Session 5: Communication Supports for Informal, non-symbolic communicators.

This narrative is part of a series of CDAC 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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Hello. My name is Dr. Jo Watson, and I'm joining you here from Melbourne, Australia and it is lovely to be here with you. I'm a Speech Pathologist by background and I currently work as a Researcher and a lecturer in disability inclusion in our post-grad course in disability and inclusion at Deakin University here in Melbourne.

I've been asked to talk to you today about communication supports and what they might look like for someone who communicates informally or non-symbolically. I'm going to draw on my practice experience, but also my research to provide you with some ideas around this very important topic. For those of you who are blind or visually impaired, I will make sure that I describe any features or photos that I have. I will do my best and I will also let you know when I am moving on with slides.

We have a picture here that I have permission to show you this picture. This is a picture of a young man that I worked with and his dad. The man is looking up towards his dad in what I think is a very loving gaze. His dad is looking down at him. He's sitting in his wheelchair and it looks like they are having a very kind and warm moment there. I put this picture here because this man that I worked with he was a informal or non-symbolic communicator.

So who are we focused on? We are focused on people who communicate informally or non-symbolically. This means that they are not using formal symbols. Symbols like speech, which is what I am using now, or any kind of symbol whether it be word, or it's ok, I am giving you a sign for it is ok, sign language, it's not just speech, so written word. Anything with symbols in it.

I'm communicating using a group of symbols right now. I'm using my speech which is symbolic method of communication. I'm also using written word which is on the slides in front of you, pictures they are symbol of something. The people that we are talking about today who we are focused on are informal or non-symbolic. They are not communicating using these names. Instead, they communicate with their eyes, which you can see here in this photo, facial expression, lots and lots of facial expression. Generally, body language and sometimes behaviour that some might find challenging. Really importantly, they rely on their communication partner to have their expression preference acknowledged and interpreted and acted upon.

That's a really important point, that they are dependent on others and that's why it is really important for us as communication partners to be equipped with some strategies and skills to support people who communicate informally. So the other characteristic of someone who communicates informally is that they are most likely to have difficulty understanding communication that is symbolically. So if I'm just using speech with someone who is an informal communicator, it is going to be very difficult for them to understand what I'm saying. So as a good communication partner I would omit what I am saying with a lot of sound and gesture, I might use real objects, use a very topically a bottle of liquid sanitizer, so that is a real object to help someone understand what's going on. So that's who we are talking about here.

Now changing slide

Now here we have here a slide that says a person who communicates informally is likely to need a range of supports to have their preferences honoured. That's no surprise, but what are those supports? I'm going to spend the remainder of this webinar talking about some these supports. So firstly, what I would like you to do, is to understand your role as a decision maker supporter. We will talk about that. We will discuss the model of decision making support and the importance of relational closeness. We will talk about getting to know a person's history and life story and getting to know someone beyond their disability. We will talk briefly about supporting the building of networks. If we understand that relational, or autonomy, or autonomy is important for this group and we understand then that other people are really important in supporting that autonomy, we need to focus on how best to support the building of these networks. We are also going to talk briefly about breaking down systematic barriers. Supporting risk taking as well, another important concept that comes up often when we are talking about decision-making for this group.

So I have changed slides

And here we have a model of that I think this model helps us understand our role as a communication supporter. So in front of us, we have two interlinked circles. The first circle has text inside that says "role of the person being supported" and the other circle which is interlinked to that circle says "role of supporters". So what we say here is that the role of the person being supported is to express their preference using informal communication and people do that all the time. The people that you are supporting, they are living up to their end of the bargain. They are using a lot of expressive preferences using informal communication. Then there is our role as supporters is to be responsive. Our role is responsiveness. To respond to that expression of preference and what we are seeing is from my research what has come out of that is that there are three key components to that responsiveness. Firstly, we need to acknowledge and not ignore someone's expression of preference, then we need to interpret that expression of will and preference, and then the final component is to act on that interpretation. So these are the three roles that I would like you to go away with thinking about in terms of your role as someone who supports someone who communicates informally. So, for the rest of this webinar, I'm going to unpack some of the concepts that underlie this responsiveness.

