

[“People have the right to communicate in the method that is best for them, period.”](#) An Interview with Derek Burrow

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Transcribed by Julie Ann Lee

(Theme song – soft piano music)

Anne: Welcome to the Noncompliant podcast. I’m your host, Anne Borden King. Today’s guest is Derek Burrow, an Ottawa-based librarian and writer who is also deeply passionate about tabletop role playing games with 25 years in the hobby. He uses Augmentative and Alternative Communication or AAC, specifically [Proloquo4Text](#) to communicate and is exploring how Augmentative and Alternative Communication can be normalized within society, and also incorporated into tabletop gaming. He wrote the latest support documentation for [Proloquo2Go](#) and Proloquo4Text and also is involved in Autistics4Autistics, the Canadian Autistic Self-Advocacy organization.

Derek, thank you so much for being on the podcast!

Derek: I am happy to be here!

Anne: In a recent blog for AssistiveWare, you wrote about discovering role playing games, or RPGs around age 10 and you said this: “something about the small social environment, the intense involvement with the story, and being able to speak as a character who was not me helped me a lot. RPGs became the one place where I could avoid speaking neurotypically and where that wasn’t just accepted, but encouraged, especially when it let me engage more with the story.” Can you say more about what that moment of discovering RPGs has meant for you?

Derek: Discovering role playing games was like freedom. As a kid who had trouble communicating all of the ideas in their head and just had trouble getting what was in their head out into words, role playing games became a perfect outlet for me. I loved comic books and cartoons and suddenly I had a place where other people could share my enthusiasm and where I could talk in a funny voice and not be called stupid or weird. I think the shared enthusiasm was huge for me, socially. I didn’t have many friends, I got bullied a lot. For a lot of people I was just the special ed kid who behaved weird, didn’t speak well and freaked out a lot. I didn’t connect with my peers in school but at the table I could connect with them and share my enjoyment with them. Speech was easier when I was speaking as my character in a safe environment hedged in by rules and charts. It was still forcing myself to speak but it also gave me an environment where funny speech became entertaining for everyone, and that made me feel good. I have met probably about 75 percent of my friends through them. They have given me a way to express myself and bring my ideas to life.

They also make the world more comfortable and sense making. Everything has rules, limits and

explanations. The worlds they present are logical even if they are bizarre because they're all within said internal rules and structures. As time has gone on, I have found it much easier to use AAC to communicate and that includes when playing games. It hasn't really changed the quality of my gaming experience but has created one where I am even more comfortable.

Anne: That's really interesting. You write about why RPGs work from a neurodiversity perspective, like you were talking about just now. It's--in part--that the game world also can be tailored to players, so as you said in your blog piece, 'each character has a number of attributes, skills and abilities which make them unique from others at the table.' There seems to be an egalitarianism where everyone gets to play, and I was interested when you brought this up because it made me think about what the RPGs illuminate could be possible in other contexts besides in RPGs. If more of these principles were applied outside of RPGs how might life be different for us?

Derek: That is a really tough question. I think that RPGs have a lot of room to accommodate players because they're a moderated social experience. There is a game master, a dungeon master, a master of ceremonies or story teller or whatever who controls the world and the overarching narrative. They can step in to make sure that everyone gets a turn, and help adapt the game to the needs of the players.

The real world application of this is a bit tricky but I think it comes down to accommodation and fairness. I admit, I can be kind of obsessive about being fair. I am very concerned with the world being a fair place for people and games are somewhere that my desire for fairness isn't weird. Accommodations help make things fair, both obvious physical ones like wheelchair ramps and sign language interpreters but also just letting people answer in their own time. It's the understand that people can think and act differently. I need people to be aware that it takes me a bit longer to communicate because I have to type what I want to say first and that sometimes I need something explained a different way because I didn't understand the first time.

It's also understanding that **everyone has something to contribute, even if they are not doing so in a capitalist sense**. Everyone has strengths and weaknesses, and in any group of people someone is going to have a skill that no-one else possesses. In gaming, we design characters around their strengths and the world is set forth in such a way as to let them succeed through them. That's a far better model than real life where we are often put in places that attack our weaknesses and we are expected to excel.

