



# Communication**FIRST**

Because communication is a human right.

## AAC Users Interview Jordyn Zimmerman About This Is Not About Me

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November 10, 2021 - 7:00 pm ET**



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## Webinar Transcript

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[TAUNA SZYMANSKI] I would like to welcome you to this opportunity for AAC users to interview Jordyn Zimmerman about her educational experiences and the remarkable new documentary, *This Is Not About Me*. My name is Tauna Szymanski, and I am the Executive Director and Legal Director of CommunicationFIRST. I am a white woman with long, wavy, brown hair. I'm wearing glasses, and I have a wonky left eye, and I'm wearing a red sweater.

Before I introduce Bob and Jordyn, a few words about logistics and accessibility. First, to turn on live captions, please click on the CC button at the bottom of the Zoom window. You can have the captions appear either at the bottom of your screen or in a separate window if you prefer.



Second, American Sign Language interpretation is being provided. We are displaying slides with text to help with accessibility, but if you can make – you can make the slides smaller and the video boxes larger by sliding the dividing line left and right.

Third, this is a webinar and not a meeting, so you won't be able to see the other attendees or use the chat box.

AAC users were asked to submit questions in advance so Jordyn could have some time to prepare her answers. If we have time and she has the energy, we may take additional questions through the Q&A box in the webinar.

Fourth, we are recording this webinar and do hope to have the recording and a separate – a corrected transcript and captions available in the future.

I hope everyone has had the chance to watch this incredibly powerful documentary. If not, please be sure to do so as soon as possible. It can be accessed at <https://thisisnotaboutme.film>. We are grateful for the filmmakers for donating some of the proceeds from the film to CommunicationFIRST.

And while you're on that website, please don't miss the educational toolkit CommunicationFIRST sponsored with the help of two autistic AAC users with degrees in education, Cole Sorensen and Jordyn Zimmerman herself. The toolkit includes a discussion guide and is designed for educators in the K-12 school system.

I'm now very pleased to introduce my colleague, CommunicationFIRST's Policy Director, Bob Williams, who will be moderating today's webinar. Bob co-founded CommunicationFIRST after a distinguished four-decade career in federal and state government and the nonprofit sector, most recently as director of the US Independent Living Administration at the US Department of Health and Human Services.

Bob also served as Commissioner of the US Administration on Developmental Disabilities, Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, and head of the Social Security Administration's Office of Employment Support Programs. He is a lifelong AAC user and a nationally recognized leader on policy issues relating to supporting people with the most significant disabilities to live, work, and thrive in their own homes and communities.

Now I'll turn it over to Bob, who will make some opening remarks and then we'll – he will introduce Jordyn. Bob?



[BOB WILLIAMS] Thanks, Tauna. I want to join you in welcoming everyone who is taking part in what I know will be a very important and insightful next hour with Jordyn Zimmerman, whose film, *This Is Not About Me*, we will be discussing tonight. Hopefully everyone has had the chance to view it prior to this evening. However, even if you have not watched it yet, I am certain that every one of us who are listening and asking questions of Jordyn will find what she has to say and teach us, as well as millions of others, to be compelling and a call to action.

It is an honor and pleasure to introduce her as my friend, colleague, and mentor in the truest sense of the word, someone we all can learn from and seek to emulate. So, before I formally introduce her, I would like to share the following. Jordyn and I first met in the summer of 2019, which she spent in Washington, DC, interning with the National Disability Rights Network.

We met in the Student Center at The George Washington University, where she was living in a dorm. I also had earned my bachelor's at GW in the 80s, so it was a good place to meet up. But this was the second time we had agreed to meet there. The first time she did not show up. And it was looking like she also would not show up this time either.

