

Transcript of CKUT Radio Interview with A4A member Darla about AAC, COVID-19 and Disability Access

CKUT Radio (Montreal) interviewed A4A members about COVID, neurodiversity and access to health care, for its disability rights program The Avalanche.

In Part 2 of the interviews (below) A4A Executive Board member Darla talks about AAC and health care access the age of COVID-19

Transcript

Zosia: Hello, welcome to the show. Would you be able to introduce yourself to the audience?

Darla: My name is Darla. I am an autistic self-advocate and AAC user from Ottawa, Canada. I work as an e-learning specialist and freelance editor and technical writer. I am also a member of the autistic self-advocacy group, A4A, and have been involved in some of our presentations to community groups.

Zosia: So, what is AAC?

Darla: AAC stands for augmentative and alternative communication, which is a very proverbial long mouthful of a phrase. AAC is essentially any method used to communicate which is not mouth speech.

Most often it is using either a specialized app or device, a board, or a book of symbols or letters. In high tech AAC, the user selects symbols corresponding to words or phrases, or types on a keyboard, and the program will read what we say out loud. In low tech forms, like a letter board or a book of symbols, the person will point or indicate via eye gaze which they mean and a communication partner will interpret them.

For example, I use two different apps for Apple devices, Proloquo2Go and Proloquo4Text, which are made by a Dutch company called AssistiveWare. Proloquo2Go uses symbols, so if I want to order a large black coffee I might touch the symbols for *I, would, like, a, large, black,* and *coffee*, and then I would have the device speak my message. But I mostly use Proloquo4Text, which is a text to speech app. It also lets me type and store messages and responses, so I can prepare what I will say at a meeting or appointment beforehand and play it when I need to. But everyone uses some form of AAC. Text or instant messaging, Facebook posts, even sending memes is a form of AAC.

Some people also use sign language, although there is some contention in calling it AAC as it is the primary language of the deaf community and thus is not an alternative.

Zosia: So what has been developed to aid those using AAC to communicate about COVID-19?

Darla: The level of support coming from the AAC community overall has been just fantastic. One company, CoughDrop, expanded their trial period to four months so that people who used the app on a device owned by a school or day program could remain connected with their support teams. AssistiveWare has started organizing video chats, some for families, some for adult users, to keep people connected and help maintain community. Nonprofits like Communication Disabilities Access Canada, and the International Society for AAC, ISAAC, have been putting out a lot of materials to assist there. Disabled self-advocacy groups have been doing some amazing work writing clear language explanations and suggestions of what to do and how to cope.

Zosia: Do you feel that the accessibility measures regarding language have been adequately shared to those needing them?

Darla: That is a really good question...and I am honestly not sure. The issue with any disability advocacy is that it always transmits well within a limited circle, but outside of those circles things get more complicated. With that said, groups like CDAC and ISAAC have done phenomenal jobs communicating with their members. So...I guess I hope that they are getting shared far enough, but I worry that there will always be communities--especially since many resources are just produced in English--which are not reached.

Zosia: And have Canada's governments, or international bodies like the World Health Organization, released information for AAC or has it been primarily created by the community that uses it?

Darla: It's been pretty much entirely coming from the AAC community. I don't think I have seen anything from WHO or Health Canada or the like specifically speaking to AAC users.

Zosia: What are the benefits of these softwares being community-sourced and how can official information be beneficial?

Darla: Oh. Wow. Tough question. So, the benefit of working with the AAC community is the same as any software developer working with their user base. We help identify major issues and changes that would help us the most.

For instance, many of us need to make phone calls for things like medical appointments, but don't always have someone else to make the call for us. So AssistiveWare recently added a feature to their apps which lets them interface with the phone function of iPads and iPhones so that what you type is heard by the person you are speaking with. This has been a game changer, especially during social distancing and isolation where we cannot visit friends or loved ones, let alone our doctors or therapists.

Zosia: What needs to be implemented to ensure proper care for those requiring AAC should they contract Coronavirus?

Darla: That is a scary question. First, all AAC devices and objects need to be cleaned thoroughly, as they are high touch, high contact items, meaning they can be vectors for the virus to spread. AAC users may require more communication support, as being sick and feverish makes communication harder. For me, for example, when I am sick I have a lot more trouble with motor planning, and I stim a lot more, so I will use a symbol app like Proloquo2Go because typing is harder.

We may also see otherwise abled people benefit from AAC use because they are intubated or unable to speak due to coughing. Everyone benefits from wider AAC access during these situations.

