for determining their capacity to make decisions.
  - Understanding that people who have disabilities that affect their SLCD have a right to the supports they need to communicate and/or make decisions that matter to them regardless of whether they make decisions independently, with support from trusted people or rely on someone who knows them well to make decisions on their behalf, based on their known will and preferences.
  - An individual who has a communication disability may or may not require support to make a decision. If a supported decision-making arrangement is required, communication supports are integral to the process.

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- Communication supports include policies, practices, tools and assistance that an individual may require in one or more areas of understanding spoken and/or written information; retaining information; problem-solving, weighing up risks, consequences and making decisions; expressing questions opinions, preferences and decisions.
- Communication supports must be in place before a person’s capacity is determined and throughout the process of decision making to ensure their opinions and preferences are heard and acknowledged.
- Alternate decision-making arrangements and guardianship should not be considered unless ALL effective communication and/or decision-making supports have been put in place.
- Engagement of a Speech-Language Pathologist or Communication Intermediary if required to ensure that an individual has the communication supports in the areas of:
  - Identifying and providing an individual’s communication support needs for effective two-way communication
  - Determining and confirming an individual’s understanding of critical information
    - Providing impartial communication assistance in critical situations and when there may be evidence of a conflict of interest, undue persuasion, or coercion from support person(s)

### **3.4 Human Rights Agencies**

Together with the communication disability community, we recommend that human rights agencies:

- Build an analysis and knowledge base about what the human rights duty to accommodate looks like to promote the exercise of legal capacity, choice and autonomy on an equal basis for people who have disabilities that affect communication.
- Develop a policy or guidelines specific to the Duty to Accommodate in the exercise of legal capacity, choice and autonomy for people who have disabilities that affect communication.
- Coordinate with all human rights commissions in Canada to develop a unified approach to communication accommodations and supports in the exercise of legal capacity, choice and autonomy.
- Engage in public awareness-raising activities to promote an understanding of the duty to accommodate in decision-making and what this entails. Focus on key sectors such as health care, capacity assessors, finance, social services, police, legal and justice services.

### **3.5 Speech-Language Pathologists and Augmentative Communication Clinicians**

We recommend that Speech-Language Pathologists and Augmentative Communication Clinicians and professional associations and regulatory bodies:

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- Develop and implement practice directives and standards for communication clinicians to work with individuals to document their communication support needs in different service contexts as well as specific instructions they want to include about decision-making in critical situations.
- If applicable, encourage and facilitate individuals, families and support persons to develop supported decision-making arrangements.
- If appropriate, support individuals to understand and communicate with a social worker or lawyer when putting a power of attorney in place for personal care and/or property in the event they become incapable and need another person to make a decision on their behalf.
- Promote the development and implementation of policies, procedures and safeguards for the provision of communication supports within key decision-making contexts such as healthcare, financial, social services, education, police, legal, justice sectors.

### **3.6 Accessibility Policy Makers**

We recommend that provincial, territorial and federal accessibility policy-makers:

- Recognize that communication accommodations and supports are as significant as better known accommodations, such as those which provide access to the built environment, alternate formats and plain language documents.
- Engage people with speech, language and communication disabilities and their representative services in the development of accessibility legislation at provincial, territorial and federal government levels for effective two-way communication and decision-making in face-to-face interactions, communicating over the telephone and remote communications, at meetings, when reading and understanding written information, using websites and social media, completing and signing forms.
- Develop accessibility standards, training and guidelines for generic, community services and essential services such as healthcare, legal, justice, financial, supportive housing, and independent living services where effective communication and decision-making is critical.

### **3.7 People who have SLCDs**

We recommend that people with SLCDs be supported to:

- Know and exercise their communication access rights
- Complete a communication support form that describes the supports they may require when using community services.
- If needed, authorize people to assist with communicating or making decisions.
- Consider putting a power of attorney in place for personal care or property in the event of incapacity.
- If required, request a Speech-Language Pathologist, or Augmentative Communication Clinician to assist with communication and a communication intermediary in a police, legal or justice situation.

### 3.8 Support Persons

We recommend that support persons and allies of people with SLCDs:

- Negotiate and document their role with the individual they are supporting. Determine if they are a communication assistant, an advocate, an interpreter, or a combination of these roles; or if they are supporting the individual to make a decision or making a decision on behalf of an individual reflecting their known will and preference.
- Ensure that they use techniques that maximize the individual's authentic communication and input into the decision-making process.
- In a formal situation, inquire about signing a confidentiality agreement with the individual and/or professional.
- Provide access to communication tools (picture boards) that the individual may require in the decision-making situation.
- If assisting with decisions, use a decision-making approach to explore preferences that may inform decisions such as [Taking Mats](#)
- Acknowledge, honour or negotiate the individual's choices and decisions.
- If applicable, support the individual to put a power of attorney in place if they become incapable and require someone to make decisions on their behalf.
- For people who have severe, profound cognitive disabilities work together with the individual and other people who know them well to interpret, document and act upon their expressed preferences and non-preferences; take into account an individual's known past and current preferences and non-preferences, will, values and beliefs, and specific intersectionality needs relating to health, emotional wellbeing, home language, gender, sexuality, religion, spirituality, ethnicity, culture, safety from abuse, neglect, self-harm or harm to others. Recognize that an individual's preferences and non-preferences may, in some situations inform decisions that are beyond their capacity to understand or express.