So I began asking myself, "Who does this Jordyn Zimmerman think she is, anyhow?" When she walked in five minutes into our conversation, it became crystal clear to me that Jordyn Zimmerman knows exactly who she is. Quite a story she had to tell about both oppression as well as liberation is not hers alone but all our story to share and most urgently change for the better. **Our life histories can never be rewritten or made more just, but we and others must learn from them in order to create greater justice moving forward.**

So I will leave it to Jordyn to tell you who she truly is, but here is the CliffsNotes version. Jordyn Zimmerman is in her final semester as a graduate student of education at Boston College. Before that, she interned at the National Disability Rights Network, and completed her bachelor's degree in education policy at Ohio University, where she founded an inclusive collegiate cheer team called the Ohio University Sparkles.

As a non-speaking autistic student who was denied access to effective augmentative communication until she was 18, like all great human and civil rights leaders, Jordyn draws on the injustices done to her and others too to reveal and challenge the flawed educational status quo. Technology helped open Jordyn's world, and in 2014 she began advocating for students, speaking in a series of national and global speaking engagements. An avid typist and advocate for all students, she is passionate about ensuring every



student is able to access effective communication, and can exercise their right to a truly inclusive education.

You know, Jordyn, when you first told me your story that day in 2019, I was not surprised by it because, over my lifetime, I have known many who have experienced the same. And I am sadly convinced there are more people than we might imagine still are experiencing it today. So I was not surprised by it. But from then to now, I am angered by what you have experienced and others still endure. I say this for the following reason: Anger for me is an emotion that I can channel to constructively drive how I respond to and challenge injustice.

We all draw on different emotions and sources of strength to guide us. My ask of all of you with us is that you tap into whatever those sources are for you. And to use what we all learn this evening for what it is: a call to conscience and to justice-making.

Jordyn, we are proud to have you serve on our Board of Directors. It is all yours. Lead on.

**[JORDYN ZIMMERMAN]** Thanks for welcoming us, Tauna. And thanks for the amazing introduction and for moderating this discussion, Bob. I'm Jordyn. Pronouns: she/her. I am a white female with brown, curly hair past my shoulder. I am wearing a grey shirt and sitting in front of a white wall. As it was mentioned, I am currently a graduate student at Boston College and student-teaching within the Boston Public Schools. I am honored and excited to be with all of you tonight.

**[TAUNA SZYMANSKI]** Okay. I will read the questions aloud that were submitted. They're also printed on the slides for those who would like to read along. The first question is from Bob: "The title of your film, *This Is Not About Me*, is extremely powerful. It comes, of course, from a speech that I believe you made at your high school. You used the phrase and go on to explain what you mean by it in that speech. I have several things I would like to ask you. Can you say why you felt it was important to use those simple, five words, "This is not about me" in an auditorium filled with teachers?"

**[JORDYN ZIMMERMAN]** As you mentioned in the introduction, we all know there are so many other students who continue to face the very same injustices I did. My story is so much larger than just me. My experiences are shared by many other individuals who use AAC, who would benefit from the use of AAC, or who have faced any difficulties in their journey to obtain an education. Those simple words I shared were a guide for helping educators examine my story, but also dive deeper when reflecting on the students in their lives.



[BOB WILLIAMS] Thank you.

[TAUNA SZYMANSKI] The second question is also from Bob. And he says, “I have a couple of related questions. From your experiences with the high school teachers you addressed, how many do you feel took what you told them to heart? And how could you tell?”

[JORDYN ZIMMERMAN] I believe they all took something away. At the end of the presentation in the auditorium filled with educators, there was an opportunity for a few questions. One teacher stood up, who is also the speech and debate coach for the high school, and asked if I would be interested in joining the team. I laughed because how would I ever be able to participate?

However, when I discussed the idea with her later, she mentioned I would be the first non-speaker in Ohio, and while there would be some rules that would need to be changed, I would be an important member of the team. She clearly heard my words of needing to be included and wanting to be part of the larger school community.

I also had numerous people reach out in the days that followed, asking questions or sharing words that resonated with them. I was always really excited when these people came to me in order to try to make things better for their students.

