



Communication Disabilities Access Canada

Session 1: Communication and Capacity: Context and Guiding Principles

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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Welcome to our webinar series on Communication and Capacity. In this session, we provide you with a context for this resource. You will hear from a number of stakeholders about the essential role of communication supports for people who have disabilities that affect their communication when exercising their autonomy to make and communicate preferences and decisions in their lives. We will also explain the guiding principles upon which this resource was developed.

1. Captioned Video.
2. In this resource, we focus on a range of topics about the supports people may need to exercise their legal right to make decisions and control what happens in their everyday life, healthcare, legal or when using services in their community. You will hear from many people who have very different perspectives and who have come together to share their knowledge and experience on this important issue.

In this session, we discuss the central role of communication in exercising control in one's life, why this resource is needed and the guiding principles or beliefs upon which this resource is built.

In session 2 we will discuss how communication disabilities can impact on one's ability to exercise autonomy and control in life.

In session 3 Lana Kerzner provides an overview of the legal context for determining and exercising one's capacity and implications for people who have disabilities that affect their communication.

In session 4 – we will explore a range of communication supports people who speak or who use communication boards or devices, may need to make and communicate preferences, choices and decisions.

In session 5 - Dr, Jo Watson provides a webinar on facilitating preferences and choices for people who communicate using body language, vocalizations and facial expressions.

3. We designed these webinars for a wide audience – because the responsibility to provide supports for a person who has communication needs lies with the professional with whom they interact – and who may be in a position to empower their capacity to make informed choices and decisions in their lives. That may be a healthcare professional, a capacity assessor, public guardian, community service provider, banker, lawyer, disability service provider, residential and attendant service providers. We think that people who have communication disabilities, and their family members, will get valuable information about their human rights to request and get the communication supports they may need. We also hope that speech-language pathologists, augmentative communication clinicians, social workers and other therapists will get useful information about the important role they can play in supporting people to exercise control over their lives. We see this webinar series as laying the foundation for the future development of context specific to training and resources that can be used by all of these sectors.

Let's hear from some of the people who have contributed to the development of this resource...

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12. Principle

This resource is based on a number of beliefs or guiding principles.

We believe that communication is the foundation for exercising autonomy – which involves the right to make choices, express preferences and decisions that matter to us. A person cannot exercise control their life without communication.

Article 12 in the CRPD clearly states that people have the right to supports they may need to control their lives and make decisions. We recognize that right to communication supports in all decision-making arrangements – whether the person:

- Independently makes decisions
- Makes decisions with assistance
- Relies on others to make decisions on their behalf

We recognize that there is a continuum of complexity in decision making – some decisions are less complicated than others – what to eat, what to do, where to go.... Some are complex – what treatment to have, who to choose as a power of attorney, how to spend my money? Where will I live? Who will I live with? Will I start a family? Should I go into a nursing home? We know that people may need support to make one decision and not another.

13. Principle

Because communication disabilities can mask a person’s capacity to make decisions and we believe that it is not possible to determine what an individual understands or thinks if they have no means of communicating. We believe that a person who has communication needs must have the supports they need prior to determining their capacity and throughout the process of decision making.

Depending on their communication needs, we believe people need different types of amounts of supports in the areas of understanding what others are saying, expressing what they want to communicate in face to face interactions or over the telephone, reading materials as well as completing and signing forms.

We believe communication supports may include strategies that the person with whom they are communicating can use, tools or communication aids for comprehension and expressions and assistance from people who know them well. And in some situations, they may require the services of a qualified Speech Language Pathologist.

14. Principle

We believe that Support persons who know the individual well can play important roles in assisting a person with communication. They may facilitate the process by being a:

- Communication Assistant – a person who conveys exactly what the individual is communicating to someone who may not understand them or a message that the individual has authorized them to convey to another person. If required, a

communication assistant would also support in understanding information that another person is saying.

- Proxy Communicator or advocate is someone who says what they think the person would communicate in a situation... in other words they are communicating in their own words and not conveying a message that is generated or approved directly by the individual with the disability.
- Decision Supporter – someone who assists an individual to make a decision.
- Substitute Decision Maker – a person who make decisions on behalf of an individual.

We believe that professional Speech Language Pathology services may be required in critical situations, when a person has a complex communication disability that is beyond the scope of practice of the professional who is determining their capacity, when a person who has a communication disability is negotiating medical assistance in dying, or testifying in court or in a situation where the authenticity of communication assistance provided by a support person is questioned and when there is evidence of undue persuasion, coercion or abuse of power.

15. Principles

We acknowledge that people have different communication support needs depending on the decision to be made and whether they are symbolic or non-symbolic communicators.

Formal, Symbolic communicators communicate using:

- Speech, pictures, symbols, writing, spelling, typing, communication device
- May or may not require supports to make and / or communicate decisions
- May or may not have challenges understanding spoken language

Informal, Non-symbolic communicators communicate using:

- Body language, facial expression, vocalizations, pointing or looking at objects and people, behaviours
 - Rely on other people to interpret preferences and choices
 - May have significant challenges understanding spoken language
- We also recognize people who cannot communicate and/or make informed decisions, even after assessment by a Speech-Language Pathologist and the provision of communication supports to maximize their communication. They may have acquired or degenerative cognitive disabilities or they may be unable to communicate due to a medical condition – intubation, drugs or medication or general level of awareness and unconsciousness. They may have to rely on trusted people to speak on their behalf and to make decisions based on their current and past known preferences, will, values, advanced directives and wishes, personal, emotional and spiritual needs.

In this resource we focus on the communication needs of formal and informal communicators – the first two categories because all too often people who have speech, language and communication

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needs find that they are perceived to be unable to make their own decisions and their lives are controlled by substitute decision makers.

Our resource aims to describe ways to maximize people's communication so they take centre stage in exercising autonomy and control their lives – with or without assistance from people they trust.

16. The Big Picture

While we will focus on communication supports in this resource, we recognize that there are many factors that relate to the implementation of Article 12 for people who have disabilities. We know that people need strong responsive personal and community networks, we see the need for independent advocates for many people who have complex communication needs; we see the need for more functional communication services and funding for communication systems, urgent need for legislation, policies and procedures that define and enforce supports for people who have communication disabilities; we see the need for public education about communication disabilities and support and the need for people with communication disabilities to be active participants in all of these initiatives.

We hope that this resource will set the stage for a greater focus on these issues in the very near future.