[5:15]

Anne: I think that is so interesting that all of those ideals fit under the model of an inclusive society. You've written about using augmentative and alternative communication in RPGs and I want to get into that more too. But before I do, let's define what augmentative communication is for listeners who may not be familiar with it. The term **Augmentative and Alternative Communication** or AAC describes **a tool, system or strategy for communicating rather than**

speech. It can be a high tech tool like an AAC app or like Proloquo4Text or Proloquo2Go on the iPad, or it can be a lighter tech, paper based tool like a communication book or board. You're using the app called Proloquo4Text to communicate in this interview, right?

Derek: Yes! Proloquo4Text is my regular go to AAC app. AAC as a concept encompasses basically **any method of communication not relating to verbal mouth speech. Sign language, picture cards even texting can be AAC.** A friend of mine has even mentioned that wearing slogans on their shirts is a form of AAC since it's alternative to saying them out loud.

Anne: Oh, that's so true. What is the Proloquo platform like? What's the process of using like, say, Proloquo4Text?

Derek: First, I need to note that Proloquo2Go and Proloquo4Text are two very different apps.

Proloquo4Text is a designated text-to-speech app. I type my message into a window using the keyboard, and can supplement it with phrases I have already programmed. Then I hit play and it speaks my message. I can also select the voice I use from several options and then customize the pitch and speed of that voice. Right now, I am using a voice named Rod set to normal speed and a deeper pitch.

Proloquo2Go is a symbol-based communication system where I form messages out of individual symbols, each representing a word or phrase. I don't use it as often...more often when I am having a hard time typing, or when precision of language or speed of response aren't as important. I have heavily customized the app for my use, moving and adding buttons for ease of access and being able to talk about my interests.

Proloquo2Go also includes a text-to-speech option but as it doesn't give me access to easily accessible saved phrases as Proloquo4Text does, I do not use it as often.

With that said, Proloquo2Go is genuinely fun for me to use because it feels in part like how my mind puts words together. It makes language modular, breaking it into its individual components and letting you arrange them in a way that's more natural. It feels very powerful to have such absolute control over how language flows and to see the pieces you are putting together. When speaking with other AAC users, it's not uncommon for us to not necessarily use proper grammar but just use the words that come to mind or in the order they occur to us in.

Anne: So, you use augmentative communication in RPGs with other players that aren't using it. From your experience, what are some tips for AAC users and for players in a game who aren't using AAC.

Derek: I am playing in a fantasy RPG game right now and everyone is really great. If you are playing with an AAC user, be aware of when they are typing and when they have something to say. Take an extra pause in conversations to give them a chance to contribute, because otherwise someone is often two or three points ahead before I get a chance to say anything.

For AAC users, I recommend programming and preparing wherever possible. Program in common phrases and questions. If your device has word prediction, use it because it will help you keep up with the rest of the table. Be organized with your papers and dice, so that you only need to use your device as a speech generator.

Anne: That makes sense. I wanted to talk about AAC in general. There are many non-speaking autistics in general--I'm thinking of the writer **Ido Kedar**--who were assumed to be unable to reach by the so-called professionals until someone finally obtained some AAC for them to use. And one of the most frustrating things to me is that AAC is still being held back from autistic people by some therapists or schools who believe in ABA and so-called *verbal behaviour theories* despite the clear and best evidence that AAC is the correct approach; the empowering powerful approach and the humane approach to take.

It seems similar to me like the earlier oralist movements to stamp out sign language in deaf children, and similarly we have schools across North America where teachers and instructors are refusing to authorize AAC for students, or they're giving students only rudimentary picture boards as a way to try to 'force' the non-speaking children to speak though this faulty behaviour therapy...verbal behaviour theory. The Autistic Self-Advocacy Network is working on several cases now, appealing to the Justice Department, that under the Americans with Disabilities Act, denying AAC in schools is a human rights violation of the students and they're moving forward with those cases on behalf of many students, and hopefully they'll resolve the cases in favour of that AAC access. What are your thoughts on this issue of denied access to AAC?

[10:51]

Derek: Many people still see AAC inferior to mouth-speech. They will accept even the most basic, barely functional speech to be sufficient because they don't want to accept their alternatives. Activist **Jordyn Zimmerman** got access to AAC later in high school and credits it as the reason she was able to go on to college because her actual speech isn't sufficient to properly express herself or her intelligence. This is actually pretty common as they are finding a lot of students not just autistics who are labelled as being severely intellectually disabled due to lack of speech or lack of varied speech, are actually quite bright when given access to AAC. It was a longstanding assumption that people with Rett Syndrome or Angelman Syndrome, both characterized by lack of speech were unable to communicate. That is not the case and Speech Language Pathologists have made great strides in both communities with augmentative communication.

