Communication Disabilities Access Canada

Session 4:

Welcome to Session 4: Communication Supports for Formal, Symbolic Communicators

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.

Presenter: Barbara Collier

July 2020

1. Agenda

    In this session, we are focusing on a range of communication supports that people may need if they speak, or use pictures, letter boards or communication devices. We refer to these communication methods as formal, symbolic communication methods.

    We are going to focus on strategies, tools and assistance for:

    • Identifying Communication Supports
    • Understanding Information
    • Expressive Communication
    • Assistance in Decision Making

    This is the landscape for communicating about choices and decisions regardless of whether a person makes a decision independently with assistance, or relies on another person to make decisions on their behalf. The session is a bit longer than others because there are so many factors to consider and we remind you to check the handouts if you want more information on any of the issues we highlight here.

2. Identifying Support needs

    Let's begin by exploring how to identify a person's communication support needs.

    There are three main areas to be addressed:

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

1. Practices to identify communication support needs
2. Tools to identify communication support needs
3. Defining the role of an accompanying person and whether the individual wants the person to provide support and in what areas

3. Captioned video

4. Communication Strategies

As Glenda tells us - Do not make assumptions to assume about a person's communication support needs. Begin by finding out and documenting an individual's communication support needs, either at the first meeting or, if possible, ahead of the meeting. In the next slide we will describe a tool you can use for this.

- Be prepared to allow extra time for communicating because a person with a communication disability typically takes longer to communicate – whether that's to speak, or use an augmentative communication system, or to understand what you are saying.
- Arrange to meet in a quiet, distraction free space. It sounds obvious but many communication barriers occur simply because people can't hear or concentrate on what is being discussed.
- Slow down and be patient. That's not always easy to do in a fast paced setting but rushing through communication can make it much harder on both you and the person with whom you are interacting.
- As you continue to interact with the individual, you may identify specific support needs – so always review and check things.

5. Communication Passports

Some people will have instructions on how they communicate and the supports they may need. Sometimes people refer to these instructions as communication passports. And you can get information about these passports in the handouts.

6. Communication Support Questionnaire

We have also developed a Communication Questionnaire, which you can download in the handouts.

You can either email it to the person ahead of your meeting, or complete it together with the person in your first interview. That allows you an opportunity to get to know how they communicate and discuss the supports they may require. With permission, it is good to keep this form in your files and to update it as required.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 2

You can also use this form, not only to collect information about a person's support needs, but to also guide you in documenting how you addressed their support needs.

We just showed the first page of the questionnaire here. The questionnaire guides the person to give information about:

- How they communicate
- Whether they have or want any support persons, such as family member, friend or staff person, to assist with communication or making decisions
- What supports they may need when setting up their appointments
- What supports, if any, they may need to help them understand spoken and / or written information
- What supports, if any, they may need to help them express what they want to communicate, complete forms and sign documents
- And if required, what supports they may need to make decisions

7. Identify the Role of Accompanying Person(s)

If the individual has a person with them, find out if they want that person to attend the meeting – don't assume that they do, and don't assume you can speak to the accompanying person, unless you have first checked with the individual.

Never assume that an accompanying person is a substitute decision maker.

Some people have support person agreement that assigns specific roles to people in their personal network (see supplemental resources).

Ask the individual if the accompanying person is to:

- Assist with communication
- Assist with personal services
- Assist with discussing issues and making decisions
- Be present for moral support, listen and take notes

Be sensitive to privacy issues and find out what the individual wants shared with the support person. Determine if there is a need for a confidentiality agreement.

Cindy DeGraff tells us why it is important to be very clear about the role of the support person(s).

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 3

8.   Captioned video

9.   Need for Comprehension Support

Now let's explore supports that a person may need to understand information. Understanding information is critical if a person is to make an informed decision.

It's important to remember that people who have disabilities that affect how they speak do not necessarily have difficulty understanding what you are saying.

However, many people have disabilities that do affect how they process or understand spoken language. They may have traumatic brain injury, intellectual disability, learning disability, or aphasia after a stroke.

Depending on the decision to be made, people may have limited life experiences and may not be familiar with the issues being discussed. Some decision-making situations are highly stressful with lots of new information that needs to not only be heard but processed before a decision can be made.

A person's challenges to comprehend spoken language may be hidden – they may not feel comfortable telling you that they are not understanding – they may pretend to understand when in fact they don't.

It is important to check comprehension and to provide supports that a person may need.