[TAUNA SZYMANSKI] Bob’s third question says – this is the last question on this topic: “As someone that is getting her master’s in education policy and, who without a doubt, will shape and transform education policy at the national, state, and local levels for generations to come, what are the film’s major messages and lessons that you believe policymakers, teachers, and others should learn, and most importantly, take action on?”

[JORDYN ZIMMERMAN] I believe action should be taken on bettering the education system in general, but there are a few hot topic areas the film addresses, even if it’s not always explicit in the messaging. The most obvious is communication access. As the film showed, the lack of access directly impacted opportunities for me to be included, my test scores, what professionals believed I was capable of, access to challenging curriculum, and more. **Communication is a basic human right, and all students should have access to a reliable method.**

Another area the film touches on is inclusion. No matter the programming or services, when I was in a segregated environment, I was 100% less successful compared to when I was in various classrooms, actively engaging with a range of classmates.



While policies exist to help with this, the reality is that creating justifications for not providing services in the least restrictive environment is easier than doing the work. And even in my situation, as powerful and as life-changing [as] inclusion was, I had to travel over an hour to experience that sense of belonging. When I graduated from Mentor High School, the community and all the students became quite distant.

In addition to some other hot topics, the film also addressed the issue of restraint and seclusion. It really highlights how ineffective that strategy was and the trust that had to be repaired and sometimes could not be.

Lastly, hidden within the film is the vital message for school districts, policymakers, and educators urging them to be conscientious of their potential bias to expect less from certain students, and the challenge for educators to presume competence.

**[TAUNA SZYMANSKI]** Thanks, Jordyn. Bob, there is a comment in the chat. Should I read that?

**[BOB WILLIAMS]** Yeah.

**[TAUNA SZYMANSKI]** So someone in relation – in relation to the comment that Jordyn made on the last question said, “I actually have a student that is in our school’s debate club and we are trying to be creative with his participation. I’m very excited that he’s chosen this club to participate, and the teacher is very supportive.”

The fourth question is from Tyrone C., who asks, “How did you feel after that teacher/principal realized you did have things to say, and all you needed was a way to reveal who you were?”

**[JORDYN ZIMMERMAN]** I felt heard and understood. **Being heard and validated is vital for creating any type of trust between a student and educator, or anyone for that matter. As the relationship continuously developed between us both, my confidence and feelings of self-worth increased. This all contributed to me being able to express my feelings, needs, and desires.**

**[TAUNA SZYMANSKI]** Question 5 is from Isabella, who asks, “Need to know how you learned to type independently.”

**[JORDYN ZIMMERMAN]** I started using an iPad when I was around the age of 18 years old. While there was a process of trying different applications, some of which used real



images and some that relied on symbols, I began typing within about a year and it definitely was not a seamless process. I was very resistant to the use of my iPad and did not begin using it more until I was wearing it, which is so important for an AAC user to have that direct access, instead of the device being laid somewhere out of reach. As you may have heard in the film, there was a lot of modeling happening, so I was constantly watching others type. It's also important to recognize that my typing is not perfect. **Sometimes I type something different than what I mean or what I intended to say.**

I also have many gaps that I constantly have to work through. For example, I know many more words in my head than I can spell. Some words that I have visually seen I can spell, but I don't necessarily know what they mean in every context.

**[BOB WILLIAMS]** Do you think you would have ever learned to type if you remained segregated? What would have been the challenges?

**[JORDYN ZIMMERMAN]** That's a loaded question, and I will never know the answer for sure. However, I will say that when I was with one to two teachers in a room with just me, I inadvertently learned a lot. I was constantly listening and watching everything these people did, which basically acted as makeshift lessons they didn't know they were providing.

If I would have been included at a younger age, there's a chance I would have been given access to various augmentative communication methods, thereby hopefully learning to type sooner.

