



Session 2: Communication Disabilities: Barriers and Impact on Autonomy and Control

This narrative is part of a series of online webinars that address communication supports and legal capacity. It accompanies the slide presentation at www.cdacanada.com/communication-supports-article-12.

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1. In this session you will get background information about:
 - Disabilities that can affect communication
 - You will hear from people who have communication disabilities about the ways they communicate
 - You will learn about some of the common communication barriers that they can experience
 - How these barriers can result in erroneous judgements about their capacity and how the impact of these perceptions can affect all aspects of their lives.

2. People who have communication disabilities

There are over half a million people in Canada who have disabilities that affect their communication. In this resource we focus on speech, language and communication disabilities which are not caused primarily by significant hearing loss. Other organizations address the needs of people who are Deaf or hard of hearing.

CDAC focuses on the accessibility needs of people who have disabilities that affect how they speak, and / or how they understand what others are saying, or how they read and write. It's important to know that having a disability in one of these areas does not mean a disability in another area.

There are disabilities that affect a person's speech. A person may have slurred or unclear speech or they may not be able to speak and use other ways to communicate.

There are disabilities that affect how a person understands what another person is saying. They may have a cognitive disability which affects how they can process abstract concepts or complex sentences or a person may have aphasia after a stroke which affects how they process spoken language but does not impact on their cognition.

It's important to know that there is a very wide spectrum of disabilities that affect communication in very different ways.

3. Disabilities that affect communication

Many disabilities can affect different areas of communication. Some of these disabilities are lifelong such as Cerebral palsy, cognitive, intellectual or developmental disability, learning disability, foetal alcohol syndrome, Down Syndrome, autism spectrum disorder.

Some disabilities are acquired later in life. For example, multiple sclerosis, Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease), aphasia (after a stroke or other neurological damage), dementia, acquired or traumatic brain injury, head and neck cancer, Parkinson's disease and other disabilities.

Some disabilities are very obvious – especially if a person uses a communication board or device. However, some are more hidden or invisible and affect how a person processes or understands what another person said, or remembers information that is being discussed – these disabilities can have a serious impact on a person's ability to communicate and make decisions.

Some disabilities can be described as mild – others as severe or complex. However, even mild disabilities can have serious consequences for an individual when expressing their will and preference and making informed decisions.

It's also important to note that people who have communication disabilities may have other disabilities such as physical, cognitive and hearing or vision disabilities.

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8. Barriers in Choice and Decision making

Capacity is demonstrated through communication – how we understand information and the opinions and views we express. For people who have disabilities that affect their communication, their capacity is often masked by their communication disability. They may be fully competent to make and communicate choices and decisions that matter to them and be unable to do that because they do not have the supports or communication tools they need to accommodate their communication disability.

Rather than addressing the need for communication supports, people who assess a person’s capacity often assume that their communication disability is a manifestation of diminished capacity.

People who have communication disabilities report that people talk down to them, assume they don’t understand, assume they can’t manage their affairs, and defer conversation and decisions about them to people who may be accompanying them.

On the other hand - Assessors can also make the mistake of over estimating a person’s capacity. For example, a person who has a cognitive disability such as early dementia may be very skilled at hiding their diminished ability to understand and cover that up with social chatter, which can make it difficult for service providers to get a true sense of the supports they may need.

And Professionals often assume that trusted people know best and can communicate what the individual wants – and you will hear from people about the consequences of deferring to others to speak for them.

There are currently no guidelines or safeguards in place for capacity assessors to support them to recognize authentic two-way communication with the individual and to protect people from undue persuasion and influence from other people.

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13. Perfect storm

Due to confidentiality issues, we will not show people telling their stories here – however, we are aware of many situations where people who have communication disabilities have either been denied supports to communicate, not had their decision honored or were not believed.

We know of a young woman who could not speak and signed over her entire inheritance to a family member because she could not understand what the lawyer was saying or read the documents he gave her. We know of a man with significant injuries from a car accident – being kept against his will in a hospital setting because healthcare providers think it was too risky for him to live in the community – despite the fact that the man is fully aware of the risks and is willing to live the life he wants. We know of a woman who was not believed by a police officer when she communicated about an abusive situation in her home. We know of people capable of managing their support services being denied the opportunity to live in the community solely on the basis of how they communicate and the lack of communication supports they need to live the life that they want to live.

We are not saying that everyone who has a communication disability is fully and independently capable in every situation – however, we are saying that many people with communication disabilities experience significant restrictions in their lives based on how they communicate and whether they have appropriate communication accommodations and supports.

And this is layered with an almost lack of regulations policies and procedures in essential services that specifically address how communication supports should be provided. And the lack of services and funding for the communication devices that people need to exercise their autonomy... and we have a perfect storm where people's dignity and rights can be too easily ignored or violated.

14. Take A-ways

These examples illustrate the need for a paradigm shift - moving away from medical, paternalistic, ableist approaches towards a human rights approach. Article 12 in the Convention provides a way forward by recognizing that people with disabilities have the same rights as everyone else to make choices, express preferences and decisions that matter to them.

In this session, key take a-ways include the following key points:

- There is a wide continuum of communication needs and people require different types and amounts of support.
- Communication disabilities can mask capacity.

Erroneous judgements and lack of appropriate communication supports can result in violations of people's rights and have serious consequences in all aspects of their lives.

Please join us to explore this legislation in more detail and to learn about the range of communication supports that people may need to exercise in their capacity.