10.   Areas for Comprehension Supports

We will address supports that people may need understanding spoken and or written information in the following areas:

- Practices that you can use to support comprehension
- Visual tools to support comprehension for spoken information
- Comprehension assistance form to support persons
- Accessible reading materials

11.   Strategies to Support Comprehension

We all benefit when information is given to us in clear and easy ways to understand. That's even more important when a person has a disability that affects how they process and understand spoken language.

Some general good practice includes:

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 4

- Using clear, everyday language – Avoid jargon and terminology
- Use short sentences
- Give key information
- Slow your speaking rate – keep it natural but slow down a bit. Like the way I am talking now
- Pause between sentences to give the person time to process. This is one of the most effective strategies that you can use. Wait for the person to process what you have said before continuing to speak. Look for their engagement – are they following you – are they nodding their head, using facial expression to show you they are with you?
- Chunk information into manageable bits and frequently review information and check for understanding

There are different ways of doing this:

You might:

- Ask the person to tell you what they understand so far
- Ask forced alternative questions – are we talking about…or …?
- Ask yes and no questions – are we talking about a nursing home?

12. Tools to Support Comprehension

One of the most effective ways to support a person understand spoken words, abstract concepts or events is to show what you are talking about.

- If appropriate, use gestures and point to objects when talking about them
- If the individual can read, write down the key words of what you are saying
- If the person has limited literacy – point to pictures and illustrations

There are a number of excellent picture resources for Healthcare, Wellness, Justice, Community Services. These resources cannot only facilitate comprehension but can reduce a person's anxiety and fear by helping them understand and prepare for events. It's a good idea to have picture resources in your organization to use when needed.

The sample resources shown in this image includes a First Response communication book by Widget, Preventing Falls, which is a picture resource developed by the Aphasia Institute, and some books from Beyond Words, a company in the UK.

Check out the handouts for links about where to get resources to support comprehension.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 5

In the next slide you will see a video from Beyond Words about their picture books and how they can assist people with learning disabilities to understand events.

13. Captioned Video

14. Supports to Read Information
A person may want to read what you are talking about.

Always ask the person if they want you, or their support person, to assistant them to read and / or understand that information.

Use plain language in your booklets, brochures, consent forms, agreements, and contracts both in hard copy or on your website.

Plain language is a set of writing guidelines that makes it easier for people to read and understand written information. Plain language is useful for people who have low literacy due to developmental disability, learning disability, an acquired brain injury, or people who have English as a second language or poor education outcomes.

Plain language guidelines focus on simplified language and grammar, short sentences, minimal punctuation, clear font and layout and the use of pictures to support meaning.

There are a number of resources to help develop plain language documents in the handouts.

15. Comprehension Assistance

A support person can greatly facilitate a person's comprehension because they know them well, and have a sense of what they may need to help them understand information. It's your responsibility to ensure that the support person conveys accurate information and that means you must be present and observe the process.

A support person can assist by:

- Checking comprehension in respectful ways
- They can let you know if they think you are speaking in ways that are too complex for the person to understand
- They can rephrase information in ways the person understands
- They can also relate information to the person's lived experience that you may not know about
- And they may be able to provide appropriate visual support tools to assist the individual.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 6

Please refer to the handouts for a link to CDAC's online training for support persons on ways to assist people to understand information.

16. Captioned video.

17. Expressive Communication

In this next section, we focus on expressive communication. Expressive communication is how we convey what we are thinking through speech, pointing to pictures, writing, typing or using a communication device. We need ways to ask questions, express concerns, opinions, preferences and decisions.

People may require supports to express what they want to say if they:

- Speak in ways that is difficult for unfamiliar people to understand their speech
- Do not have the words to express exactly what they are thinking
- Have little or no speech and need another way to communicate
- Or if they cannot write to complete a form or sign a document

In this section, we focus on supports people may need to express what they want to communicate.

18. Areas for Expressive Communication Supports

Let's explore supports that people need to communicate what they want to say.
They may require:
- Practices you can use to facilitate their expressive communication
- They may need communication aids and tools
- Their support person to assist them to effectively communicate their message in a way you understand

19. Practices to support Expressive Communication

Basic best practice strategies that you can use to support expressive communication include:
- If it is not obvious, ask the person how they communicate
- If they use a board or device, make sure that they have access to their communication system at all times
- Ask what you should do when communicating with them
- Ask one question at a time. It's hard enough for anyone to take in several questions at a time and much more difficult for a person who communicates more slowly

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 7

- If possible, ask open-ended questions. Avoid a series of yes and no questions. Open questions begin with what, when, where, why, and how.
- Give the person opportunities to communicate what they want to say
- Tell the individual if you do not understand them. This is more respectful than pretending to understand. It allows the person an opportunity to clarify.

