AAC User Chat with Judy Heumann

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WEBINAR TRANSCRIPT

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>>TAUNA SZYMANSKI: Good afternoon, everyone. My name is Tauna Szymanski, and I am the Executive Director and Legal Director of CommunicationFIRST. I'd like to welcome everyone to today's AAC User Chat with Judy Heumann. This is CommunicationFIRST's first public event since our launch last October.

For our attendees with low vision, we are going to ask people who appear on screen to please consider describing themselves if they are able. I am a white woman with shoulder length brown hair wearing glasses. I have a wonky left eye. I'm wearing a navy blue top with the CommunicationFIRST logo button. Behind me is a light gray wall hung with a woven basket and a bright purple wall visible in the medium distance.

CommunicationFIRST is the nation's first and only non-profit organization dedicated to protecting and advancing the civil rights of the estimated 5 million people in the United States who are unable to rely on speech alone to communicate.

We are a cross-disability organization run by and for people with communication disabilities. We represent people who are born without the ability to use speech to communicate, as well as those who lose speech later in life.

Our mission is to educate the public, advocate for policy change, and engage the justice system to advance the rights, autonomy, opportunity, and dignity of our historically marginalized community.

Some of the things we've worked on since our launch include filing a lawsuit against the 10th largest school district in the United States, challenging its widespread use of abusive restraint and seclusion practices against students with disabilities.

We filed comments recommending that the diagnostic criteria for intellectual disability be modified to reduce its discriminatory overuse among people for whom IQ tests are not reliable, including for a significant number of people who cannot use speech to communicate.

We are working with Temple University and a team of national thought leaders to help AAC users develop toolkits for how to communicate with their doctors and nurses.

Back in March, we issued a COVID-19 Communication Rights Toolkit. And we have a number of other toolkits underway, including one relating to IEPs.

We are working on an initiative to improve the quality of data about our population, which is consistently undercounted by the federal government.

In April, we also helped file the first federal complaints regarding COVID-19 hospital no-visitor policies, to ensure that patients with disabilities can access the in-person supports they might need to communicate while they are hospitalized. This led to a precedent-setting resolution in early June from the Office for Civil Rights at the US Department of Health and Human Services, making clear that states and hospitals can and must safely allow disabled patients to access these in-person supports.

We encourage you to check out our website at CommunicationFIRST.org to learn more about what we are doing and to sign up for our newsletter if you haven't yet.

We are thrilled to host today's webinar with civil and disability rights legend and CommunicationFIRST Board member, Judy Heumann.

Today's webinar will be co-moderated by two prominent AAC users: my colleague Bob Williams, and UC Berkeley student Hari Srinivasan. We've had over 200 registrants from at least 29 US states and eight countries, including Canada, the UK, Romania, India, Turkey, Australia, and New Zealand.

To ensure we can accommodate everyone, we're also live streaming the webinar to our YouTube channel. Before I turn it over to Bob and Hari, I wanted to go over some ground rules and housekeeping details.

In addition to American Sign Language interpretation and live captioning, you will see a chat box where attendees can type in questions and comments. These can be directed to all participants, or more privately to a host or a panelist.

Because this event is specifically for AAC users, we are going to ask people who can speak to refrain, for these 90 minutes, from using the chat box today.

AAC users will tell you that people who can speak often drown out the voices of those who cannot. We would like to take this opportunity to respect and elevate the voices that are often drowned out.

The vice chair of our board, Clarissa Kripke, will be monitoring the chat box today and may read some, but not all, of the comments or questions. And I may assist her with that as well. To ensure we credit you correctly, we ask that everyone please use your full, real name on your Zoom screen.

If you do type in the chat box, please be respectful. If anyone makes disrespectful or inappropriate comments, we will remove them from the webinar.

To turn on the live captions, click on the CC button at the bottom of your screen, if they're not visible now.

You can change the font size by clicking on the little caret, or up-arrow, to the right of the CC button and select "Subtitle Settings." If you'd prefer to access the live captions on a separate screen, click on the caret, or up-arrow next to the CC button and select, "View Full Transcript."