**[TAUNA SZYMANSKI]** Okay. Question 6 is from Lily K., who asks, "Do you use other forms of AAC besides typing?"

**[JORDYN ZIMMERMAN]** Typing is most reliable for me, but I also use symbols, facial expressions, and gestures. I specifically use symbol pages in low-tech form when I'm doing something that involves water.

**[TAUNA SZYMANSKI]** Thank you. Question 7 is from Rachel K.-L., who asks, "What successful strategies do you have for regulation? I am struggling with sounds."

**[JORDYN ZIMMERMAN]** I don't use just one strategy, but rather I have many. For sounds in particular, I will often wear noise-canceling headphones when I'm overstimulated by the noises in my environment. I will say I didn't like the pressure of headphones on my ears for many years, so I can relate if you are facing similar difficulties with that.



I got used to them in very small increments and that helped a lot. Sometimes my body feels like it's on fire, and moving often helps with that sensory experience. The repetitive motions and different movements, such as running, really helps me relax and be ready for whatever happens next.

**[TAUNA SZYMANSKI]** Question 8 is from Sarah A., who asks, "How did you get into college?"

**[JORDYN ZIMMERMAN]** I went through the same college application process as anyone else would. However, before attending college or confirming that's what I definitely wanted to do, I spent three weeks at a college summer program for autistic high schoolers. That experience gave me the confidence I needed to know that college was possible.

It also helped me understand the complexities of different programs and how I didn't want things such as separate residential housing for students with disabilities, nor did I want a small school. When I did decide on potential schools, my family and I met with the various offices on campus, including the student accessibility office, the dean of students, and residential life.

We asked general questions to get a feel for how they support students, but also asked questions related to my specific needs. The school I happened to like the most was planning a pilot program, pairing autistic students with graduate students majoring in communication and science disorders. This seemed like a natural fit and the school was eager to try to support me in the best ways they could.

**[TAUNA SZYMANSKI]** Okay. Question 9 is from Gabrielle H., who asks, "What do you hope to do after you finish your master's in education?"

**[JORDYN ZIMMERMAN]** After graduation, I have a job lined up to work at the Nora Project. In this role, I will serve as the Director of Professional Development. If you are unfamiliar with this organization, the Nora Project is committed to building inclusive classroom curriculum for students ages three to 22, as well as creating professional development for educators and community leaders around disability inclusion, a topic in which most adults have never received adequate education.

As the film mentioned, inclusion is very important to me, and I'm excited to work with educators who share my same drive about ensuring all students have access to a meaningfully inclusive education, where students are actively taught about disability as an





integral part of human diversity, and where educators implement a curriculum that allows disabled students to feel proud of who they are.

**[BOB WILLIAMS]** Do you have advice for high school students for how they might begin to prepare for college?

**[JORDYN ZIMMERMAN]** I think visiting campuses and conversing with other students is an integral part of preparing for life after high school, recognizing that not everyone wants to go on to higher education. I was lucky in that I have an older brother who went to a four-year university while I was in high school. I absolutely loved visiting him and told myself I'd have that same opportunity one day, no matter what it took. But visiting campuses and deciding what supports different schools can potentially offer, plus if the school matches your desires in terms of size and campus climate, is a good first step.

**[TAUNA SZYMANSKI]** Okay. Question 10 is from Tiffany J., who asks, "Do you feel there is anything that speaking autistic people can do to better support non-speaking autistic people? If so, what?"

**[JORDYN ZIMMERMAN]** **One thing that I believe would help make our community stronger is if non-speaking autistic people were given more platforms to share about our own experiences and perspectives. It typically isn't helpful when others talk for us or try to share our stories, even if it is unintentional.**

**[TAUNA SZYMANSKI]** Question 11, also from Tiffany J. This question asks, "How do you feel about people who can speak using AAC? Like autistic people that can speak sometimes and not others? Does it seem like they are using accommodations they don't need? Does it help normalize AAC?"