Denial of AAC is just silly. It's stubborn neurotypical assumptions about how human communication should work...except we have never just communicated with our mouths. Now more than ever, people are texting more than they talk on the phone now. I have five different instant messaging apps on my phone. People post to Facebook, to Twitter. They post pictures

about what they ate for lunch on Instagram. This is all AAC. These are alternative ways to communicate that are not verbal mouth speech. Priority needs to be placed on equipping the student with communication tools that are best suited for them: for some that might be speech; for others a combination of speech and sign language or a high tech AAC system; for others it would be sign language or a tablet; for some people it would just be pointing at pictures, and that is okay. All of those methods are valid. Some people are never going to be great communicators and there is nothing wrong with that so long as the people around them are putting in the work to understand them. Too often, however, parents and educators will not respond to pointing or the like. They will only accept speech.

But here's the thing: AAC users are doing things in the world. **D.J. Savarese**, and I am positive my device is pronouncing his last name wrong, won a Peabody award for his autobiographic documentary. **Amy Sequenzia** is an accomplished poet. I have a friend in the UK who just got their degree in pharmacology. The single most famous physicist in the latter half of the 20th century was so well known for his AAC use that he had exclusive rights to the specific voice that he used. There are a surprising number of AAC-using autistics who are in university right now and I can only imagine how much better university would have been for me if I had this method of communication then.

The really sad thing is that many parents (and many autistic people as well) just genuinely do not know that AAC is even an option. There are so few resources for it, and if it is not presented up front as an option people may not even realize it's possible. I know that I didn't for a very long time.

People have the right to communicate in the method that's best for them. Period. End, stop. There can be no genuine argument there because that is what we must work to prioritize. One of my goals is to normalize AAC use. I want people to see I am out there in the world. I have a job, several jobs in fact if you count the one I am starting that actually involves going to the office and the ones I do from home. AAC isn't scary. Being non-verbal isn't the end of the world.

Anne: I'm glad you brought up the movie **Deej**, and we'll put a link to that on the blog for the podcast. Now Speech Language Pathologists as you mentioned...there's a movement in Speech Language Pathology to really to normalize AAC and move towards AAC but in the ABA context we still have many therapists who will only accept verbal speech. The issue seems to be so much a part of ABA, this idea of denying a person or forcing a person rather than working together or accommodating or assisting a person. I wanted to ask you because you were in an ABA setting when you were younger and I'm wondering if you would comment on that mindset within ABA?

[15:22]

Derek: The special education classroom I was in from grades 1 – 3 had ABA aspects though was not full ABA because not all of the students were autistic. I also had speech therapy for many

years in that context. I know that my teachers were coming from a place of wanting to help but this was the early 90s and there was just so much focus on having me appear as normal as possible. I remember things like 'quiet hands' or being told to sit on my hands to keep from moving them. I want to be clear, I don't hate the classroom I was in and the *non-ABA* teaching methods really did help me learn to better self-regulate. But I also developed a lot of psychological issues around being required to talk – that kind of thing.

But I think a bigger issue that I ran into was that it was isolating, because I spent 3 years not going to school with other kids and then after that another 3 years of getting maybe two-thirds of the classes that other kids got, I was not well prepared for socializing with students in regular education. Our recesses were held at a different time than the school's recesses and we were under strict supervision by maybe 4 or 5 teachers and support workers, so we didn't interact with students there except on the most rare of occasions. Our classroom was located up a flight of stairs and around a corner at a far side of the building. I spent 3 years in segregated special ed before I mainstreamed in grade 4. I was totally not prepared for it. I was not used to going to other classroom for classes or how to handle being in a room with 30 or more kids, or even how to do things like journal writing, which is really not great for an autistic kid who gets anxious over the smallest things and has bad social anxiety. I was excluded from a number of regular classes like Math, English and all but one year of music so I was pretty far behind my peers in some areas.