A live transcript should then appear to the right of your Zoom screen. To maximize the transcript screen so that is all you see on your monitor, click on the little down arrow to the left of the word "Transcript" in that box and select, "Pop-out." From there you can size the box however you like. You can have both the chat box and the transcript visible at the same time by going through the same steps with the chat box. Pop it out, and then you can have the transcript box and the chat box visible side by side.

Today's webinar is being recorded, and we do hope to make the recording available as an accommodation for those who may not be able to sit through the entire program today.

If you experience any issues today with access, please send a private message to the host or to Ed Hirtzel in the chat box. That's H-I-R-T-Z-E-L.

I'm going to turn it over to my colleague Bob in a second, but before I do that, I thought I'd lay out the schedule so you can know what to expect today. Bob will say a few words, and then he will turn it over to Hari to introduce Judy and to kick off a discussion until about 1:15 PM Pacific Time, and 4:15 PM Eastern time. At that point, Bob and Hari will be inviting some members of the audience to ask questions of Judy.

I am pleased now to turn it over to Bob Williams, CommunicationFIRST's Policy Director. Bob has a very distinguished, nearly four-decade career in the public and non-profit sector. To my knowledge he is the highest ranking serving US government employee to be an AAC user. Before he joined CommunicationFIRST a year ago, he was the head of the US Government's Independent Living Administration in Washington, DC. Bob is a pure joy to work with. And I feel privileged every day to learn from him and to work with him to build this groundbreaking organization led by and for people who cannot rely on speech alone to communicate. Bob?

>>BOB WILLIAMS: I am having a problem.

>>[OFF-CAMERA VOICE]: He's having a problem right now. Just a second.

>>BOB: Oh, why don't you talk, Hari?

>>[OFF-CAMERA VOICE]: All right.

>>[OFF-CAMERA VOICE]: This first?

>>BOB: Yeah.

>>[OFF-CAMERA VOICE]: Tauna, can you let Hari speak first?

>>BOB: Wait, wait a minute.

>>[OFF-CAMERA VOICE]: Or just wait a second?

>>BOB: Yeah. I'll try.

>>BOB: You know that [when] most people think about Judy Heumann, her work, and the contributions she continues to make, they naturally reflect on the roles she has played and the parts she has had in securing greater justice and equality for people with disabilities, both here and around the world. And this is understandable.

There are literally thousands of us in the US, as well as the farthest flung corners of the earth, however who in varying degrees, and over the years, have gotten to know, become the friend of, or at the very least ... [pause] have gotten privileged glimpses into Judy Heumann, who she truly is, what makes her tick, what her strengths and personal doubts are, and yes, what being Heumann is all about. I am eager and excited for each of you to have the chance to experience some of this for yourself over the next hour. I first met Judy in 1982. She had come to DC along with Ed Roberts and Hale Zukas.

Thank you, Tauna, for your kind words of introduction and for your leadership and vision that is helping to drive CommunicationFIRST. And I want to thank and welcome each of you who is joining us today. Over 500 people from across the US, Canada, and other countries like the United Kingdom, India, and New Zealand and many others, but by no means all of the places that Judy has visited in her career. Largely to meet people just like us, and to have conversations just like the one we are about to have.

As someone who has known, worked with, and worked for Judy over the last 40 years, and someone who loves to tease her– as any younger brother from hell would do to an older sister– I have frequently joked and played the game with her of where in the world is Judy Heumann this time? Because one can never be certain exactly where on the globe, or off on some distant star far, far away one will find her when you call her.

But typically, when you do find her, she is deep in conversation with one or more other people. That is her passion, mission, and gift to all of us.

Hari will offer more details on the life, times, and career of Judy in a minute. I want to just preface this a bit by saying that I could not be more pleased than to be having this webinar this afternoon, just days before the 30th anniversary of the ADA because it is so fitting a way to celebrate the achievements of the law to date. And far more importantly, I believe, to commit ourselves, both individually and collectively, to doing the work that still remains in creating greater justice and equality of opportunity for all people with disabilities, writ large.