Changing slides

The first thing I'm going to do is share with you a model of decision making support that I developed a while back for informal communicators. I had implemented this model, developed this model and implemented it through an actual research project and this is what we have sort of come up with. This is embedded into a research of listening to those needed to be heard and there is a video, you can access the video around that online. Now in front of you is a circular diagram. It is a pie diagram. There are four segments of that pie and they represent stages of decision making support. So firstly identify decision and options together, secondly listen together, then explore options and build evidence together and make decision and act on it together. Around this circle is the word 'document' because documentation, however we do it, whether it be with the written word or with video, we'll explore some of that in a minute, is really very important. And also I'm reluctant to talk about these elements as stages and the reason is what we have found in our research is that this process is dynamic, and it is fluid. It's not linear. Okay. So we might start with listening, but then we might move to going back to identifying a decision and the options together. So all of these we also might listen together, explore some options and then go back and listen. So all of these stages, whether they identify the decision, listening, exploring the options and making decisions, documenting, they all intersect. You will see what I mean as we move on.

So moving slides

Let's start with that pie, the first part of the pie and that is "identify decisions and options together." Now a person's voice can be very, very loud when information is gathered and documented properly. Try to remember that it is really important that we document through all these stages. So the first question is, is there really a decision to be made? So ask yourself the question. Whose decision is it? Whose agenda is it? If a decision is placed on somebody because it might be a decision around, this is a decision that happened to me, not to me, that I supported that was placed in front of the gentleman that I was supporting and the decision was whether or not, not whether or not, but what kind of new bed he was going to buy? So his supporters around him felt that it was really important that he get a new bed. That is because they were having difficulties his supporters were having difficulties with their backs. Their backs were being injured and so the decision was in front of him of how he and what bed he was going to buy. Really important decision. There is no argument about that. But the question is whose decision and who was it important to. He was very comfortable with his bed, however the decision was focused on him, because he was the one that was spending the money. So having think about the decision that is being made and whose agenda is it. Who is it about? Who is likely to benefit from that decision.

In the case that I just spoke about, the people that were going to benefit were his supporters. Okay. Then we need to think about all the options. Think outside the square. What has traditionally happened to people with intellectual disability in particular is that options have been restricted, particularly when it comes to decisions around relationships. Okay. We need to think outside the square. All options need to be put on the table, okay, and we need to keep our own values and our own perceptions of what is important at the door. Then we need to document, document, document. Okay. Really important that we get this down and document it. This whole decision making process.

The next slide

We're talking about listening together. So we need to listen, we need to listen to a person's sounds, their cries, their laughter, their scratches, their smiles and their grimaces, their tapping, their shouts and their silences. We need to listen, sit and listen and we need to discover what is important to them by following their eyes to things that might interest them, excite or perhaps scare them. Okay. So really zoning in to what that person is telling us in their communication. Listen to people who know and love them. That's really important because they are likely to know their history and their life stories. Our identity, our preferences, likes and dislikes, they are reflected in the stories that we tell ourselves and we tell each other. We'll explore that concept a little more in a minute.

We need to discover who the person is beyond their disability. So if they have complete control of their lives, who will they be? Again we are going to talk about that a little more. And we need to explore a person's sensory preferences, because they can form the building blocks to their decisions. Okay. So I am somebody that really enjoys place around the therapy. Around me at the moment is a lovely orange set which is my favourite and that is something that impacts on my decisions about what I cook, what I eat, where I might go on a holidays. So all of those things are really important. So we need to be really clear about what people's sensory preferences are. Guess what, we need to document, document, document. It doesn't have to be in written form. It can be using video.

