



Communication Disabilities Access Canada

Report to Ms. Catalina Devandas Aguilar
Special Rapporteur on the Rights of Persons with Disabilities

Issues relating to communication barriers and supports to justice services for people who have disabilities that affect speech, language and communication.

April 4, 2019

Barbara Collier
Executive Director

Website: <http://www.cdacanada.com/>
barbara.collier@rogers.com

Communication Disabilities Access Canada (CDAC) is a Canada-wide, non-profit organization dedicated to advancing access to services for people who have speech, language and communication disabilities, that are not primarily caused by Deafness or significant hearing loss.

Context

Over half a million people in Canada have disabilities that directly affect their communication and thus their interactions with individuals, organizations, and institutions. People who have disabilities that affect communication may have cerebral palsy, autism spectrum disorder, Down Syndrome, learning disability, fetal alcohol syndrome, cognitive disability, acquired brain injury, aphasia after a stroke, dementia, head and neck cancer, Amyotrophic Lateral Sclerosis, Parkinson's disease, or Multiple Sclerosis. They may, or may not have an intellectual disability.

People who have speech disabilities may have slurred or unclear speech; or they may have no speech and communicate using gestures, pictures, letter boards, communication devices or assistance from a person who knows them well. People who have language disabilities may have reduced vocabulary, challenges putting words together into sentences and organizing sentences into a narrative. They may have difficulty processing or understanding what another person is saying and require pictures or written words to facilitate their comprehension.

While some communication disabilities are obvious, many are invisible, yet even a relatively mild concussion or stroke can have devastating consequences, particularly in highly stressful situations.

In a 2018 national survey, over 2,200 respondents identified a range of communication barriers experienced by people who have communication disabilities in everyday life. Recurring themes included not having communication clinical services and funding for communication devices, people ignoring them, not knowing how to interact with them, not understanding what they are communicating when they use alternate methods of communication, narrowing their communication to answering yes and no questions, assuming that they cannot hear or cannot make their own decisions, and relying on family members or support staff to speak on their behalf without their approval.

They told us that the consequences of these recurring, daily communication barriers can lead to social isolation, severe frustration, mental distress, loss of autonomy and control over one's life, loss of dignity, and reduced or no access to community services and opportunities.

We heard, that in the same way as people with mobility disabilities need ramps to get into buildings, people who have communication disabilities may need "communication ramps" to interact with other people and to access services and opportunities. These ramps include having ways to communicate, responsive people with whom they can communicate, and in many situations, having human communication supports to assist with communication.

We believe that communication access is fundamental to all articles in the CRPD, and that Canada can do more to address access to all goods and services for people who have communication disabilities. In our written brief, we address the urgent need for communication supports in accessibility legislation, in supporting people to exercise their legal capacity, in communicating in healthcare

131 Barber Greene Road, Toronto, Ontario, Canada M3C 3Y5 Telephone: 416.444.9532 Email: admin@cdacanada.com
Information: www.cdacanada.com

CDAC is a Registered Charity 87160 1712 RR0001

situations and especially in end of life directives and medical assistance in dying. However, in this presentation I will focus the need for communication supports when accessing the justice system in Canada.

Communication Barriers to Justice

There is ample research about the vulnerability of people who have disabilities for all types of abuses, crimes and violation of rights. We know that abuses can often occur behind closed doors and by people in positions of trust. We know that the best victim is the one who cannot tell or who is perceived not to be able to tell.

We hear stories about police officers making judgements about a person's ability to testify, based solely on their communication method. We hear of judges denying people access to the communication supports they need in courts. We hear from people who have nobody they trust to assist them communicating about abuses. We hear from people who don't know where to go for trusted advice because they know they won't be understood or because they are afraid if their concerns are known it would disrupt their family life and support services.

In 2012, we conducted a national survey of justice services across Canada to find out what accommodations, if any, they provided for victims, witnesses and accused with communication disabilities. We heard that there were no protocols, policies and procedures, no services to support people communicating in justice services and no specific training on ways to accommodate the communication needs of victims, witnesses and accused with communication disabilities. We heard that people often have to rely on ad hoc arrangements for communication assistance from family or support staff who may not always be appropriate because they may not use evidence-based techniques to demonstrate authentic communication and because people may withhold information because of privacy concerns.