And for the millions of us who, due to disability or condition, must use often multiple means of augmentative communication to effectively express ourselves so that others can understand us.

We can do this best by doing something Judy excels at and is loved for deeply throughout our world: engaging with, listening to, learning from, and acting together.

When I am asked what CommunicationFIRST intends to do, I say we mean to expose and shatter the walls of stereotypes, the bias and the discrimination that forces far too many of us, and far too many of our parents, our spouses, sons and daughters, brothers and sisters, students, friends, and millions of others, of being unjustly judged to be incapable of learning and connecting, institutionalized, abused, and worse. In fact, because of this entrenched culture, many are, in effect, being sentenced to what I call lives [in a state] of incommunicado.

And by this I mean being denied the right, the real opportunity, and the tools and supports to express ourselves, and therefore to be recognized and treated as equals of all others. That is our fundamental goal.

To achieve this goal, we need all your help. Most especially, we need the help, the experience, inside knowledge, skills, and most of all, the passion of those who, like Hari and I, cannot rely by themselves on speech alone, if at all, to express ourselves and live our lives, to work together with us in creating that greater justice and opportunity I just mentioned.

To do this we must have many conversations like this one aimed at helping us to take two steps that are fundamental to all human and civil rights struggles.

The first is to recognize that regardless of how much we differ in our ages, cultures, life experiences, as well as the real or perceived disabilities and needs we have, or are thought to have, we are more alike than we are different, especially regarding the prejudice and discrimination we face.

And the second is that because of this, the justice, accommodations, and other solutions we seek to achieve, as the ADA puts it– equally effective access to live life fairly and fully– are essentially the same as well.

Flexibility to meet the individual and specific needs of the person. But the essentials we seek are the same.

As Tauna mentioned, we are already building on as well as building out the effective communication requirements of the ADA and Section 504 of the Rehabilitation Act, specifically regarding what they must mean for people who need access to AAC. And through conversations like this one, we will be learning what we can do to refine and increase our efforts on this front as well as other civil rights issues.

So thank you once more for participating.

>>HARI SRINIVASAN: I am Hari Srinivasan. I will begin with an image description of myself as that is another important accessibility feature for the disability community at large. Just another illustration of how accommodations come in many shapes and forms depending on your specific disability.

I'm a young college-going male in his 20s of Indian-American origin and with brown skin. I have short, black hair and am wearing a yellow and blue cap with the word CAL on the front. I'm wearing a dark blue shirt with the word BERKELEY on it. I am sitting at my desk in front of my Mac laptop in my room at my home.

Behind me on the wall and on my closet door are various college banners and posters with words like University of California, Berkeley, Cal, Golden Bears, or catchy phrases like, "This is bear territory" or "Bear den, enter at your own risk."

We have with us today Judy Heumann, who in President Obama's words, has helped bring about incredible change in this country and around the world.

Judy is also featured in the recent documentary *Crip Camp* produced by the Obamas.

During a surprise appearance at one of the virtual Crip Camps that are now going on. President Obama described the film as the story of a bunch of disabled teens, who by getting together, awaken to their power to start a global movement for a world that would treat us with dignity and respect.

What had begun as a personal journey for Judy to overcome the obstacles in her early education turned into a civil rights crusade where she led 150 people with disabilities in the 504 Sit-In, the longest sit-in in US history, lasting 28 days at the San Francisco federal building.

Can you just imagine? Til then, disability rights were not even thought of as civil rights. Section 504 is widely regarded as the first disability civil rights legislation.

Judy helped set up both the Center for Independent Living in Berkeley as well as the World Institute for Disability, which focuses on policy issues.

Judy was also involved in the passing of most of the important disability legislation we know today such as the Americans with Disabilities Act and the United Nations Convention on the Rights of Persons with Disabilities, and Section 504 of the Rehabilitation Act.

If my generation has a shot of being included in the education system today, it was because of laws like the Individuals with Disabilities Education Act that was set in place by giants like Judy.

