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Supporting People with Complex Communication Needs
to be Public Speakers.

*An exploration with the Merger of Minds peer group for adults with Complex
Communication Needs.*

Merger of Minds

Introduction

People with Complex Communication Needs (CCN) are generally not expected or supported to consider themselves to be public speakers. However, it is not only possible but is also important to offer experiences which support people to have a voice in public forums and to know that their perspective on a range of issues matters, and can be shared in the wider community.

This project focussed on supporting the group of adults with CCN who are members of the Merger of Minds peer group to explore public speaking. Most of the group can at times have behaviours which others might describe as non-typical, and which could make the process of engaging in public speaking more complex.

Merger of Minds is hosted by Perth man Eli Dickenson who has CCN and is a nationally recognised advocate for people with CCN. Eli is an experienced presenter and has given talks nationally. His role in this project was as a mentor, but he also developed his public speaking skills and experiences further through engagement in the project.

This project

The purpose of this project was to support people with disability to have the capacity and confidence to be public speakers, and for the community to have increased awareness of the contributions that people with disability make and how to support and appreciate them. Whilst some of the group members have absolutely made tangible contributions to their communities, the main theme of this project is that people with disability make a contribution just by being themselves - the gift of the person that they are is enough. Therefore the focus of each individual presentation was about each person expressing more about who they are, and also to share how they want people to engage with them.

Preparation and support

The complex support needs of this group involved challenges with accessing Alternative and Augmentative Communication (AAC) systems such as PODD books and iPad software. Sensory processing was also a factor for all of the group members and presented barriers to engagement. Consequently it was necessary to engage with experienced communication practitioners to have skilled support in navigating the needs of the group. With the right support members of the group were able to do much more than their supporters had previously thought possible. This is important as we come across many adults where it has been assumed that they have limited capacity for communication, whereas it is more likely that the right support approaches haven't been used.

Addressing anxiety and self-belief

The most significant barrier in terms of engaging the group was their levels of self-confidence. We have been aware for some time of the discomfort people who use AAC systems can have using their communication system in public, for example to order food from a cafe. People can experience significant pressure and performance anxiety in social settings too where they feel an expectation to communicate, and this stress can affect their ability to engage.

Starting a process of working towards public speaking introduces an additional layer of anxiety which is familiar to most people, so before starting work it was essential to address this.

Most of the group members told us that they either definitely didn't want to present in public, or that they weren't sure. We were very careful throughout the process to reinforce the message that nobody would have to speak if they didn't want to. We also introduced the idea of alternative formats for public speaking as a continuum which they could engage with however they liked, namely:

1. Give a talk by yourself, and control your own technology (this might mean initiating a pre-recorded speech with a switch, and then engaging with the audience non-verbally)
2. Give a talk with a supporter of your choice, who might control your technology
3. Pre-record a talk and ask a supporter or peer to present it, while you are present in the audience or nearby
4. Pre-record a talk and ask a peer or supporter to present it, and you don't have to be present at all
5. Pre-record a talk and make it available online
6. Don't give a talk at all

Having these options mapped out seemed to really help group members to allay their anxiety and to give the project a go. However, addressing their self-belief to be able to be public speakers was also important. We addressed this more incrementally by doing smaller presentation tasks and practicing in the safe and familiar context of the Merger peer sessions. It can not be reinforced strongly enough that participants needed to be confident that there would be no pressure on them at any point to engage unless they really wanted to.

We also tried to address group member's self esteem in a fun way by doing an introductory topic of Super Heroes which everyone seemed to enjoy, with the theme that everyone is a super hero. Many super heroes in popular culture have a disability or difference as well as extra-ordinary abilities. The group enjoyed making comics with members as their favourite super hero.

Saying hello

The process of writing talks was scaffolded into a series of smaller tasks over a number of months to build confidence and avoid group members feeling overwhelmed. This began with exploring different ways of greeting people, at first generally in life and then when giving a talk. We explored the different types of greetings, and when more and less formal greetings were appropriate. We engaged in shared writing and created a reader with different ways people in the group say hello, and then made a language display to share. Group members really enjoyed and engaged in having a broader menu of greetings to choose from in the group and in their life, and we practiced different ways of saying hello to a group of people in the Merger sessions as well. Some group members chose to add a wider range of vocabulary for greeting people to their AAC system as well.

Acknowledgement of Country

The group members were given the opportunity to watch examples of Acknowledgement of Country and also to have this modelled at the start of each Merger peer group session. We made a reader explaining why we do an Acknowledgment of Country. One of the

group members was very interested in this and with support has programmed an Acknowledgement of Country into his communication system, and has taken a number of opportunities to use this, including for his support team meetings.

Things I like

For a first presentation the group decided to talk about things they like. Firstly in sessions the facilitator, and then two of the peer group members, modelled talking about the things they like. For peer group members with more confidence using their communication system we made a reader which suggests scanning the different categories in their system to find an overall topic related to things the person likes and then exploring the vocabulary in that system to identify the topic in more detail. Whilst this is an area often explored, we did discover some new things that were liked or of interest to most of the peer group members with a more focussed approach.

