

The Heumann Perspective Podcast
Access to Communication with Elizabeth Bonker
Transcript

Kylie Miller

Welcome to The Heumann Perspective, a podcast with the internationally recognized, badass, disability rights activist, Judy Heumann.

This episode, Judy interviews Elizabeth Bonker. Elizabeth is the founder of Communication 4 ALL, a new nonprofit with the mission to bring communication to non-speakers with autism worldwide. Elizabeth was also valedictorian of Rollins College this past May. Her commencement address went viral so if you haven't seen it yet, please find it in the description of this episode. As you'll hear, Elizabeth uses an AAC device which stands for augmentative and alternative communication. Please note that pauses while Elizabeth types have been edited down for this podcast.

The Heumann Perspective is produced by me, Kylie Miller, and Judy Heumann. So let's roll up, lay down, dance around, whatever makes you feel best, and let's meet this episode's guest.

Judy Heumann

Hello everybody and welcome back to The Heumann Perspective. Today we're going to be talking with Elizabeth Bonker, who I had the privilege of meeting in 2021 and first got to meet in person in 2022. I remember, Elizabeth, when we first met, it was like I kind of knew you because we talked so many times on Zoom, but then it was a completely different experience when we met in person. What was it like for you when we first met?

Elizabeth Bonker

Judy, I was starstruck when we first met. I had read your book, watched *Crip Camp*, and studied your advocacy work in college. I was honored when you agreed to be interviewed for my senior thesis and thrilled when you asked to be my mentor. When we finally met in person, you were so generous with your time. I loved being in your home and talking with you about my mission, Communication 4 All.

Judy Heumann

Elizabeth, let's also begin by enabling people to understand the communication device that you're using. Maybe you could start off, Elizabeth, explaining about what your disability is and why you're using a communication device.

Elizabeth Bonker

I am affected by autism and cannot speak. I type on a wireless keyboard into text-to-speech software that says my words. When I am out with friends or in a classroom discussion, I type on an iPad.

Judy Heumann

So what we're going to be doing today is learning more about you and the work that you're doing, and also in that process learn about the importance of ensuring that people can have mechanisms to be able to communicate. Can you introduce yourself a little bit more?

Elizabeth Bonker

I graduated from Rollins College in May and my valedictorian commencement address went viral. Four billion impressions have given my mission a big boost. I am the executive director of Communication 4 All. Our mission is to give all non-speakers access to typing on a keyboard as I do.

Judy Heumann

Elizabeth, do you remember— and this obviously is many years ago. Do you remember when you began to realize that you were not communicating the way other children were your age and how that made you feel?

Elizabeth Bonker

I had no way to communicate and I felt so helpless. I was in special education and getting so frustrated that I started to hit myself. Then when I was six years old, my life changed. My grandmother saw a woman on *60 Minutes* teaching her non-speaking son how to communicate by pointing to letters. My mother made an appointment for her to teach me and my whole world changed. I could finally start to show that I understood everything going on around me and participate. I was thrilled to be mainstreamed in first grade.

Judy Heumann

And for our listeners, mainstreaming means what, Elizabeth?

Elizabeth Bonker

I was in a regular classroom in public school, not special education. And after a few months, my teacher asked for me to be tested for the gifted program.

Judy Heumann

Was this happening when you were six years old? That you were being tested for a gifted class?

Elizabeth Bonker

Yes, I skipped kindergarten and went right to first grade after I learned to type at six years old. I am so grateful for my aid, Terry, and my first grade teacher, Mrs. Buser, who believed in me.

Judy Heumann

Elizabeth, can you talk with us a little bit about what it felt like before you were able to communicate?

Elizabeth Bonker

It was like being locked in a silent cage. People underestimate your capabilities and talk about you as if you are not there. That is what drives my mission: knowing what it feels like to be locked in your body with no way to communicate what you are thinking and feeling. I wrote a song about it called, Silent Cage.

Judy Heumann

Yeah and that's another whole aspect about you, getting into music and composing. Why did you start doing that and when was that?