Judy has been both an activist and government policymaker serving key roles in both the Clinton and Obama administrations as well as the World Bank.

Her social media platform, *The Heumann Perspective*, explores intersectionality and disability rights. And earlier this year, Judy published her long-awaited memoir, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*. The book is a must-read.

What is remarkable is that so much of her story is our story too.

For example, on page 21 is a line that goes, "I was conscious of feeling dismissed, categorized as unteachable and extraneous to society."

That experience is unfortunately still a reality for many of us AAC users today. In the movie *Crip Camp* too Judy remarks, "We are being sidelined." And I remember thinking that's still so true. It's déjà vu.

I will just echo President Obama's words when he said that Judy's resume is just too long to list.

I have to add that I am so super proud to attend UC Berkeley where giants like Judy created disability rights history.

Last year, I had the privilege of interviewing Judy for the *Daily Californian*. Not wanting to make an utter fool of myself, I was preparing by reading everything I could about her. There are over 460 pages of just her oral interviews alone in our library's disability history archives, and a ton of other information online.

Wow.

I even had my questions looked over by my Disabilities Studies professor, Victor Piñeda, just to be sure I was not putting my foot in my mouth.

Any conversation or interview with Judy is never one way. She asks you questions right back. So it was a good thing I had done some homework. Along the way, I was not quite sure who was interviewing whom.

I walked away in a daze that day. The final 2,200-word article could not quite do justice to the conversation we had that day.

Judy had described fortitude as her personal strength during the interview. OMG. She is very much the chingona or “badass girl” that her husband calls her.

How do you manage to pull together this incredible non-stop amount of energy, Judy?

And isn't Judy's virtual Zoom background so appropriate and mysterious? She came riding in from the infinity of space. At the end of the call, we will see her ride back into that infinity.

We hope to bring you all into this amazing conversation with Judy today.

I expect she will have questions for the audience today as well.

Judy, I want to start by asking you the same question you asked Senator Tammy Duckworth on your show, The Heumann Perspective. As we approach the 30th anniversary of the Americans with Disabilities Act, what does the ADA mean to you personally?

>>JUDY HEUMANN: Thank you, Hari and Bob. It's like, an amazing introduction.

Thank you, Tauna, for the great work that you've been doing with CommunicationFIRST. It's really an honor for me both to be on the Board and to be with all of you today.

Let me first say you know that I've had the privilege of knowing Bob for many years. But, we also worked together when we were over at the Department of Disability Services. And it was really very meaningful with Bob and– I was the director, he was the deputy– but depending on the day who was doing what.

But the reality is Bob is such a thoughtful, articulate, driven person to ensure that people with different types of disabilities, particularly those who are individuals that can be cast to the side, AAC users, and others.

So it was a real privilege for me to work with him for those three or four years, really, so closely together.

And Hari, you are an emerging star.

You are so great with your words. And when you asked me to be– when you asked me to be interviewed for your article, I was not knowing what was going to happen. And it was a great experience. Both as a Berkeley graduate but also as a disability rights leader yourself, it was great to be able to partake in that discussion.

So let me get down to answering the question. Why is the ADA, why does it mean so much to me? I think basically for me, it's a number of things.

One is that as disabled people we were able to come together over the course of many years and in many ways, put aside our differences to come together to talk with the Congress who did not understand– and in many ways still don't understand– the types of discrimination that we face, why we needed a law like the Americans with Disabilities Act.

We were able to come together, cross-disability, and work with every Congressperson and every US Senator.

And I think that really was one of the most important parts of the passage of the ADA. We, in part, made it a bipartisan piece of legislation because we worked with everyone.

So for me, that is what resulted in our being able to put together the Americans with Disabilities Act.

Plus to say that there was an amazing team of people that were working in a very deep and substantive way, both Members of the Congress on the House and Senate side. People like Justin Dart, Pat Wright, Mary Lou Breslin, Arlene Mayerson and Bob Williams, many others who were in DC, Tony Coelho, Senator Harkin, Senator Kennedy, Steve Bartlett, on and on.