I'm changing slide again

And we are talking about exploring options and building evidence together. We are just going to highlight this word together. You will see throughout this whole model that I'm talking, that the word together is tacked on to every phrase. We say that because if we can continue on with that big collective decision making of relational autonomy, togetherness is the key. So this is not just about one person supporting someone to make a decision, this is about a whole circle of support, with checks and balances in place. So together is really, really important when we do this. We might disagree and that is okay, but often it's just about unpacking some of that. So we all need to explore options and make decisions. We all need to do that and we need to do it in a way that is likely to understand as well, and that is no different from people with intellectual disability. Someone who communicates informally is likely to understand their options when they experience them first hand in the 'here and now'. So very, very concrete. Okay. So they are more likely to understand the real objects, so we need to think about how options are presented, and based on what you know about someone's preferences, you can likely collate a list of activities or options for them to explore. So we are going to unpack this idea in a minute when I talk to you about someone that I supported.

But what I'm saying here is, if we think about the things that he enjoys, a man that I supported recently, he really enjoys magazines and clicking through magazines. He also enjoys laminated things. So when we did his activities together as a circle of support, we came up with a bunch of activities that involves those things, so lamination and newspaper. Okay. So try to work out what is really important to someone and taking that and putting into their activity. We need to support them to feel, taste, listen to their options, to someone's options. Okay. So when I explore my options, I'm looking for a house for example, I might go look up a bunch of options online, touch the walls or physically go there and have a look. That's the same for the people that we are supporting, that communicate informally. We need to allow a lot of time. This takes time okay, any kind of approach like this if we are going to do it right takes time and we need to document this, what did we find out when we explored someone's options.

So **moving on to our next slide, and this is make decisions and act on it together**

So together, what we want to do his support the person to make and act on their decision. We want to check that no particular agenda is driving the decision. Remember we talked earlier on in the model on the importance of understanding whose decision it is and keep in mind that the choice may not reflect what is important for the person, but what is important to them. That's something those of you who have been working in the field for a long time will be very familiar with that person-centered planning man track which says that we need a balance of what's important to us and what's important for us. So for me, I have Type 1 Diabetes. It's very important that I don't eat seven donuts a day. Very important for me that I don't, however it is really important to me that I eat some. Okay. So we need to have that balance. Really, really important.

So moving slides now

I spoke earlier about some of the things that I wanted to explore with you that underlie good support for informal communicators. So I wanted to explore with you some of the conflicts that have come out in my research and other people's research that are really, really important. Now one of them is relational closeness. On this slide we have a picture of a lady that I worked with and she is having a dance. She loves music. This is a quote from some of my research from a support worker and he said “he is just not as lucky as some other guys in the house. The only people who really give a …..about him are us support workers. Imagine a life like that.” So what they are saying here is highlighting that relational closeness is important for everyone, including people with intellectual disabilities.

So how can we foster this relationship? So we know it’s really important, and we do. We know that it’s really important to that role that we have of responsiveness. Remember the two circles that I talked about before that our role is to be responsive. What I found in my research is that the closer that someone is relationally to someone the more responsive they are, not a surprise. So what underlie this relational closeness, what we have seen is that getting to know someone’s history and life story is really important and also getting to know someone beyond their disability and supporting someone to increase their social networks. So let’s unpack that a little bit.

So here we have a photo of a beautiful little baby and I would say a grandma looking gorgeous and smiling. And the title of the slide is to get to know a person’s history and life story. So this is where I want you to think about the people that you support. If they were able to tell you their life story what would they say? Have you think about how you might document that answer? What do these stories when all pieced together tells us about that person’s preferences? Okay. So one activity that some of the people in my circle that I support and work with will do is just write down someone’s life story and from there it’s amazing how much we can learn about someone’s preferences. We need to document these stories. Document, document, document. Again, it keeps coming back to documentation.