Elizabeth Bonker

I started writing song lyrics about three years ago. The band, The Bleeding Hearts, set my words to music and we have an album called, *I Am in Here* that explores the dimensions of living without speech.

Judy Heumann

I think that's really very important that you're using so many different modes of communication. And we'll put information on how people can listen to the music. Let me continue to talk a little bit, Elizabeth, about when you were younger because you started going to school when you were six and you were in a program with non-disabled children. My experience was, I started going to school when I was nine, but I was only in classes with disabled children. And for me one of the values was that I got to speak to other children like myself. So we began to talk about how we were feeling having not been treated equally. And I'm wondering when did you start meeting other children, or did you meet other children and when was that, who are not what I would say typical communicators? So they're using communication devices. And how did that feel to you

when you were able to start talking with other children who communicated in a similar fashion to you?

Elizabeth Bonker

Judy, my situation was very different from yours. I only met other typers when I saw my teacher in Texas. I had no one to commiserate with at school. I was trying to fit in the best I could with my slow, one-finger typing. Now, I am thankful to have hundreds of friends who are typers. They are all such fierce advocates and we are working together to bring communication to 31 million non-speakers with autism. So, you could say I was alone in the beginning, but I'm now a member of a vibrant and growing community.

Judy Heumann

That's great. So if we could also focus for a minute... Your grandmother saw someone on *60 Minutes* who was teaching, I believe, their child how to communicate. And so now you were just saying that you had a teacher. I didn't know that. So were you being taught individually, or was it with other people who were beginning to use communication devices?

Elizabeth Bonker

Teachers usually work with students individually. There are only a few hundred typing teachers for millions of non-speakers. Our mission is to expand that capability so all can learn. Communication 4 All will be launching C4A Academy to show how to teach typing to nonspeakers in pre-recorded video lessons for free on the internet so everyone can have a voice.

Judy Heumann

You know, in the 1990s when I was an assistant secretary in the Department of Education, I became friends with a gentleman by the name of Bob Williams, who I know you know. And Bob also is an AAC user. And facilitated communication was something that was becoming more known in the United States, and Bob and I had a meeting with a number of people who were using communication devices and had an assistant with them and. There was pressure put on me not to have that meeting. And we of course went forward with the meeting. and it was one of my most powerful opportunities in the seven years that I worked for the Clinton administration. Why do you think there is so much controversy around people using alternative communication approaches?

Elizabeth Bonker

I am grateful that you introduced me to Bob. He is an AAC pioneer. I don't use facilitated communication, but I do need someone to hold my keyboard. The reason there is resistance comes down to two things. Money and ego. Service providers lose money

when we enter mainstream school, and they would have to admit they were wrong about our capabilities.

Judy Heumann

Thank you. Elizabeth, how long did it take you to become a proficient AAC user?

Elizabeth Bonker

It took a couple of years for me to transition from a letter board to a keyboard. Most people with autism are like me and have dyspraxia or difficulty with planned motor movements. So, we need to be taught to type in small steps and practice a lot. C4A Academy will show families with non-speaking members how it is done. I hope your listeners will follow Communication 4 All on social media to hear about our progress.

Judy Heumann

So about how long did it take you to feel like you were proficient?

Elizabeth Bonker

I felt proficient by second grade. I am one of the lucky few non-speakers to be taught to type as I was entering school. We are looking to change that with our schools program. Communication 4 All is working with public and private schools that serve non-speaking students to start typer programs. If your listeners know a school that may want to partner with us, please contact us through our website. I also want families to know that it is never too late to teach a non-speaker to type.

Judy Heumann

You know I'm wondering, Elizabeth, in the first grade, which is where you were at the age of 6, most children are just learning how to spell. So did your need to spell words out also help you learn how to spell at an earlier age? Formulate sentences and things like that than your non disabled peers?

Elizabeth Bonker

What we have found out from hundreds of typers is they are obsessed with language and most have taught themselves to read at a very young age.

Judy Heumann

You have a sister, right? And is she older than you?