It was really something that I think today would be very difficult to replicate because the bipartisan nature of what happened that brought the ADA forward.

It really is my hope that we will in the very near future be able to really recreate the ability of the Congress to represent diversity in itself and bipartisanship.

Bob, you want me to read this?

>>BOB: Laws like the ADA and the movements that bring them about occur of course at a fixed moment in time. But such laws and movements must be lasting and must be responsive to change.

Especially changes of the human, societal, and global magnitude and importance we have had for the past six months, 24/7. COVID-19 and the brutal murders of George Floyd and so many other Black, Indigenous, People of Color, many who have disabilities, are revealing the pervasiveness of racism and oppression in our country.

Give us a sense of what you believe are the greatest risks and opportunities they pose to the nation, the world, and people with disabilities.

>>JUDY: Thank you, Bob. The last number of months with the murder of George Floyd has brought in my mind attention to the racism in the United States.

And has made me, like millions of other people, really begin to look more deeply at what we, as individuals and as a society overall, can do to address these problems.

I think as disabled individuals, we have a particularly important role to play and voice that we need to bring forward because disability is really the most diverse community.

The onset of our disabilities does not occur all from birth. Well, Bob and Hari, you had your disability, I don't know– Hari, is your disability from birth?

>>HARI: Yes.

>>JUDY: Yeah? I wasn't. I had mine when I was 18 months old. And I believe Tauna's daughter's disability came on when she was younger.

But we see people– AAC users for example, or people who could benefit to be an AAC user, frequently being denied the technology they need for a whole host of reasons. And when we look at issues like police violence against black and brown people, we see numbers of those individuals are actually people with various forms of disabilities.

When we look at the juvenile injustice system and the adult prison system, we likewise see large numbers of disabled individuals with intellectual disabilities, mental health disabilities, and in some cases, blindness, physical disabilities, deafness, learning disabilities.

So we really have a responsibility, regardless of our race, to ensure that we are speaking up and speaking out. One, to make sure that people who have disabilities are getting the services they need at the point that they need them.

And today, we're focusing a lot on AAC users.

My job in the Clinton administration was Assistant Secretary for the Office of Special Education and Rehabilitative Services. Which meant that, amongst other things, we had responsibility over the Individuals with Disabilities Education Act. And we were learning that there were some school districts who would not allow children to take their AAC communication devices home during the school year or over the summer.

And we had to issue a policy statement to say that these kids needed to be able to have their AAC technology to go home with them both in the evening, and on the weekends, and in the summer.

Now, one has to ask the question– why in the world is this something that we had to put a policy statement out on? How could anyone fathom that you were giving someone a device to enable them to communicate and then, at 3 o'clock at the end of a day, or on a Friday, or over the summer, take that away?

And I think that really speaks to the fact that we have many good pieces of legislation. And it's very important because we can really be working on being able to put out a policy statement to address this.

But at the end of the day, we have so much further to go to really allow the broader society to understand the collaborativeness that we need to be working on to ensure everyone gets an opportunity.

Black lives matter, and black disabled lives matter. Latino lives matter. Et cetera.

Again, we need to ensure that individuals who are kids, that their families understand what their rights are, that their families can help support their children. That advocates are available to help their families ensure that they can get the services they need.

And then, as we're getting older, we all need to be working together. And we need to speak out together against injustices. And there are so many different types of injustices. But we really need to have a much better understanding of the history of racism in the United States.

>>HARI: Thank you.

>>JUDY: You're welcome.

>>BOB: Hari– question. Of all the things you said. Hari? Hari, back to you.

>>HARI: I want to read you all a passage.

Judy, I have to tell you that pages 152 and 153 in your book resonated so much with me and I feel applies for so many in the AAC user community. I want to read you all a passage from page 152 on facing down negativity.

Begin quote: "One of the simplest arguments against change is to say something is too expensive, unsafe, or impossible. This pushes you down a rabbit warren of arguments. It forces you to discuss various interpretations, and it distracts from the issue that when something is a civil rights issue, we must have ingenuity. People need to assume that it is possible to figure things out, that we can problem-solve and act." End of quote.