The ABA aspects of my education were not good. They did not prepare me for being in the real world. They just taught me that all of the behaviours that came naturally to me, all of the ways my body wanted to move in were wrong and bad. If they had taught me how to advocate for myself, how to accept myself and how to actually transition to mainstream school, I think I would have been a lot better off.

Anne: I think what's frustrating for me now is that we have a generation of autistics like you and many others who experienced this – experienced the segregation in special education, the problems with methods in special education and the inequalities that arose from that. We have a generation of autistics who are speaking about this and it's like there are people saying 'well you can't talk about this because you're not me, you're not my child', and shutting down the conversation. And they're saying this to people who *have literally experienced it* and who are trying to help and I'm wondering where the resistance comes from in terms of making these connections. There's certainly are connections being made but there's also some resistance. Can you speak to this frustration?

Derek: I was just saying to **Emma Dalmayne** from the British group Autistic Inclusive Meets, that I am very frustrated how often we are expected to divulge very personal and often very embarrassing medical facts about ourselves in order for our observations to be respected. Many autism parents just have to say 'oh, my kid is autistic' and instantly they are treated as experts. But, when an autistic person tries to speak from their experience, they are

interrogated unless they are willing to list off every little detail about their symptoms just to prove their right to an opinion. It is frustrating. I have aspects of myself in the ways my autism affect me that give me solid perspectives on what many autistic kids, teens and adults are going through, but for my perspective to have validity in the conversation I have to divulge details about my life and my medical history that are very embarrassing and very private.

The fact is **autistic kids grow up to be autistic adults** and **we know what it is like**. There are a ton of issues that autistic kids are dealing with that we can help provide perspective and experience on. The thing is that when we try to participate in this conversation we are often treated as selfishly only thinking of ourselves. It's assumed if we can take part in the conversation we cannot possibly be speaking for other autistic people, and this attitude affects all autistics. Nonverbal advocates who require high levels of support have doubt thrown on their words by people claiming they could not require the level of care and still be able to eloquently express themselves. Very well educated autistics, some of whom study autism itself, are disregarded because their support needs are significantly less.

It is a Schrodinger's cat sort of situation. An autistic adult is either deemed to be too disabled to hold an opinion and speak for themselves, so it is assumed that someone else wrote it for them. Or, they are considered too abled, often ignoring very personal and private issues that they deal with in many aspects of their daily lives, and thus not entitled to an opinion. I honestly do not understand where they are coming from. I have tried but I cannot understand why they would turn away help. Maybe it's a parent thing?

[20:49]

Anne: In November, you and I met with **Dainius Pūras** who's the United Nations Rapporteur on Health and the UN is doing a human rights report. They wanted to reach out directly to autistic self-advocates in Canada and met with you and I in Ottawa. It was an amazing meeting and I wonder what your thoughts are since we had that meeting, about that meeting and in general about the direction that those kinds of projects are going in.

Derek: Kind of wish I had brought a print out with links and maybe some charts and graphs... I am still just stunned that he was so respectful of me as an AAC user. I had gone in not knowing what to expect but he was just such a nice guy and seemed very receptive to listening to us. Meeting with him was also the kind of turning point in my confidence levels. If I can present to an official from the United Nations and be accepted and listened to, then nobody else has an excuse to brush me aside.

Anne: Do you have anything that you wanted to add to the conversation before we do our wrap up?

Derek: I wish I had a link to provide right now, but a group of AAC users and I are starting to work on a YouTube channel to help discuss and normalize AAC use, particularly by autistics. We are hoping to reach out to non-autistic AAC users over time. I am hoping to get it off the ground in the New Year.

Anne: Wow, that's amazing! When it gets off the ground, we will be putting the link up on the blog and I love the connection too that's being made across communities on AAC. This has been such an interesting conversation.

Derek Burrow, thank you so much for being on the podcast.

Derek: Thank you for having me.

(Theme song – soft piano music)

Anne: We were just speaking with Derek Burrow, a librarian, writer, and RPG player who uses augmentative communication, or AAC. He's exploring how augmentative communication can be normalized within society. We spoke to him from Ottawa.

You've been listening to Noncompliant. I'm your host Anne Borden King. Noncompliant was recorded at DB Audio and MCS Recording Studios. Various episodes were engineered by Dave Boir, Nathan Greavette, and TJ Liebgott. Thanks to our engineers and thanks for listening.