You can get many more tips on communicating with people from our webinar about making services accessible for people who have communication disabilities. The link is in the handouts.

In the next slide, Glenda Watson Hyatt tells us about the importance of having communication tools.

20. Captioned video

21. Expressive Communication Aids and Tools
Personal Communication systems belong to the individual and are used for everyday communication.

- People who are literate and who can write may use a:
    - Pen and paper / Boogie boards / white board or they may spell out words on a letter board, type on a tablet, a smart phone or a speech output device
    - People who are not literate may communicate by pointing at pictures, symbols on a board, or selecting items on a tablet, smart phone or device
- People use devices by typing or selecting items on a keyboard, touch screens, switches, or eye gaze technology

People usually get these boards and devices through speech language pathology or through specialized augmentative communication services.

It is beyond the scope of this resource to list all the different ways people communicate. However, there are links that can provide more information in the handouts.

22. Sample Topic Communication Boards

Some people may require context specific topic boards because they may not have the vocabulary they need in their device or on their board. People who speak and who have cognitive or learning disabilities can also use topic boards because they can provide them with options that they may not think about or may not be comfortable talking about.

For example, here is one side of a hospital board from Vidatak with phrases to communicate about health and what a person might need in hospital.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 8

Here is an example of a pain scale from Widget. It shows pictures representing no pain to severe pain and quick responses for yes, no, don't know and good and bad.

Here is an example of a board that CDAC developed to communicate court matters.

Here is a CDAC board about safety and emergencies.

A CDAC board about physical abuse.

In addition, we have a series of topic boards that people can use to tell you how to communicate with them.

We have included a list of resources in the handouts. Many of these topic boards are free and have instructions on how to use them.

In the next slide, Tracy Shepherd demonstrates the use of one of these topic boards to explore what a person may want her to do when communicating with them.

23. Captioned video

24. Role of support persons in assisting with expressive communication

A support person who knows the individual well can play a significant role in assisting with expressive communication.

To help understand the roles that support persons may play, we distinguish a person who assists with communication from an advocate or proxy communicator.

A communication assistant conveys messages generated or approved by the individual. In other words, the individual being supported is the communicator. For example, the individual may be spelling a message on their letter board – and their assistant is saying what they are pointing to. In this situation, the communicator is the user of the letter board – not the assistant.

A proxy communicator, or advocate, uses their own language. It's not generated by the individual being assisted. They are saying what they think the person wants or what they think is in the best interest of the person. This is appropriate in some situations when a person cannot communicate, even with communication supports.

For the sake of efficiency or energy conservation, a support person may shift to a proxy or advocate role rather than assist the person to communicate their own message. When this happens, we need to make sure we are checking in with the individual to ensure we are truly hearing from them.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 9

25. Captioned video

26. Captioned video

27. Expressive Communication Assistance
A support person can assist with expressive communication by:

- Explaining how an individual communicates
- Communicating what the individual has generated in situations where you have not understood
- Conveying information that the individual has directed them to share with you

They can use techniques such as echoing or repeating what the person has said or communicated, or if they can probe what the person wants to communicate if their message is not clear.

The support person must verify or confirm that what they are saying is what the individual is meaning to communicate.

When assisting with communication, a support person should not:

- Persuade or influence the individual's communication in any way
- They should not provide their own opinions, advocate or make decisions

In critical situations where there is evidence of abuse of power, coercion or undue pressure, it is important to engage a qualified Speech Language Pathologist to assist with communication. We will address this in later slides in this session.

28. Decision-making Support

Now let's focus on the supports people might need to make decisions. Remember, not everyone who has a communication disability requires support to make a decision.

However, like everyone, they have a right to get input and advice about a decision they need to make from people they trust.

This assistance may be called supported decision making, co-decision making, and shared decision making. People who assist a person to make decisions may be trusted family members, support persons, friends or anyone that the individual chooses to assist them.

Assistance to make a decision does not have to be a legal arrangement. However, as Lana Kerzner mentioned in Session 3 – there are jurisdictions in Canada where support in decision making is legally recognized.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 10

29. Communication and Decision Making

Decision making is a communication process. For formal, symbolic communicators, decision making is based on understanding information about the issues, knowing the options and consequences of options and communicating a decision.