Access to justice for people who have disabilities that affect communication requires a formal system that is accessible to all, that is regulated, and that protects the integrity of a person's communication while safeguarding their privacy and dignity.

While there is a precedent, in Canada for the provision of communication support services such as a sign language interpreter for a person who is Deaf, an intervenor for a person who is Deafblind or a translator for a person who does not speak English or French, formal communication support services are not available for a person who has a speech and language disability.

Emerging Best Practices

In 2016, with one-time, project funding, CDAC started to develop communication intermediary support services, using an adaptation of a well-established, evidence-based model that has been in place in the UK since 2004. The Witness Intermediary Scheme provides communication intermediaries to assist vulnerable communicators in the justice system. The program receives 530 referrals a month, which includes people who have communication disabilities. There are 200 regulated communication intermediaries working in the UK justice system. The benefits of their services are well documented in providing communication assistance to people, who would otherwise not be able to communicate in justice situations.

131 Barber Greene Road, Toronto, Ontario, Canada M3C 3Y5 Telephone: 416.444.9532 Email: admin@cdacanada.com
Information: www.cdacanada.com

CDAC is a Registered Charity 87160 1712 RR0001

With input from the UK trainers, we provided basic, online training to Speech-Language Pathologists on ways to facilitate two-way communication between a victim, witness or accused with a communication disability and a justice professional – whether police, prosecutor, Crown or in court.

Over 250 Speech-Language Pathologists took the training and agreed to go on a communication intermediary database that justice professionals could use to engage them in providing communication support. Their role, as a communication intermediary is to assess an individual's comprehension and expression; to identify areas of concern and make recommendations to justice professionals on how best to communicate with the person; to clarify a person's level of understanding; to give the person communication aids, such as pictures, or objects that they may need to communicate; to assist the person to understand questions and ensure that they can communicate their messages as accurately and authentically as possible.

Over the past 2 years, we received 56 inquiries from across Canada for communication intermediary services and we are aware of the engagement of at least, 11 intermediaries to support people communicating in police, legal and justice situations. Anecdotal feedback on the involvement of an intermediary has been overwhelmingly positive from justice professionals, victims, witnesses and accused and communication intermediaries.

The numbers of inquiries and engagements obtained through this one-time project does not reflect the true need for these services. This may be due to the fact that these services are new and new services take longer than two years to become established. It is interesting to note that the UK program started with 20 referrals in the first year of operation and in 2018, they had 6,391 referrals for intermediary services.

In our project, there was also little or no resources to promote, train and inform justice professionals on how and when to use these services and no information for people with communication disabilities on their right to request these services as an accessibility accommodation.

The need to mobilize communication intermediary services is illustrated in the case of MGW, Toronto Star June 22, 2017, which raised serious questions about access to justice for people with disabilities who have compromised communication abilities. As MGW's father notes in that article, "It seems incomprehensible to me that the justice system is not prepared to offer a disabled person who has suffered an alleged sexual assault a voice of her own in court." Despite the fact that there are seventy-nine communication intermediaries available in Ontario, none was engaged to facilitate communication between MGW and justice professionals.

Canadians who have communication disabilities have constitutional and statutory rights to have the communication supports they may need, when interacting with police, legal and justice services. The UK model is a proven example of how communication supports can be provided in a justice context. The Canadian communication intermediary project is a good start and with appropriate funding and support, has the potential to grow to address this accessibility gap in justice services. However, at this time, communication intermediary services remain inadequate, under developed and underused.

Recommendations

131 Barber Greene Road, Toronto, Ontario, Canada M3C 3Y5 Telephone: 416.444.9532 Email: admin@cdacanada.com
Information: www.cdacanada.com

CDAC is a Registered Charity 87160 1712 RR0001

CDAC proposes that Canada:

- Maintains and expands the existing database of communication intermediary services in Canada
- Provides accredited training for communication intermediaries
- Adopts a protocol to engage an independent, professional communication intermediary in situations where there is any question about the communication process and/or the reliability, and neutrality of an untrained, familiar communication assistant.
- Provides guidance and training to all justice sector professionals on communication accommodations and how and when to engage a communication intermediary
- Provides information to people who have communication disabilities on their right to request and use communication intermediary support in justice situations.