I think one of the issues is that many of us are not given the benefit of doubt to begin with. For instance, no one questioned the cognitive skills of the late Stephen Hawking because he had established his brilliance to people around him before the onset of his disability.

So accommodations were made to whatever extent possible to help him continue his work.

But if you have a disability from childhood, how do you show competence to begin with? The door is slammed shut on any kind of learning and teaching early on as we are not presumed competent to begin with.

It's a very high bar to meet on top of our struggles to learn alternative communication modes with dysregulated bodies.

I wish they would hurry up with a non-invasive wearable brain computer interface technology, kind of like a wearable baseball cap, that would turn your brain signals into communication instead of relying on motor pathways. Then, all of these arguments would be put to rest.

In the meantime, we face down continual no's. As you said earlier, the status quo loves to say no. What advice would you give to change this status quo and overarching arguments that say it's impossible or expensive? And how do we shore up our own people to handle these no’s?

>>JUDY: Great question, Hari. I think there are many ways to address this.

One, now that there are more well, you know, CommunicationFIRST as an organization, which didn't exist before, is a great opportunity to be able to reach across the United States and other countries to work with allies who are both AAC users, family members of children who are or need to be AAC users, and really get people much more engaged in this discussion.

AAC users yourselves really need to be out there telling your stories more, allowing people to understand what it is like when you're not able to use your augmentative communication devices.

And also to be able to continue to have research being done, as you're implying here, that would enable more and more sophisticated pieces of technology to exist to make it easier for people to communicate.

But at the end of the day, one shouldn't have to be a Stephen Hawking. And I think your point is so eloquently raised.

You think of someone who is older, and has a stroke, or some other form of condition that is adversely affecting their ability to communicate the way they did in the past. All too frequently, there is a presumption that the person will not be able to communicate.

It's the perfect way that people come in and start taking over responsibility for somebody else's life instead of continuing to work with them to ensure that they can communicate.

So this, as you expressed it, belief that there are exceptions to the rule, like Stephen Hawking, but most people couldn't benefit, that I think is really something that we have to continue to push forward on.

I think it's really important that we get the media doing a much better job of really allowing people to understand what augmentative communication is, how it does benefit people from the viewpoint of the people using the AAC technology themselves.

>>HARI: Thank you.

>>JUDY: You're welcome.

>>HARI: That was great.

>>BOB: Of all the things you say in your book the one that affects me the most is– on page 186– is where you say: "I think what people miss sometimes when they think about disabled people is our vulnerability." End quote.

This strikes me to be a statement of fact as well as a call to action to people with disabilities in particular. Can you tell us why you made it and why it was important for you to do so?

>>JUDY: Sorry. Hold on.

>>BOB: Did you understand?

>>JUDY: Yeah. I'm looking on page 186. I lost where you were reading from. Hold on. You're talking about vulnerability, right?

>>BOB: Yeah.

>>JUDY: So I think you know, one of the incidents that we were looking at is, in the book, I was talking about how a child came up to me when I was pretty young and asked me if I was sick.

And I also describe in the book an incident when I was in India, and I was visiting in a rural community with a group of disabled individuals who had come together in this village basically to organize. Because they were being treated as second-class citizens, third-class citizens.

They weren't being called by their names we had met. They were being called limp, or mute, or whatever people thought their disability was. But they didn't call them like a Bob, or a Hari, or a Judy.

And they came together to really be able to, in many ways, unify their voices, but also to protect the rights of others.

And we met this little boy who had been born without arms and were told a story about how the grandmother had directed the mother not to feed the child.

And how this group had gotten together, and gone to the police, and had worked with the police earlier, and informed them of what was happening, and asked them to please intervene.

So the child, in fact, had not died because he was fed. And when we met him, he was about a year old– a very healthy young boy. And we'd given him a crayon and paper, and he was happily– maybe he was two– he was happily drawing away.

But I think, in many cases, people do not view us as their peer. I believe that laws like the IDEA, and 504, and ADA are changing that.