Elizabeth Bonker

Yes, my sister Gale is the oldest, and my brother Charles is the middle child. Charles also has autism, but he is able to speak.

Judy Heumann

I didn't realize you had two siblings. What do your sister and brother do?

Elizabeth Bonker

Gale lives in Harlem. She is an activist and software engineer. Charles lives with us and also graduated from Rollins College. He runs a social enterprise called Love Your Neighbor Books, to give meaningful work to people with disabilities.

Judy Heumann

That sounds great. Very competitive family. When did you start thinking about going to college, Elizabeth? And what areas of study were you interested in?

Elizabeth Bonker

I have always wanted to go to college to show what non-speakers are capable of doing academically. I majored in social innovation and minored in English to be a more effective advocate.

Judy Heumann

What do you like to do to have fun? I know that, you know, you're a very serious person, very committed to the work that you're doing as an advocate. But what are some things that you do to have fun?

Elizabeth Bonker

I went to Disney for my birthday yesterday. That was fun.

Judy Heumann

You know, Elizabeth, when my husband Jorge and I got married, we went to Disney in California for our honeymoon. I had always wanted to go. What do you like about Disney?

Elizabeth Bonker

I think they are magical storytellers. The rollercoasters are great too.

Judy Heumann

I'm laughing about the rollercoaster. Oh my God, when I used to wear braces— I grew up in Brooklyn, you know, and we had Coney Island and my father would go with me on the rollercoasters cause my mother was terrified of them. I did it but... You find them exciting? I found them scary. That's great though. So now I know you're a role model for more and more people, but as you were growing up, did you have role models? And

who might one or two of them have been? And also why did these people become your role models?

Elizabeth Bonker

Growing up, Helen Keller and Martin Luther King Junior were my heroes because they were driven to set their people free. I want to look back at my life 50 years from now and feel like I made a difference in the lives of people with non-speaking autism.

Judy Heumann

So you incorporate their vision into work that you're doing now. That's great. Are there any AAC users that you were learning about as you were growing up that have helped be a sounding board for you? Or really are a part of the work that you're doing now?

Elizabeth Bonker

There are many AAC users who are being advocates in their communities. One of my friends has been fighting in court to use his AAC in school for more than four years. This insanity has to stop. As you well know, title two of the ADA mandates effective communication of our choice. Yet schools routinely deny non-speakers this civil right.

Judy Heumann

Do you have other role models? I appreciated that you know you're highlighting Doctor King and Helen Keller, both of whom are very important figures in the civil rights movement, the disability rights movement. But when I think, for example, about some of my role models: Marca Bristo, Ed Roberts, some of my friends that were just older than me when I was in high school. Do you have any people that you think about who really you could seek guidance from or just have fun with and talk about when things were not going well, when you were frustrated? Do you have any friends like that?

Elizabeth Bonker

Judy, you are my role model. You always give me encouragement and help me understand how this work is a marathon, not a sprint. When I need a boost, I also have friends I can talk to. In college, I had people who I typed with, like my friend, Virginia. We could go off by ourselves to talk about life. We even talked about our love lives.

Judy Heumann

So you had friends at Rollins, who are also communication users?

Elizabeth Bonker

Not AAC users. I was the only one in college. These are people who know how to support my AAC use.

Judy Heumann

Ok. So do you have other close friends who are AAC users?

Elizabeth Bonker

Yes I do. But they are not local. We Zoom with each other.

Judy Heumann

Do you have a Zoom group that you speak with regularly? I have a number of those that have popped up over the last couple of years of people who don't live in the area but just get together and communicate.

Elizabeth Bonker

The only zoom group I meet with regularly is the Autism Society's Council of Autistic Advisors. I do have weekly zoom calls with several close friends, both speaking and non-speaking. This summer, I met by zoom and in person with several typer groups wanting to understand how to make college work for them.