Here is a new slide

And there is a picture of a book here representing stories. I really love this quote from Nick Grove who has done some beautiful work in the UK around story telling for people who communicate informally. She says “Stories are important! They nourish our imagination, fill our dreams, entertain and inspire us. We use stories every day of our lives – every time we see friends, visit the doctor, return something we have bought, explain key facts to policemen, solicitors, teachers, social workers and ticket collectors. Stories are the way we make sense of what has happened and so they are critical to our sense of who we are. Our identities exist in the stories we tell ourselves and others.” And I think that probably that last sentence is really important. Our identity exists in the stories we tell ourselves and others. So what I would like you to do is think about how we can tell the stories of the people we support

So changing slides here

What can we learn about someone's stories? Here are some quotes that I will share with you about some of the people I've supported that were kind enough to share their quotes with me for my research. So the first one, "we used to take him up to Echuca. (Echuca is a place probably about 3 hours north of me here in Melbourne on the Murray River. It's a very beautiful spot, very dry) He liked to go for a ride in the speedboat. We used to sit him up in the speedboat and he used to get excited with the water splashing and that sort of thing. He might be like me I'm a bit of a speed freak!" So those kinds of stories enable us to unpack what someone's preferences might be. And then another quote here. This was about the same man. This was actually at this man's funeral. And I was commenting on the jelly slice that was at his mom's place and she said to me, "it was everything that we all know he wanted, coz you know, we know him love. We have known him all his life. And Dave reminded me, you know his cousin, you know the one with the hair, (he had very curly hair) he reminded me about the jelly slice that he loved before the peg (gastronomy the tube that was in his stomach that fed him) when he was teeny tiny. So we had to have that after didn't we, with a cuppa you know. He would have loved it."

So really pulling apart these stories which tells us so much about someone's preferences. He really loved that jelly slice. What was it in the jelly slice that he loved? Was it the texture of the jelly? Was it the smell? Was it the sweetness? He really loved being on the speedboat? Was it the water? Or just being there? Was it how windy it was? So unpacking some of this.

The other thing that is really important, is the concept of getting to know someone beyond their disability. A Norwegian Researcher and Psychologist called Bylin did some work many, many years back which has resonated with me so much to the point that I've used it regularly in my practice. What he says, or asks us to do is to think about who someone might be beyond their disability. So seeing someone beyond their disability. This is a picture of me and riding a horse in the Andes in South America. So if I was to unpack that story you would learn a lot more about me. And what we saw were people who were really responsive to someone in our research. Someone's expression of their preference was more likely to see them beyond their disability. So we ask people to think about those they supported beyond their disability and we ask questions like this, "If Kevin had control over the stereo in the bus, what would he listen to? Yeah, oh yeah he likes some like rock type music, like ACDC (an Australian band). Yeah something with a bit of guts" "yeah, you're right, something with guts, loud loud loud! Yeah louder the better hey Kev. A deep heavy base line don't ya reckon, Nirvana or maybe even Primus." So asking people to unpack things, to ask these questions and then unpack it gives us so many more clues about someone's preferences.

Here's another photo of me in Chile

Well not of me. It's a picture of some food and some lovely mountain in the background. So we ask this question if he had complete control over his life what food would he want? "he'd be a foodie I reckon. You know creamy yummy cheese, flash wine, chocolate, the works."

This is a new slide

If she had control over her life what would it look like? “she just really like interacting with other people, singing, dancing, you know. She would make a great cheerleader.” (Why wasn’t she a cheerleader? You would ask that question) “ he would be comfortable, but stylish. He wouldn’t wear these trackie daks (Trackie daks are track suit pants.. trying to pick up on the Canadian term…they are like sports pants). I think he would be quite social. He has that Scottish sense of humor. He would have to have a very fast car. I always thought he would be a courier or something like that.” So when we think about some of these things that support workers are saying, we ask ourselves the question, why isn’t he eating cheese and drinking flash wine? Why is he wearing those trackie daks?

