

## **CKUT Radio Interviews: COVID, Neurodiversity and Disability Access (1 of 2)**

CKUT Radio (Montreal) interviewed A4A members about COVID, neurodiversity and access to health care.

In Part 1, A4A co-founder Anne Borden King talks about plain language COVID resources, the problem with Autism Speaks, AAC and autistic access to health care, ways that COVID impacts our communities, building community and meeting the challenges of sheltering in place.

**Zosia: Hi and welcome to the show. I'm here with Anne from Autistics for Autistics Ontario. Anne, would you be able to describe the history of your organization?**

Anne: Yes, it's great to be here too...thank you for inviting me. Our organization was founded in November 2017 and it was co-founded-- I'm one of the co-founders—as a way for autistic people to be able to speak for ourselves, so it's an autistic *self*-advocacy organization. We do work in community education, political advocacy and community support and community building.

**Zosia: You recently wrote a plain language guide on COVID-19. Would you mind describing it?**

Anne: Yeah, sure. We came up with this idea to get something out there about COVID-19 in plain language, meaning that people can understand it... it's not full of a lot of technical jargon. And also specifically for autistic people, talking about some of the things that we would specifically be concerned about.

So it starts out with talking about what COVID-19 is, explains why we're sheltering in place or staying at home (as we are here in Ontario) and then it gives some resources for people who use AAC, which [are] alternative communication devices, for people who are non-speaking. It gives some resources for non-speaking people for navigating the medical system and what's going on, and for having access to communication. And then it talks a little bit about coping, how to connect with people, how to cope what's going on... and some advice for caregivers, if someone is living with a caregiver. And then a brief discussion about what might happen next because that's a big question that a lot of people have.

**Zosia: Could you describe why plain language is necessary in communications for COVID 19?**

Anne: It's really, really important and we don't see much of it. I'm actually really surprised with COVID how little communication is coming out of the medical field that could be understood by the average person. A lot of it is really technical and you start looking at all these big words and long paragraphs and it feels very overwhelming and it's hard to understand. It's really important in the case of something where it's about health and safety, to make sure it's in plain language.

The challenge with plain language is that sometimes plain language guides – if they're not written by actually disabled people-- they can come across as kind of patronizing, right? and talking down to the person. So ...people who are autistic, have Downs Syndrome or a variety of intellectual disabilities, [should] really driving these projects, be writing these projects or at the very least at least very heavily consulting and involved with these guides so that they really speak to people in a way that is comfortable.

**Zosia: Have there been any other plain language guides circulating? And how does yours differ from those?**

Anne: Yeah, there are some good ones. I will say, Harvard (Medical School) did plain language but then they kind of messed it up because they had it like by age group, like “for 5-7 year olds”... like that doesn't really work, you know, cognition doesn't break down like grades in school. However, Brandeis [University] did a really nice one. And that could be read by people of any age.

Another great one was written by Green Mountain Self Advocates, and that was actually written by people who are disabled, have intellectual or developmental disabilities, so that was written in a really accessible way. And then there's our guide. These are the major ones.

And then there are guides by AAC-makers... CoughDrop has a guide, Assistiveware has a lot of good guides and information for people who use AAC to communicate.

**Zosia: Do you believe that the methods that the government has used thus far to communicate vital information regarding COVID-19 have been sufficient?**

Anne: I think they could do a better job with plain language, especially by consulting with people who understand plain language and know how to write using plain language, and who benefit from plain language.

**Zosia: So governmental briefings on Coronavirus have only recently begun using accessibility measures; for example, sign language, the week of March 16. Why do you think the implementation of methods like this were considered later as opposed to quote “traditional” communication?**

Anne: I think it's that way so much of the time that disabled people are an afterthought. I don't know why especially *federally* since they made this big statement about how they're going to start including disability in everything they do, right from the start, so I was surprised at how long it took them because I knew that they have this new commitment, but I haven't seen a lot of legs to that commitment, and I think there still is more work to be done to reach various disabled communities in the way they communicate.

**Zosia: The Accessible Communities Canada Act in its current status primarily refers to federal physical bodies, such as government buildings. Do you feel that language should have been**

**included in the creation of this act?**

Anne: It really, really should have. And like any disability accommodation, it would benefit everyone—not just disabled people—if they had included that. The legislation also really didn't have anything for autistic people and there was no consultation done with autistic people for that legislation, so there are a number of things missing there.

**Zosia: Are there methods of communication that the government hasn't yet implemented that the government would be able to better assist disabled people?**

Anne: I think so. They need to communicate more directly with disability self-advocacy groups and disability self-advocates and ask what our different communities and individuals need and then respond to that need.

I don't think having a bunch of quote-unquote *experts* who are non-disabled trying to just do guesswork on the fly in the background as an afterthought is going to be a good way to do it. We'd like to see the government reaching out directly to groups like ours and asking us what's missing and what we need.