Article 10: Right to life

Currently there is no government oversight and monitoring of communication supports that may or may not be provided when negotiating Medical Assistance in Dying (MAiD). This is of great concern as a substantial body of research on the communication barriers, experienced by patients who have communication disabilities in healthcare situations, documents that practitioners may not understand how they communicate and restrict their communication to answering “yes” and “no” type questions. There are numerous reports of practitioners either underestimating or overestimating the capacity of patients with communication disabilities to give consent. In addition, the majority of practitioners have little or no training about the provision of communication accommodations and supports and often defer decision-making to family members, or in some cases caregiving staff who do not have power of attorney or the patient’s approval to make these decisions and in some cases, have conflicting interests.

Recommendations

CDAC proposes that Canada:

- Adopts the recommendations in the Vulnerable Persons Standard <http://www.vps-npv.ca>
- Establishes procedures to ensure that Speech-Language Pathologists are engaged to inform patients about alternative options and services, and assist patients who have communication disabilities to provide informed consent in MAiD situations
- Establishes regulations relating to the provision, collection and reporting on who, when, and how communication supports are provided in MAiD negotiations.

Article 12: Equal recognition before the law

Communication is at the core of exercising one’s legal rights and expressing one’s preferences, choices, wishes and decisions. People who have communication disabilities may experience challenges understanding their options, considering consequences and problem-solving around options and effectively communicating what they want. In order to exercise their legal rights, they may require appropriate methods of communication and/or human assistance. Yet, to date there has been no attention given to the role of communication assistance supports as these relate to legal capacity and supported decision-making.

Recommendations

CDAC proposes that Canada:

- Ensures that people who require alternate ways of communication have access to augmentative communication services and funding for technology
- Provides training and guidance to people who support individuals with disabilities on ways to interpret and support people in exercising their legal capacity.

Article 9: Accessibility

The federal government of Canada recently amended its emerging Accessible Canada Act to include communication disability in its definition of disabilities and communication (as distinct from information and communications) as a priority focus area for accessibility legislation. However, a review of provincial, territorial and local accessibility and human rights legislation shows that the accessibility requirements of people with disabilities that affect communication are not adequately addressed beyond information and communications technology, websites, plain language and alternate formats. These guidelines fail to address the two-way interaction needs of people who have speech and language disabilities. In addition, people who have speech and language disabilities are not included as members on accessibility standard development committees.

Recommendation

CDAC proposes that Canada:

- Adopt a broader definition of communication as a two-way process of expression and comprehension between two or more people either in person, over the telephone or via written communication.
- Include people who have speech and language disabilities on accessibility committees and as instructors in communication accessibility
- Provide information and training to service providers on how to communicate with people who have disabilities that affect their communication
- Develop regulations relating to qualified communication assistance in essential services such as healthcare, police, legal, justice and education services.

Resources

Communication Disabilities Access Canada: <http://www.cdacanada.com>

Communication Barriers: Public consultation (2018) at http://www.cdacanada.com/wp-content/uploads/2018/01/Final_Community_Consultation_for_Federal_Accessibility_Legislation_Digital_2.pdf

Communication Intermediary Services in Ontario (2017) at http://www.access-to-justice.org/wp-content/uploads/2019/01/Communication_Intermediaries_In_Justice_Services_DIGITAL_14.pdf

Communication assistance database: <http://www.cdacanada.com/communication-assistance-database>

Access to justice: <http://www.access-to-justice.org/>

Webinars for police, legal and justice professionals: <http://www.access-to-justice.org/education>

Guidelines for working with a Communication Intermediary: <http://www.access-to-justice.org/justice-sector/guidelines-for-working-with-a-victim-or-witness>

Communication Intermediaries in UK. Lexicon: <https://lexiconlimited.co.uk/>

The Advocate's Gateway: Responding to communication needs in the justice system: <https://www.theadvocatesgateway.org/>

Communication is the Key: Vulnerable Persons Standard (2018) at <http://www.vps-npv.ca/blog>

Communication Access trainings: <http://www.communication-access.org/>

CDAC brief to HUMA Standing Committee on the inclusion of communication as a priority accessibility area in the Accessible Canada Act: http://www.cdacanada.com/wp-content/uploads/2018/10/CDAC_Presentation_to_HUMA_2018_Oct_22.pdf

Communication access: <http://www.communication-access.org>

Communication access symbol: <http://www.communication-access.org/communication-access/communication-access-symbol/>