I think it's certainly fair to say that the life that I was leading in the 1950's is very different than life today. In part because of these laws and the resulting changes, like accessibility of buses and trains, and movie theaters with bathrooms, and captioning, and audio description, and on and on and on.

And augmentative communication, quite frankly. Because when we were all younger– Bob, there was some augmentative communication devices coming out when you were younger.

But when I was– because I'm about ten years or so older than you.

So, so many important things have been evolving. But I think people need to realize that treating us in a demeaning, derogatory way is– you can't legislate that away. But people need to understand what is wrong when they are doing things like this. They need to understand that. And we need to defend ourselves, which I think can be very difficult.

And we need others to see that when bullying, or things of that nature, are happening, that it really is our responsibility to protect the individual who is being bullied.

>>BOB: Yeah. For me, what you were saying is that as people with disabilities, we need to embrace our vulnerability and join together to move beyond it.

>>JUDY: Yes.

>>BOB: –together to move beyond it. For me, what you were saying is that, as people with disabilities, we need to embrace our vulnerability and join together to move beyond it.

>>JUDY: Yes. Hari, are you next?

>>HARI: During our interview for *The Daily Californian* last year, you had said that you want to be remembered for two things, your belief in fighting against discrimination and for "collaboration cooperation."

I have to tell you I was so impressed by the term "collaboration cooperation." Do you know if you do a search online, the two terms are always one or the other, never together.

My question is, who are the natural allies or potential allies for the AAC community for this collaboration cooperation in this fight against discrimination?

>>JUDY: I mean, I think it's thoughtful people.

I mean, obviously you know, engineers. People who really are challenged to make the technology that's coming forward.

But I also think there shouldn't be anyone that is not a potential ally.

And one of the reasons why I believe it's so important that children and adults are integrated in society using whatever technology they need is so that people can understand how, in this case, technology in the area of augmentative communication devices, can benefit people, can allow others to see and learn from people who are AAC users.

The population of AAC users is still relatively small compared to the overall population of society.

So, like the television program *Speechless*, I think it was an important program because it did show a young teenager using augmentative communication.

Now, for me, I would– I don't think he used his augmentative communication to the maximum. But then again, people have a right to use their technology any way they wish. And I think it maybe was a Hollywood gimmick also the way they used the technology.

But I think the mere fact that there was a program for a couple of years that had a star who really had cerebral palsy and was using augmentative communication was great because it was probably the– I'm sure the first time that there was a character not only who had a disability, but was using technology.

And we don't see enough disabled people– with any type of disability– in a positive way in films or television programs. And so we need to be looking at ways of keeping those stories alive and front and center.

I mean, for me, who should be involved? Everybody. And we bring in people that know us the most, who believe in us, and recognize that AAC is so valuable. And then we expand our circle.

So if you're in a religious community, getting them involved. If you're at school, getting them involved. If you're working, get them involved.

Look at ways of amplifying this story because I think AAC is interesting because, as we were saying, as people get older, people may need different forms of technology.

And if people see people using augmentative communication, different levels of sophistication of the technology, that also will allow people to be thinking about, if somebody needs it, of asking for it.

>>TAUNA: Thank you, Judy.

I think given time constraints, Bob has asked me to sort of jump in. Thinks it might be a good time to switch and pivot over to audience questions. Due to technical issues, he's also asked me to read the introduction he prepared for this.

Is that all right with everyone? OK.

So when we sort of cut off the questions for consideration, it was around 11:00 this morning. There were questions from over 75 registrants who submitted them. Bob and Hari made the tough calls about deciding who to invite among the questions that were submitted.

They did invite eight and I'm hoping we have time to take most of them, at least, during the last half hour of the program today. And we apologize in advance if we can't get to yours.

Bob and Hari tried to choose questions that represented not just diverse topics, but also the diversity of questioners and AAC users in our community, both in terms of disability type, type of AAC used, age, race, gender, et cetera.