And we can provide it, it is very simple for us to do that rather than having them kind of doing guesswork.

**Zosia: Do you feel that the accessibility measures regarding communication have been adequately communicated by caregivers to the populations that require them? For example in the blog post you mention there are sound boards specific to COVID 19. Is this a feature that's widely known to caregivers as a resource?**

Anne: I think the companies that make these boards are trying to get the information out there, but I don't think it's entirely successful. It all depends on the quality of who's caring for the person and where the person lives. If they're living in a residential program where the [carers] are really not making an effort to know what's going on and what's available and really querying these things, I don't think they're going to find them. This is all happening really ad hoc, by private groups, groups like ours, in the case of AAC it might be a company that makes AAC, but if you don't use that brand you might never hear about it.

Ideally you would have kind of a Master Post, a master list, that the government had, of accessibility resources and then they would distribute these resources to all of the residential programs and all of the schools, in terms of how they're doing education now, and they would have a way to get it to parents as well through various agencies, but that's not happening.

**Zosia: And why do you feel that's not happening?**

Anne: I don't think they have had a plan... I don't know, I'm just speculating at this point but it doesn't look like they had thought about these moving pieces when they were getting ready for

something like a pandemic. So they need to reach out and ask people in the disability community.... And I mean really [actually] disabled people.

In the case of autism, there is really a whole bunch of non-autistic people who claim to speak for us, groups like CASDA and some of these other ...like Autism Speaks. If the Government is going and asking them, they're going to the wrong people. Those people are not disabled and they don't know what it's like to be autistic and they don't know what autistic people need. [The Government needs] to reach out directly to self-advocates to understand what's needed.

**Zosia: How does the level of recommendations vary when provided by someone such as a representative from Autism Speaks, who doesn't have autism versus directly from a person with autism.**

Anne: Well, we're asking everyone in the broader disability community *not* to partner with or work with organizations like Autism Speaks or CASDA because they are...first of all, in the case of Autism Speaks there is the broader issue of the genetic research and some of the eugenics that they support...

But aside from that, they also really follow what's known as the medical model of disability, where the disabled person is the "problem" and you "fix the child to make them fit" in a world that isn't built for them. The social model of disability tells us, why don't we make some changes to the world around us, so that it can fit us? And it's just the same for autism as it is any disability, right?

I think that these big groups that tend to speak as though we're broken puzzle pieces that need to be fixed, and "what kind of therapies can we get so we're not so 'weird'?" and whatever like, is really damaging to autistic people in many, many ways.

And it doesn't make for successful outcomes either, if the Government and policymakers are looking for successful outcomes, the only way you're going to have that is if we look at autism from the social model of disability and start making changes to the environment. And the only people that can communicate what changes are needed, whether it's in schools, or healthcare or anywhere else...the only people who are really going to be able to articulate what's needed are actually autistic people.

Like for example, our group, Autistics for Autistics, goes to the University of Toronto medical school a couple times a year and give a talk to [medical] students on "How can you make your practice accessible" for people who use AAC, for people with sensory issues, communication differences, all of the types of challenges that we have faced when we try to seek health care. We know what the barriers are and we know that there are some really simple solutions. And when we go speak to the med students about how they can make their practice more accessible, they're very receptive, they're very open.

It's really a simple matter of teaching them some really simple accessibility measures that will have an impact on hundreds of people throughout their career.

But we're the only ones doing it... it's the autistic people who are doing it. When you have a big organization like Autism Speaks or someone coming in [to med schools], they're much more likely to talk about "How To Identify Autism" or make us seem like we're sort of like, a germ in a petri dish rather than "hey, we're people and it would really help if you would learn about this, it would help if you allow your patients to email for people who are not able to use the phone, things like that. And that all comes from the grassroots, from the disability rights community, *not* from these big organizations who claim to speak for us.

**Zosia: And have these organizations spoken for or released anything in regards to COVID-19 and what are your thoughts on those?**

Anne: I've been looking and.. now I haven't seen anything from Autism Speaks because I kinda don't like looking at what they do, um... because of the eugenics, but I have seen some organizations that have put out guides. Generally, [these groups] are putting out like "A Guide for Caregivers" and then it will be like this massive long document about "How to Talk to Your Child About COVID" um, so, already they've taken the subjectivity away from the actually autistic person. They're not addressing autistic people, they're addressing their carers, and that's just symbolic of how they tend to do things.

And I just saw one today, I couldn't believe it...someone sent it to me, I can't remember who put it out...it was a Canadian group from the West [edit: It was put out by a Federal Government initiative by the Pacific Family Autism Network, PFAN] and they did this whole big thing, this whole big website... they probably had grant money for it [edit: the PFAN was handed \$10 million in federal funds for the website] **and they never once mentioned non-speaking, non-verbal autistic people.**

They had it all set up for autistic people who could speak, but we know that like 30% of autistic people are either nonspeaking or partially speaking. It's quite incredible that a big agency like that would just render all those people invisible in their document.