But COVID is also a real threat to the AAC community because so many people with communication disabilities are often in other high risk groups. They may have other conditions which weaken their immune systems, or have a greater tendency towards respiratory illness or infection, or a greater difficulty with maintaining hand hygiene due to physical or developmental disability.

Zosia: Do hospitals already have AAC software available should people needing the technology be hospitalized due to COVID-19 symptoms?

Darla: Honestly, the state of AAC in hospitals has been very haphazard. There is not a lot of education about AAC use, especially from individuals who are independent or not visibly physically disabled.

There is a huge issue in the medical community where care providers speak to support workers or parents instead of the disabled patient. There have also been cases where people's devices have been taken away from them for various reasons that amounted to ignorance of what a device is for or what a person is capable of for communication.

There is very little direct training on AAC use, and if it comes from any department it generally comes from the speech language pathologists, and hospitals generally will not be providing the software. At best they might have some printed-off symbol or letter boards, but even that is very up in the air. This is especially bad for patients who are admitted for mental health issues, as they are very likely to have their device removed, especially if they have a record of any speech ability. Given that many autistic people who use AAC may also have mental health problems, this is a huge issue.

Zosia: What are other accessibility concerns during this pandemic for non-verbal or minimally-verbal people?

Darla: The biggest accessibility concern, and fear, is this: If I go into the hospital full of unfamiliar people, will they respect my communication? Will I be allowed to keep my device? Will my competence be presumed or will they infantilize me and treat me like a child? Will I be

allowed to make medical decisions for myself? Another issue is that describing my body and what is going on inside it is very difficult for me, and for many others. If I suspect I have COVID, will a doctor or nurse take that seriously? Will I be able to speak with someone over the phone who will understand my device?

These concerns are very real, and a lot of people are grappling with them, but I am unsure how best to deal with them. One thing I do recommend is that AAC users and/or those supporting them come up with a plan for hospitalization. Have a fully written-up list documenting disability, medications, necessary equipment, how to best communicate with us, etc. I have seen some great resources for this from groups like CDAC, and I have a lot of stuff programmed into my device should I be hospitalized to help there also.

Zosia: Do you feel that the government has done enough to protect disabled lives during this pandemic?

Darla: In Canada, I think there is more awareness of it, but people are also seeing what is happening in places like Italy and America, where hospitals are publicly stating that they essentially do not value the lives of disabled people as much of those of abled. Hospitals in America are saying that they will confiscate medically necessary ventilators from disabled people who are hospitalized, even if it's not related to COVID-19 and the person has a good chance of surviving. This is going to reduce the trust that the disabled community places in hospitals.

There is also the issue that while many Canadians are receiving financial help, financial supports for disabled Canadians have not gone up in years, and yet disabled people who cannot work are still expected to pay increasing rent and inflated prices as food and medical supply costs continue to rise. I worry what may happen in Canada, and I would like to see our government speak out clearly in support of its disabled citizens. Disabled lives are already undervalued by the medical system, and we must act to ensure that disabled children and adults are not sacrificed in the name of expediency.

I am not in ODSP [Ontario Disability Support Program] but my friends who are on it are definitely feeling a lot of distress right now over it. However, I don't think we will see much change there, as the Ford government in Ontario, and Kenney in Alberta, have been pretty clear that they don't think disabled people deserve much or deserve to live well. I would hope that we would see payments increase, but I don't have a lot of confidence there.

Zosia: So what can governments do to better protect disabled lives during the COVID-19 crisis?

Darla: Aside from making a clear statement to the value of disabled lives, governments need to put more money into the welfare systems that support so many disabled people who are not able to work. There need to be more supports around shopping, such as stores having specific times for disabled and elderly people to shop.

There also needs to be an understanding and flexibility in disability policy because disability does not fit well into a single uniform box, people have different needs and so disability policy needs to be wide and flexible.

Zosia: How can listeners learn more about AAC?

Darla: I would recommend checking out groups like Communication Disabilities Access Canada, the International Society for AAC, and advocacy groups like Communication First, A4A Ontario, and the Autistic Self-Advocacy Network.

Zosia: And how can listeners support your work?

Darla: I don't have any specific projects I am working on right now to promote. But I urge all listeners to remain indoors, only go out for necessities, and to maintain social distancing. Please, take precautions, wash your hands, keep your contact with other people limited.

This will last for a while, but then it will be over...but only if we work hard to flatten the curve and minimize the spread now. I know it is hard, but there are many people, many of my friends, whose lives depend on bringing this virus under control.

Zosia: It was really nice talking to you.

Darla: You too. Have a great night and stay safe.