**[JORDYN ZIMMERMAN]** **I think anyone who feels they could benefit from the use of AAC should be given the power and freedom to use whatever system will help them.**

**[TAUNA SZYMANSKI]** Okay. The next question is from Bob. Bob, do you have this? Do you want me to read this one?

**[BOB WILLIAMS]** Yeah.

**[TAUNA SZYMANSKI]** Okay. Bob says, "Many different audiences must see this film. In my view, the most important of these are the countless children, teenagers, working age, and older adults, who, regardless of what they are branded, are going through either the same



or something shockingly similar to the identity theft and injustices you've endured. I say this because, based on my life, what I have received and what I have tried to pay forward, I believe you and I and all others like us, need each other, count on one another to pass on the hope, the possibilities we would not have dared to imagine, the dignity and will to push forward. What do you dare to hope they will take from this film? What are some ways that those who, I would argue, have the greatest to gain from viewing the film are afforded the chance to see it? What can CommunicationFIRST and others do to make certain this happens?"

**[JORDYN ZIMMERMAN]** I hope people see and resonate with some of the struggles and are then empowered to advocate for better. I hope people realize how worthy they are, how much potential humans have, and how we can all collectively bring dignity back. CommunicationFIRST took a great step in preparing a toolkit to go along with the film, and I would encourage everyone to look through that as a next step if you have not yet had the opportunity.

**[TAUNA SZYMANSKI]** Again, you can access that toolkit at <https://thisisnotaboutme.film/resources>.

All right. Question 13 is from Bob, and he asks, "How old were you when you, yourself – when you yourself first knew you could read? How much longer did it take for others to catch onto the fact that you were quite able to read and write?"

**[JORDYN ZIMMERMAN]** I don't remember the exact age I knew I could read. I definitely wasn't too old. I think others recognized it in high school.

**[TAUNA SZYMANSKI]** The next question is from Bob also. "What advice do you have for kids who need AAC, their parents, and teachers on the importance of literacy, and how to prevent what you experienced?"

**[JORDYN ZIMMERMAN]** Presume competence and please keep advocating, knowing there will be rough moments, but that not every day is hard. You won't cause harm by treating a human with kindness or teaching students how to engage with letters, but you could cause detrimental damage by [not] doing the latter. It's very important to question people and push for change within the systems that continuously perpetuate failure.

**[TAUNA SZYMANSKI]** Bob, I hope you don't mind. There's one more question, but there was a question related to this in the chat that I think is on point. Should I read that one?



[BOB WILLIAMS] Yeah.

[TAUNA SZYMANSKI] So, from Ben C. in Pennsylvania, he writes, “Is it likely that schools will change without fighting to maintain the status quo?”

[JORDYN ZIMMERMAN] [*inaudible*]

[BOB WILLIAMS] That was a bit muffled. Could you repeat it?

[JORDYN ZIMMERMAN] I think school systems and systems in higher education like the status quo, and pushing for anything different will take hard work and lots of advocacy.

[BOB WILLIAMS] Thank you.

[TAUNA SZYMANSKI] Okay. This is the last pre-submitted question. We are making good time. This is also from Bob, who says, “Bill Clinton said that if you want a friend, get a dog. He gave that advice specifically to those of us who live in DC, but I apply it wherever I am. As my wife points out, I am far more friendly with the mutts I meet than I am to most of the people with them. It is clear from the film that you are from the same school. Dogs typically are more attuned to who I am and far less judgmental. Do you find that to be true? And if so, what are its implications for education policy?”

[JORDYN ZIMMERMAN] Dogs are amazing. As you saw in the film, Einstein is so loved. Buster, the dog at school, was also fundamental in helping me feel safe, keep me out of dangerous situations, and learn. Dogs definitely know what people need and are deeply in touch with their range of feelings. I hope dogs will only become more normalized and popular in a vast range of educational settings in order to help students feel safe and regulate throughout their days.

[TAUNA SZYMANSKI] Jordyn, are you okay if we – we have a little bit more time – are you okay if we ask a couple of questions that have been submitted in the Q&A or the chat?