So far in this session we have focused on comprehension and expressive communication supports – now let's address the support people may need to make decisions.

Some people need decision making support because they have reduced life experiences to draw upon to make a specific type of decision.

Some people have little or no experience making decisions because decisions have always been made by someone else – or their past efforts to make decisions in the past have been ignored or denied.

And some people who have communication disabilities may need support to make decisions in specific areas such as problem solving, organizing their thoughts, sequencing and planning for actions and events, weighing pros and cons, and considering risks and safety issues. These areas are often referred to as executive functions. They are all cognitive linguistic or communication processes.

When we address decision making support for people, we need to consider not only the decision to be made, who will assist, but also specific type of support a person may need in this situation. In other words, decision support is not just a person, it is a process within the larger lens of comprehension and expressive communication support.

30. Captioned video

31. Captioned video

32. Decision Making Support

Although the Convention on the Rights of Persons with Disabilities clearly states that people should get the supports they need to make decisions, there is little research on how this should be done. However, existing approaches to decision making models have a few common elements that should be in place:

- Be clear about the decision to be made and keep the discussion focused on the topic.
- Ensure that the individual has the communication supports they require to communicate their questions, opinions, concerns and preferences.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 11

It is a good idea to assign one person to assist with communication if there is a group – this helps provide space for the person's opinions to be heard.

- Brainstorming about options and consequences. Use visuals such as a white board or pen and paper to document the pros and cons so that everyone can see and hear what is being discussed.
- Make sure the individual is always at the centre of the discussion – giving them time to ask questions, express concerns and opinions.
- Acknowledge and honor the individual's preferences and opinions.
- If necessary, negotiate alternatives that takes the individual's perspective into consideration.

In the next video, Charlene Cratt demonstrates how she uses a process called Talking Mats to assist people to think through options and communicate preferences and decisions. She says that using a process like Talking Mats takes away some of the bias that can exist when other people are involved in decision making, and that even people who know an individual well can be surprised when an individual is given the tools and opportunity to express their opinions.

33. Captioned video

34. Topic boards for Decision-Making

Information about Talking Mats and the trainings you can take on how to use this technique is available in the handout.

You can also get links in the handout to download for a number of communications display that we developed for decision making situations.

These include:
- An agreement / consent picture – this has vocabulary not only for yes and no and I don't know, but also I need to think about it – and the option to discuss the issue with someone
- The display to explore options and choices has vocabulary to ask about choices, what will happen and a response scale at the bottom
- The display called let me tell you what I think, works like Talking mats – with pose presented – the individual can sort the pictures into positive, and negative scales
- The display is about concerns and worries – the person can use it to communicate how important an issue is to them
- You can get these and more displays in the handouts

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 12

35. Role of Decision Supporters

The literature has identified factors that contribute to positive outcomes when supporting a person in these situations. As we have already mentioned, decision supporters should:

- Know the individual well and have a respectful relationship with the individual.
- Another key feature that has been identified in positive decision-making support, is a support person who recognizes the person's right to autonomy, to take reasonable risks, make choices and decisions.
- A Speech Language Pathologist may be able to provide input on specific ways to assist people who have challenges with executive function – problem solving, sorting through options and considering consequences as well as sequencing and planning
- When appropriate, use a collaborative approach to problem solving – One person does not know everything about another person and that's especially true when an individual has a communication disability.

36. Captioned video

37. Captioned video

38. Captioned video

39. Speech Language Pathology services

Finally, we remind you that in some situations, an impartial, qualified Speech-Language Pathologist is required.

- An individual who has a communication disability may require speech language pathology services if their need for support is beyond what you can provide
- If the individual has no trusted person to assist with communication
- If there is a perceived conflict of interest between the individual and the person assisting them with communication, or
- If there is evidence of coercion, persuasion or abuse of power
- In critical situations such as medical assistance in dying, or when communicating in a police, legal or justice setting

You can get information on Speech Language Pathology and Communication Intermediary Services in the handouts.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 13

40. Policies, practices, and document

In the same way as organizations are obliged to make their spaces physically accessible to people – they must also make their services communication accessible. That means having policies, practices and documentation that complies with human rights legislation, and Article 12 in the United nations Convention on the Rights of Persons with Disabilities.

In the handouts, we provide a form that you can download and use to guide you in documenting:

- Individual's communication support needs
- How and when these supports were provided
- How informed decisions were made and by whom

You will also get links to other resources that you can use for training purposes.

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

CDAC is a Registered Charity 87160 1712 RR0001

Page 14