For group members less confident in using their system we used the NDIS Planning card sets (photos sets) which Merger of Minds co-designed in a previous DDWA project using the topics Activities, Work, Special Events, Animals, Places and Transport (see https://ddwa.org.au/complex-comm-needs/). This approach worked especially well with two men in particular who engaged well with the cards and used them to be very clear about things that they like.

Why I like the things I like

Once group members had made a list of things they liked that they would be willing to share, the discussion was extended to an exploration of why they liked those things. We scaffolded the discussion using Categories in each AAC system, for example by exploring Descriptions - I like it because it is big/small, feels soft/rough, sounds loud/soft, is blue/green, Feelings - I feel happy, calm, excited etc or Opinions - I like it because its funny, naughty, fun etc.

Telling a story

This was a more complex task and so we ran an AAC camp weekend kindly hosted by Durham Road School to explore story writing. It was very helpful to have the school facilities which included sensory and technological supports. Initially we had a theme of Super Heroes which had been started early on in the process and then moved on to more intensive support for group members to write stories based on the template embedded in the PODD system, ie what?, who?, where? why? when? what I think, what others think.

**How to communicate with me: Being you, Being me**

Facilitator Laura Jones wrote this reader which guided the group members and their supporters through some things to think about that people with CCN might need from the community around them in terms of communication and connection.

How do you like people to be with you?

The group engaged in this reader and collectively shared their experience of what it feels like when people don't understand them. Its not a discussion they had engaged in before and was a powerful experience for everyone to have insight to what it feels like to not be understood by others.

How does it feel when people don't understand you?

Confused Frustrated Scared Bad Dizzy Frightened Upset

Pissed off Confused Angry Lonely
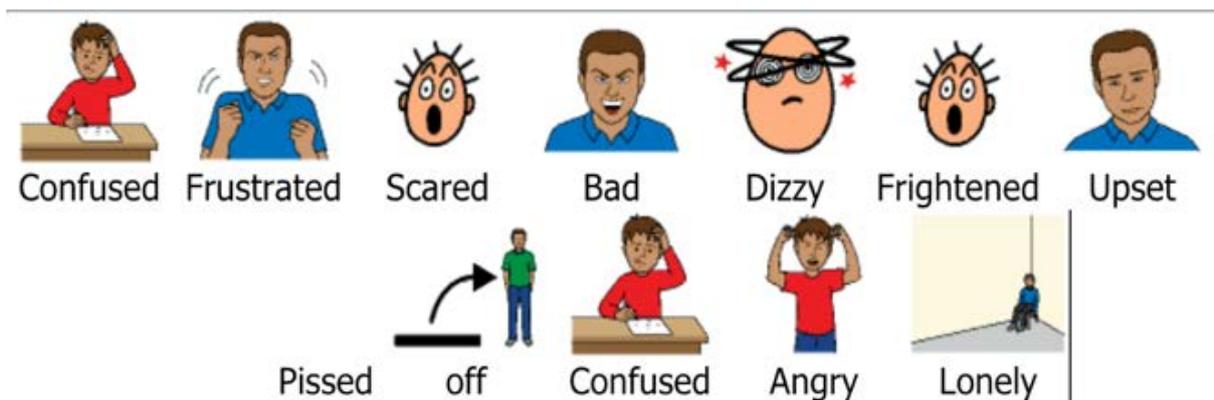
The suggestions from the group about the kinds of things they found helpful to connect with others included:

I don't like when people don't check in that I've understood.
I don't like it when people talk at me but not to me.
I don't like it when people use loud voices.
I don't like it when people treat me like a child.
I don't like being touched on my face.
I don't like it when people come over to the house and don't say hi to me. I think it's rude.
Give me more wait time to say yes or no.
I really want people to give me time.
It helps if people play music for me.
Its annoying when people ask me too many questions on my communication device.
I don't like it when people rush me.
I like it when people are calm, relaxed and happy around me.
I don't like it when people don't leave space for me to talk.

I like it when someone reads to me.
I like it when people play me music.
I think it's funny when people are fun and are funny.
Don't hug me until I want a hug.
I like it when people are calm, relaxed and happy around me.
But I don't like when people rush me. I want time to think and time to use my PODD.
I want people to be with me in a slow and calm way.
I like people to be slow, and to not hurry.

This direction from the group members became part of their presentations.

Insights

All people with CCN have the potential to be public speakers. This possibility could usefully be explored earlier in life, by therapy services, disability services and in schools. This could be approached in a scaffolded way which is designed to avoid increasing anxiety.

It is important that opportunities are not denied to people with CCN as a result of communication challenges being seen as an insurmountable barrier. It appeared to be highly validating for the people in the group with CCN to realise that others viewed them as having the potential to give a talk, and to view themselves as public speakers.

It's important that people with high support needs get the message that they are valued for who they are, and that the contribution they make just by being themselves and in their relationships with others is enough.

Giving a talk doesn't mean the person has to physically do the work of the talk in front of a live audience - there are many ways to present a person's message to a wider audience, and exploring different options means that anxiety about public speaking need not be a deterrent.

It is important to consult with people with CCN about their preferences in how others engage with them, and to find ways to share this information with people in their community.