### 3.9 Disability organizations

We recommend disability organizations that support people who have SLCDs:

- If required, engage a Speech-Language Pathologist, or Augmentative Communication Clinician to provide communication assessment, services and/or communication boards and devices.
- Work with individuals to document their communication accessibility supports needs as well as specific instructions they want to include about decision-making in critical situations.
- Encourage people to show their communication access support document when accessing community services, especially healthcare, legal, financial police, and justice services.
- If applicable, encourage and facilitate individuals, families and support persons to develop supported decision-making arrangements.
- If appropriate, support individuals understanding and communicating with a social worker or lawyer to put a power of attorney in place for personal care (healthcare, housing, food, clothing, hygiene, and safety) or property (anything the person owns or has the sole right to use, such as money, a rental apartment, or furniture) in the

- event they become incapable and need another person to make a decision on their behalf.
- For disability organizations that support people who have severe, profound cognitive disabilities, solicit input from people who know the individual well and have a long-term, close relationship with them; ensure decision-maker has taken into account the individual's known past and current preferences and non-preferences, will, values and beliefs, and intersectionality needs relating to health, emotional wellbeing, home language, gender, sexuality, religion, spirituality, ethnicity, culture, safety from abuse, neglect, self-harm or harm to others.

#### **4.0 Future Directions**

This project revealed a significant need for education and resources for healthcare, legal, financial, accessibility policy makers and professionals in community services about the nature of SLCDs and how these disabilities impact on an individual's human right to exercise capacity and control in all aspects of their lives. This lack of awareness is evident by the omission of meaningful communication access regulations at all government levels – federal, provincial, territorial and municipal. The accommodation needs of this disability cohort are also not well defined within CRPD articles relating to Article 12, which focus mainly on supports to make decisions and do not address communication as the foundation for all components involved in making and communicating decisions.

Our resources highlight the need for a broad range of practices, tools and supports that an individual may require to either make and/or communication decisions independently, to maximize their participation in a supported decision-making context or to inform substitute decision makers about their will and preferences. The concept of authentic communication, generated by the individual is at core of our resources.

While our resources and webinars will be available, at no cost for 5 years on the CDAC website, there is an urgent need to continue to directly work with key essential service sectors, human rights agencies and consent and capacity adjudicators to develop and implement communication policies, practices and procedures that safeguard the rights of people with SLCDs to reveal and exercise their capacity to control what happens in their lives. In addition, there is a need to mobilize and increase the expertise and mandate of Speech Language Pathologists and Augmentative Communication Clinicians to take on active roles in supporting people to reveal and exercise choice and autonomy. Finally, people with SLCDs must be supported to know their accessibility rights, to negotiate the supports they require in different settings and to have access to services they can use to assist them if their rights are violated.

#### **5.0 Acknowledgment**

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supports required by people with SLCDs in order to reveal and exercise their capacity to control what happens in their lives.

## Appendix A: Glossary of Terms

**Legal Capacity:** Legal capacity is the power to control decisions. Laws regulating legal capacity demarcate when a person has the right to make decisions and when someone else will make decisions for them.

**Communication:** 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. Communication methods include speech, gestures, body language, writing, drawing, pictures, symbol and letter boards, speech-generating devices, as well as human services such as ASL/LSQ/ISL interpreting, captioning in real-time, informal and formal communication assistance.

**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 Supports:** Practices, tools and assistance that enable a person with a SLCD to effectively understand and express what they want to communicate.

**Speech, Language and/or Cognitive Disabilities:** Refers to a range of disabilities that can impact one or more areas of a person's ability to speak, hear, read, write, and/or understand what is being said. Disabilities that impact communication include cerebral palsy, intellectual or cognitive disability, autism spectrum disorder, multiple sclerosis, Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease), aphasia after a stroke, dementia, acquired brain injury, head and neck cancer, Parkinson's disease and other disabilities.

People with SLCDs include children and adults with pre-existing disabilities that affect communication; patients with recent onset (first time) communication disorders (stroke, acquired brain injury); and people with recent or temporary communication limitations due to medical interventions (intubation, tracheostomy, ventilator, laryngectomy).

People with communication disabilities are diverse and are represented across all ages, ancestry, colour, race, ethnic origin, linguistic, intellectual abilities, creed/spirituality, gender identity, sexual orientation, financial, family, marital status and cultural communities. In addition, they may or may not have additional (intersecting) disabilities such as physical, intellectual, sensory, learning ability and mental health issues.

**Augmentative and Alternative Communication (AAC):** AAC methods 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 of the alphabet.

**Communication tools / Aids:** Communication aids/tools include: pen, paper, letter board, picture board, speech-generating device, smartphone, tablet, artificial larynx, hearing aids, switches to operate call bells or devices, eye gaze technology, adapted call bells, baby monitor, pain scale, pictures that support comprehension; amplifier, and “In case of emergency cards”.

**Communication assistant:** An individual who is formally authorized by a person with a SLCD to assist them in communicating with other people. A communication assistant can be a family member, a support worker, or someone else who is familiar with how the individual communicates. A communication assistant conveys messages as generated, directed and/or approved by the individual and assists if the individual’s messages are not understood or if they require support to understand spoken or written information, or complete and sign forms.

**Proxy Communicator:** A proxy communicator or advocate communicates messages that are not necessarily generated by the individual but what they think the individual would communicate if they could.

**Decision Supporter:** A decision supporter assists an individual to make a decision.

**Substitute Decision Maker:** A substitute decision-maker makes decisions for an individual based on the person’s will and preferences.

**Speech-Language Pathologist:** A professional who conducts communication assessments, and provides communication intervention and formal communication support services.

**Augmentative and Alternative Communication Clinicians:** Speech-Language Pathologists, Occupational Therapists, Technologists and Communication Disorders Assistants who work in specialized clinics and provide picture, symbol, letter boards and speech-generating devices.

**Communication Intermediary:** A Communication Intermediary © is a qualified Speech-Language Pathologist who is trained by CDAC to support people communicating in justice situations.