So really, what is important too is this idea that we also need to do our best to support people’s relationship. So we know that relationships are really important. So what can we do to support them. One of the things that has come out in my research is a little challenging for me. There’s qualitative data that suggests that one of the barriers to relationship building is people’s personal hygiene. So that’s something that can easily be fixed. So we have one of the quotes here that I will read to you from my research, “ I know that this sounds awful, but I can’t I was shock when I met him. Is it awful that I dry rench. Gary had smell, I’m so sorry I sound so awful.” So that was a quote from a support worker. And I think it is really very telling that all our supporters assist people to be the best they can be in terms of their hygiene. Really, really important and a difficult thing to talk about.

A really important part about this idea is collaboration, we come together, we support people collaboratively. This is a circle of support, some of the people and a lady that I worked with and some of her circle of support coming together for a cup of tea to really explore this process of decision-making support.

The other thing that is really important is the idea that the disability service system has a real impact on people, and we need to do all we can to make sure that some of these systemic barriers are not there just there for no reason. We need to challenge some of these.

And we can do that in a number of ways. So some of the things that have come out of my research is this idea that support workers right to occupational health and safety, so for example the back bit that I was talking about before, is more important than the preferences, and I think there need to be. I’m not saying that a person with a disability that is being supported that their preferences are completely not paramount. However, I think the pendulum has gone a little too far in some services.

The other thing that I think is really important, is this idea of support with risk taking. So when I take risks I do so often with support from people who love me and that should be the same for people with intellectual disabilities, people who communicate informally.

I want to demonstrate this conundrum, I guess, by sharing with you some information about two men that I was supporting.

One decision that is often faced with people with multiple disabilities and often with people who communicate informally, require pegs or feeding tubes in their stomachs, and often there is a decision to be made as to whether or not that peg goes in. If someone is aspirating regularly you know it is very dangerous and often there is a decision to be made whether or not food is consumed through a peg or orally.

So there were two men that I was supporting both were faced with exactly the same decision. As their Speech Pathologist I have assessed them as both are at risk for aspiration as you probably know is very dangerous. So one gentleman in particular he was somebody who was probably, he was probably more of a formal communicator. So he was able to tell us his preferences in a formal way. And then another fellow he was an informal communicator and I want to compare the two for you just to highlight the differences in the way, that due to someone's level of intellectual disability or cognition, or cognitive disability, they are supported to make decisions.

So for the man who was an informal communicator, here is a quote from his support worker, "well he as aspirating all the time. It was just too risky. We had no choice. He was always in hospital with pneumonia. No, even if he could participate in the decision he would have had no say. It had to go in, you know, it was a matter of life and death. Ask Tina the speechie (Speech Pathologist). That's just the way it had to be."

So here is a quote for a man who was a symbolic communicator, "well it was hard. Kev loves his food. I mean he really loves his food, hey guys. So, we know what he would prefer, but he had so many bouts of pneumonia and he gets so sick. Remember that Christmas he was in hospital, poor love. But we weighed things up and it was clear that he wanted to eat orally, so even though he now has the peg, we let him take risks and eat most days. It's just really important to him, so it's worth the risk. That's what we reckon anyway."

So you can see that there is an hierarchy of the right to take risks here. Kev, who has the same support network, the same support workers as the man with in the purple quote, for some reason it is okay for him to take risks, but for Dave that's not the case. I share that with you because I want to highlight the issues around having different rules with people with more severe cognitive disability.

Now one of the things we just talked about was systematic barriers to a person having their will and preference heard and acknowledged, interpreted and then responded to. We've seen from our research that relational closeness is really important and what we also see is system barriers around the development of these relationships.

So this is a quote from a Manager, “I’ve told her (the paid support worker) that she shouldn’t be dropping in there for a cuppa! She knows too much about Neil and his family. It’s ok that she shares superficial things with them, you know, tell them about what movies she has seen and what she got up to on the weekend, stuff like that. But that should be it. She’s way too open with them. I think she wants to be their friend.”

And when we think about people with intellectual disability and formal communicators and their reduced social network it’s very, very important that we challenge ourselves, or we challenge the system when we hear things like this, “it was decided that the pair’s relationship was wrong, that such a friendship was unprofessional and crossed the boundaries of what was acceptable. So it stopped. No more meals with the family. No more days out or festive fun.”

