QuickGuide

How to make sure people with complex communication needs are heard in a Peer Support group meeting

Introduction

A person has Complex Communication Needs (CCN) if they are "unable to use speech to meet all of their communication requirements, given their age and culture."
(Porter & Kirkland, 1995)

It is important that all members of a peer network are heard. It is all important that people living with CCN have a voice and are supported to be heard. Article 21 of the UN Convention on the Rights of People with Disabilities states that Peer Support should:

> *take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.*

People with CCN may become socially disconnected when they are not heard - or not given their full communication rights. Being socially disconnected has a health effect equivalent to smoking 15 cigarettes a day (Holt-Lunstad, Smith & Layton, 2010).

Communication rights help people have real choice and control over their lives, and enables people to greater safeguarding if they are able to express preferences and report abuse and neglect themselves.

Meeting a person's communication rights is the most important factor in preventing challenging behaviour in any person.

Let's make it happen

Below are some suggestions to ensure people living with complex communication needs are heard in a Peer Support network:

Before the meeting

- Peer Support organisers should make expectations clear before the first meeting. Expectations are that everyone consider what it means to have full communication rights. They can do this by completing the **Having a voice - Self Assessment tool** (which you can download from this website).

- An appropriate agenda for the meeting should be provided to people with CCN and supporters before the meeting in an accessible format.

- Peer support organisers can ask people living with CCN and their supporter if any modifications are required to meet their sensory needs e.g. people may prefer bringing a sensory object or sitting on the floor. People with CCN may need to face a certain way when communicating. Do volume or lighting levels need to be changed, or when and how food is served? etc.

On the day

- In Peer Support meetings, people should always be encouraged to use any signs, body or face movements, sounds, pointing to objects or other ways to communicate.
- People living with CCN should be given equal time to "speak" in whatever way they do.
- The group should try to recognise any and all attempts to communicate.
- Other people need to stop and listen when a person with CCN tries to communicate in any way. People should never talk over when a person with CCN is communicating.
- People with CCN can always choose not to speak if they don't want to, or "speak" in a different way. Group members should acknowledge when a person chooses not to say anything.
- If a person with CCN tries to communicate, other people should assume what they "say" has meaning (Jorgensen, 2005).
- Group members should ask the Peer Support organiser or supporters if they do not understand what someone says.
- To have real choice and control a person needs be able to say everything they want to say. This means all people with CCN have a right to use a full language system. This could be a kind of sign language, braille, an alphabet, being helped to scan or type or using a symbol-based system. (In research a "full language system" is called a comprehensive "Augmented and Alternative Communication" [AAC] system or simply a "speech system".)
- All group members should read **Don't believe the Myths about people with CCN** (which you can download from this website).
- If a person with CCN has no full language system the Peer Support organiser can help them find an provider for a full language system that suits their needs.
- No person with CCN should ever be forced to communicate in a way that they do not want to. No one should be forced to talk using any communication system.

- People with CCN are more likely to talk if the group talks about topics that are of interest to them. Watch this video by Carly Fleischmann Video (1min30secs in)

  https://www.youtube.com/watch?v=YEhc1o8oKeI

Where you can find more information

Information on the Graduate Certificate of Education (Special Needs: Complex Communication Needs) at Edith Cowan University, WA. This is perhaps the most comprehensive and up to date course for people wanting to learn about people living with Complex Communication Needs. This course can also be audited by members of the public.

http://www.ecu.edu.au/degrees/courses/graduate-certificate-of-education-special-education-complex-communication-needs

PrAACtical AAC is a website that supports a community of professionals and families who are determined to improve the communication and literacy abilities of people with significant communication difficulties.

It has an article on ten things to do when using full language systems Augmented and Alternative Communication (AAC)

http://praacticalaac.org/praactical/begin-aac-now-10-things-to-do

Another useful article on this website is practicing useful behaviours when using full language systems (AAC)

http://www.speakforyourself.org/2014/01/04/aac-detective-try-observing-five-behaviors-clues

The website below has information on what it is like to use a full communication system (AAC) yourself.

http://www.communicationmatters.org.uk/page/having-conversation

Valid has some useful Tips for Presenters:

http://www.valid.org.au/

Icebreakers: You could introduce a WIFLE practice

http://actioncoachohio.blogspot.com.au/2011/06/wifle-powerful-simple-team.html

In South Australia, the Communication Partner Service assists the communication between those with complex communication needs and criminal justice personnel to ensure the best and most accurate account of evidence can be provided.

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The service is delivered by trained volunteer Communication Partners who have experience in law, disability, community services and/or speech therapy and can help vulnerable victims, witnesses, suspects and defendants to coherently communicate in police interviews and court proceedings. See the website below for more details

http://lifelineadelaide.unitingcommunities.org/find-a-service/services/communication-partners/

References

Holt-Lunstad J., Smith T.B., & Layton J.B (2010) Social Relationships and mortality Risk: A meta-analytic Review. PLoS Med 7(7)

Jorgensen, C. (2005). The least dangerous assumption: A challenge to create a new paradigm. Disability Solutions, 6(3), 1-15.

Porter, G. & Kirkland, J. (1995). Integrating Augmentative and Alternative Communication into Groups Programs: Utilising the Principles of Conductive Education. Melbourne, Australia: Spastic Society of Victoria.

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