Judy Heumann

Thank you for sharing that Elizabeth because I know that you started thinking about going to college when you were younger, but I think for students who haven't necessarily had the opportunity to be fully included, where many of your high school friends would be thinking about going to college as well as the fact that you have a brother with a disability and he had gone to college. All of those things are very important. So again, I think what we are learning from you and others is the importance of role modeling, peer support, being able to be an example for others. And no one is going to travel down our same path, but I think what they do is they're learning about things that are possible where many people otherwise might be telling them it's not possible. So thank you. It's quite exciting for me to see you as someone who is a recent college graduate be so very focused on the creation of a new nonprofit and I'd like you to explain a little bit what some of your objectives are in the coming years.

Elizabeth Bonker

We launched communication for all in April. You have taught me to think big, so our goal is to gain communication for all 31 million non-speakers in the world. C4A Academy will empower families to teach typing to their loved ones.

Judy Heumann

It's a very big objective and I think very exciting to look at the potential of people who previously have been considered unable to contribute. What are some of your fantasies

of how the world will be changing as your work and the work of other organizations and other AAC users? What do you envision for the future?

Elizabeth Bonker

Every non-speaker will be given the accommodations and support they need to communicate by typing when they enter school. With communication, they can be educated and live productive lives.

Judy Heumann

And for me, in that vision of a future, it will also include speech pathologists and others beginning in a positive way, that all people can communicate. And how we assist people in achieving that level of communication I think is one of the very important parts of the work that you and many other people are doing.

I was just thinking of another question and you know when I'm talking with you and other friends who use communication devices, there are these long pauses when I'm listening. And I'm wondering when you're speaking with other friends who are also using communication devices, what do you think about when you're waiting for an answer?

Elizabeth Bonker

I try to clear my mind. Those of us who don't speak tend to be careful listeners.

Judy Heumann

Yeah, I think that's a very important way to view this. To really be able to focus in on what the other person is doing and I think also time for personal reflections. I know your mother, Ginnie, has played a very important part in your life and I'm wondering for other families, what do you have to say to families about using augmentative communication?

Elizabeth Bonker

I believe that all non-speakers with autism can learn to type to communicate. I am grateful to my parents and teachers who believed in me and hope we can stop my brothers and sisters from suffering in silence. Parents, please take a chance and try our typing lessons when they come out in a few months. And thank you for loving us and believing in us.

Judy Heumann

I think that's a really important way to end our program. I really want to thank you, Elizabeth, for spending time with us today and I know that our audience will have learned some new information and we look forward to following the work that you're going to be doing through C4A. I think you know for me, one of the important parts

about who you are is a young woman who is really a great example for other young people with and without disabilities. That if you have a vision of something that you want to be advancing, focusing and working hard on it will make things become a reality. Anything else you'd like to share with our audience?

Elizabeth Bonker

Thank you, Judy, for being my mentor. I want to have a life like yours, being a badass for non-speakers. I hope Communication 4 All can change the world and you are helping me in my mission. If any of your listeners would like to join us, we would ask them to get in touch with us through our website. Thank you for everything you do, from my heart to yours.

Judy Heumann

Thank you very much. It's been an honor.

Kylie Miller

Now it's time for Ask Judy, a segment where Judy answers questions sent in by listeners.

For 2023, Judy and I would love to hear from more of our listeners so we're asking you all to participate in Ask Judy in a new way. We're now accepting voice memos with comments and questions to Judy that will be played right here on The Heumann Perspective. If you're interested in sending us yours, please email it to media@judithheumann.com

Kylie Miller

Thanks for tuning in to The Heumann Perspective. Be sure to subscribe, rate and review our show on Apple Podcasts or Spotify. You can also follow Judy on Twitter at Judith Heumann and on Instagram and Facebook at The Heumann Perspective. If you want to find out more information about this episode's guest or resources relating to the discussion, check out the description of this episode or visit judithheumann.com. You can also find a shortened video version of this interview on Judy's YouTube channel dropping a week after this podcast is published. Otherwise, be sure to check back every other Wednesday for a new podcast episode. The intro music for The Heumann Perspective is Dragon, which is produced and performed by Lachi, Yontreo, and Jaurren. The outro music is I Wait by Galynn Lea.