So that is a paid supporter who was talking about a man she supported who she invited for Christmas and she was told that that was unprofessional and I think there needs to be some acknowledgement that we do need to be careful. But I also think that, particularly for people who rely so much on relational closeness, to have their own preference heard. We need to begin to start asking some questions around this relational closeness.

So this is another quote from a paid supporter, “I don’t know. We get all these mixed messages. You can’t step over the line in terms of professional and personal stuff. I don’t get it. It’s impossible. I’m meant to care, but I’m not meant to care.”

New Slide

Okay, so just to finish off I’m going to share with you a little story of my friend Tom. So Tom is someone who we felt, the circle of support, is bored on the weekends and so what we did is we used the model of decision making support and we started off thinking about whether the decision making needed to be made. And we all agreed that yes he has some money to spend and it was important that we explored with him how he might spend his money.

So we made a list of activities we have collate over the years, and one of them was, one of the things that we agreed that he really enjoyed was sunshine and warm. So he really enjoys being warm and touch objects. There is a picture here in front of us of him touching a cast iron, iron shed, we have many these here in Australia and on very, very hot days they can get very, very hot and very dangerous so we need to be very careful with Tom.

So we made a list of the things that he really enjoys, nice walks, sunny days. We also agreed that when we looked at all the activities he enjoys what was common in there was movement, he really enjoys being in the car, sticking his head out the window, whether that's the wind in his face or the movement, we're not sure. But we made a list of all of those things and what we then did is we came up with some activities that we thought he might enjoy based on that list of preferences. Then we explored those preferences and by spending a series of six weekends together videoing him and engaging him in some of those activities. So this is a video of Tom engaging with a shed in a park near his home.

So I'm just going to play this video. You don't need to hear the sound, but you can see there he is touching the shed, some interaction. So what he's doing is touching the shed and the support worker is playing a little game with him and trying to rattle his nose.

So what we did was we watched this video together, we unpacked it, we paused it, we went backwards and forward as a group, so that's the circle of support, and we tried to work out what he might be telling us. We had hours and hours of this kind of video but I am showing you this one because this is one where we began to explore. What we can see here is that he really enjoys that surface, so we explored him engaging with surfaces like that some more and then we built a picture of what he might be telling us through his preferences. And we came up with a decision about one activity that he might like to do. A decision was made based on all of this information that we collected as a group that he might like to purchase his own shed and so we did that. We supported him to go to a hardware store here in Melbourne and purchase his own shed, which is now in his back yard, which he enjoys often. So that is one activity that came out of our little exploration.

This is another video of Tom he is on a ride in a amusement park here in Melbourne called Luna Park and he's on a ride. We decided to explore his options because when we did that analysis of things he really liked, what it seemed to us is that he really liked movement and the wind in his face. So we thought we would try some of these rides. We were really concerned he never being on anything like this before. So here is a video of him.

So at the end of that video you saw a very slight smile on his face. But those of us who know him know that that is a really rare thing. He doesn't smile all that much. He is usually very agitated and he makes a very high pitch noise a lot of the time because he is often very agitated.

When we took this video back to the group there was resounding agreement that this was something that Tom really, really enjoyed. In fact we looked at this video and I find at the time with the support worker and we are very clear that he was indicating to us his preference to have another ride. So that day we had four or five rides. He spent quite a bit of his money and there's no question to us who was the author of that decision that day and it certainly wasn't us, because it was a sunny day, hot day and I would certainly have preferred to get out of there. So I thought I would just finish on that note.

It was lovely talking to you and I hope that it has been a useful webinar. Here are my contact details Joannewatson@deakin. There is a bit of typo there, but those of you who are interested follow me on Twitter those of you who like to tweet, I’m very active on Twitter as well. You can follow me at Joanne Watson.

So thank you so much everyone and take care.