**Zosia: And how has the community in Ontario been impacted by the crisis?**

Anne: I think it's been impacted depending on where you live and who you are. So for some people who are living on their own or with roommates, out on their own, they are facing in many, many cases... because poverty is a big problem in our community, facing a lot of economic insecurity and a lot of worry what might happen to their job, a lot of worry about what's going to happen with Ontario Works, or ODSP [The Ontario Disability Support Program] or some of the other programs that people are receiving... so there is anxiety and uncertainty and fear around the economic part of it.

Then there's the social isolation which everyone has to deal with but which feels a little bit

different, maybe for an autistic person than it would for a neurotypical person. I don't want to generalize to all autistic people... I think there are some stereotypes out there that we all just want to sit home and pet our cat and we don't really care that we have to stay home and we're all "introverts" and that's not really true, a lot of autistic people are really extroverted and I think anyone, whether you're autistic or not, is missing the community, missing the routine. But I think from a sensory perspective it can be more difficult being inside, than it might be for someone else.

It can be particularly difficult for people who are living in a group home setting or in a family setting where they're not happy or not comfortable, or that's not welcoming to them. I really, really worry about people in those kind of situations where there may have been an opportunity to get out for work or out for school and now they're home. So there's that as well.

And then there's the sense of not knowing what's coming. Which is something that impacts everyone, but it can be especially frustrating and can really start to lead you down a path of reading and learning and understanding and getting super-duper into understanding COVID to the point where it's like, "OK, I've learned everything possible about COVID, now I need to find ways to decompress. I need to find ways to connect with other people."

So I guess to summarise: there are economic concerns, there are stress concerns depending on people's living situations, and then there are sensory and coping concerns that do look and feel different than they do for a lot of neurotypical people.

**Zosia: And how is the Government of Ontario dealing with this crisis?**

Anne: I'm just giving my opinion as an individual. I was watching a press conference with [Ontario Premier] Doug Ford today and he was kind of being baited by a right wing media [journalist] to make negative comments about [Canadian Prime Minister] Trudeau and he deflected it and he praised Trudeau. And I was really happy to see that like, it does seem like the Government is taking its direction from public health experts, whether they're federal or provincial so that was really comforting for me.

The fallout when this is all over, I don't know, economically and socially what kind of impact it's going to have on our community because so many in our community are already living very low income and on ODSP. That conversation isn't really happening right now so it is really hard to tell, because it is a Tory government, what the future is going to be like in terms of [supports].

**Zosia: And what are your opinions on the fact that the majority of disability support plans across Canada are below the poverty line but with the Bill that's been proposed, [non-disabled] individuals would be receiving almost twice as much, for example, as recipients of ODSP. How does that proposal impact the level that we've set... essentially putting disabled people in poverty for no reason.**

Anne: Well, it certainly points out the way that the existing system isn't fair, the way that

people are constantly living on the poverty line and trying to work a little bit, get penalized for that, people who want to live with their partner, or get married obviously are penalized right now under that system? This, for us as activists, is an opportunity for us to raise awareness, to compare the aid that's being provided by the government [to non-disabled people] to what [disabled people] are getting. It's a good opportunity to make people aware of the discrepancies and the second-class citizenship that comes from those discrepancies.

**Zosia: How can non-disabled people be allies to disabled people during this pandemic?**

Anne: I think non-disabled people can be allies to disabled people by giving us a place at the podium. It's really really important in any kind of project that has to do with COVID at all that disabled people are right there, front and centre. Because we're in a place right now in Ontario where we have a place for everyone at the hospital, but as we know down in the US they're rationing care and as we know, sometimes the rationing programs exclude people that are disabled, and are discriminatory. There's a lot of worry and concern in Canada that that could happen here depending on the direction that things go with health care and this virus. So, some guarantees and some real commitment that disabled people are not left out in those kind of scenarios and that affirmation that our lives have value is really important. And visibility for autistic people and all disabled people --as much visibility as possible is really important right now. My concern is that disabled people will not be given life-saving medical care in the event that there is rationing and that it will be built into the triage policies at hospitals.

I think what everyone would like to see is an ironclad guarantee in general a positivity about disabled people coming from our government as a way to reassure people that it's not going to happen here in the way that it has been happening in the US.

**Zosia: If listeners wanted more information about your organization, what should they do?**

Anne: We're on Twitter @a4aontario and we're also on Facebook at A4A: Public Page. Our website is a4aontario.com. That's where you can find the Plain Language Guide to COVID with pictures, and we're also going to make more plain language COVID guides as well as resources for sheltering in place and a master list of AAC resources.

**Zosia: Ok, thank you Anne.**

Anne: Great it was great talking to you!