[JORDYN ZIMMERMAN] Sure. That’s fine.

[TAUNA SZYMANSKI] Bob, you ...?

[BOB WILLIAMS] Yeah, definitely.

[TAUNA SZYMANSKI] Okay. One of them is from another Board Member of ours, Melissa Crisp-Cooper, and it’s related to the film. So this one might make sense to ask first. “Have



you heard from any of the teachers that you had before you had an appropriate AAC device? Did they learn anything from the documentary?”

**[JORDYN ZIMMERMAN]** I have had teachers reach out and tell me how proud they are, but the supports or lack of supports that were provided is always ignored. I can only hope they learned something.

**[TAUNA SZYMANSKI]** Thanks. Another question in the Q&A is from an anonymous attendee, who asks, “What helped – what helped you move past your experience without feeling resentful?”

**[JORDYN ZIMMERMAN]** Maybe my parents were so resentful that I never had to be. I was never mad at the educators who so clearly failed me, but it has definitely motivated me to push for change.

**[TAUNA SZYMANSKI]** Bob, should I ask another question, or should we wrap up?

**[BOB WILLIAMS]** Yes, if Jordyn is willing, let’s do one more.

**[TAUNA SZYMANSKI]** Jordyn, are you open to one more? There’s actually several questions that kind of are all on the same theme. So I think I can combine like three if you’re open to it.

**[BOB WILLIAMS]** Yeah.

**[JORDYN ZIMMERMAN]** Sure.

**[TAUNA SZYMANSKI]** Okay. I’m going to read – they’re all sort of about systems change, how do we change hearts and minds. So I’m going to read one that was in the chat. This person writes, “As an autistic educational leader, I am trying to advocate for change, but this is not without risk due to systemic discrimination and the perpetuation of the medical model of disability in our sector and beyond. What do you think is the best way for us to help educate teachers and families about the need to presume competence and foster and normalize the acceptance of AAC use from an early age, and how do we support AAC use for those who do not know their letter sounds or have letter identification? Are there best methods you would recommend using, for example, phrase or picture cards?”

**[JORDYN ZIMMERMAN]** As someone who is studying education, I just have to say that the field is so ableist and that’s a problem. It is definitely difficult to change minds when people are set in very specific ways around terminology, providing access to



communication, trialing devices, teaching literacy, and more. The best thing you can do is create a print-rich environment that allows students to explore letters and words constantly on their own time and then pair that with explicit instruction, modeling through AAC. I hope I answered some of your question.

**[BOB WILLIAMS]** Thank you. I want to thank you for doing this tonight and most importantly for making this film. Films by and for people requiring AAC are, I believe, one of the most powerful tools for changing hearts and minds and therefore systems as well. So, I would urge all of us to do whatever we can to make this go viral. Jordyn, do you have any parting words?

**[JORDYN ZIMMERMAN]** Thanks to everyone for joining us this evening. I hope the film and the subsequent discussion pushes you to advocate for yourself, your students, and those throughout the world.

**[BOB WILLIAMS]** Thank you, Jordyn.

**[TAUNA SZYMANSKI]** That was fantastic. Thank you, Jordyn, for agreeing to be filmed for the documentary and for being willing to be interviewed by other AAC users, for your advocacy, and for your leadership and contributions to CommunicationFIRST and this important movement we are creating. Thank you to Bob for moderating today's webinar and for your own advocacy and leadership. Thank you to our attendees and to everyone who submitted questions. We hope to have the recording, slides, and corrected transcript posted on our website at <https://communicationfirst.org> in the near future. And, if you appreciated this event and our mission, please consider supporting us with a financial contribution if you like, or if you can, at <https://communicationfirst.org/donate>.

We appreciate your support and your attendance tonight. Thank you so much.

**[BOB WILLIAMS]** Thank you so much. Good night.

**[TAUNA SZYMANSKI]** Good night.