The themes really covered the gamut in terms of questions that were received. They received questions about going to college. Questions about speaking up, and being heard, and building confidence. Questions about how to make a difference. One question about running for office. Questions about the disability rights movement. And more.

Bob, should I introduce the first questioner, Melissa? OK.

Melissa is our first questioner, Melissa Crisp-Cooper, who actually is a CommunicationFIRST board member who lives in Oakland. She'll be asking the first question today, and she prefers to type her question into the chat box, but we can see her on screen now. So I'm going to turn off my—

>>JUDY: Usually you get a picture.

>>TAUNA: OK. So Melissa types, "Hi, Judy. I loved *Crip Camp* and your memoir. How can we get more people with IDD, which, for those of you who don't know, stands for intellectual and developmental disabilities, involved in the disability rights or justice movement?"

>>JUDY: I think we have to make a conscious effort at doing it. It's not going to happen by itself.

There are plenty of organizations out there now run by people who have IDD, intellectual and developmental disabilities.

We need to really be sitting down, and talking with people, and learning from them about what it is they want and inviting them to come in to the organizations that we're working with.

And I think it's like any– we tell nondisabled individuals who say they don't know what should they be doing with disabled people. And one of the first things I say to them is, you need to get to know to disabled people. Know our organizations, know what it is that we're interested in.

And so I would think, Melissa, that today, we're talking about AAC, so we'd be looking with this to people who have intellectual and developmental disabilities who are augmentative communication users, right? Is that what you're thinking about?

Yeah. So talk to people, find the right organizations.

Maybe interview some of them to find out what their experiences are, being assessed for augmentative communication devices, getting them, getting training in them, how they're using them, what more they could benefit from.

So both I would say helping them get better knowledge and ability to use good augmentative communication devices, but also get them on the board.

Get people you know meaningfully involved. Don't let people feel like they're being tokens.

>>TAUNA: Hari, do you want to introduce the next audience member question?

>>HARI: Now we have a question from Lateef McLeod from Oakland. Lateef is a Sins Invalid performer, ISAAC board member, published poet, Berkeley alumnus, and currently, a doctoral student in anthropology.

I first met him at a campus event organized by Professor Victor Piñeda, where Lateef had some very interesting observations. Lateef, you are on now.

>>JUDY: So the question is, what, in your opinion, should be the new disability rights–

>>TAUNA: Hold on. He was just on mute.

>>LATEEF MCLEOD: I am Lateef McLeod. For a short description of myself, I am a Black man with cerebral palsy and am in a wheelchair and wearing a Golden State Warriors Strength in Numbers blue and yellow shirt. I also have short black and curly hair and a beard. Good to meet you, Judy.

My question is what, in your opinion, should be the new disability rights or disability justice strategies and goals for this new generation of disabled activists, especially disabled activists who use AAC?

>>JUDY: I would say that we need to continue to be focusing in a more targeted way to really identify people who are AAC users or need to be AAC users.

Really create opportunities for mentors and mentees so that people are getting what they need. Help families be able to learn about how to get the technology, why it's important, how to use it.

And I think one of the big issues, and I talked about it earlier, is ensuring that people, regardless of their socioeconomic status or their racial background, that we know that people are getting what they need.

And we wouldn't see a lesser need in the black community or Latino community. We may likely see a greater need because of the linking to many cases of poverty to disability.

So I don't know that it's so much new as really strengthening, and expanding it, and having a more conscious approach.

And I do think that CommunicationFIRST is a very important organization to do this. But then I also think we need to be looking at the organizations in communities that people use.

So it could be the Centers for Independent Living. It could be another disability rights organization. It could be churches, and synagogues, and mosques.

I think we need to look at who are the people that the individual that we're supporting, who are the people in their lives that are most important. And how can we help all that group really understand their rights, and learn how to exercise their rights. And be there to support people when there are blocks being put in front of people to get what they need.

Thank you for your question, Lateef.

>>TAUNA: Thank you, Lateef. The next audience member who will be asking a question is Rob Stone from Maryland. There we go. Rob, can you turn your camera and audio on?

>>ROB STONE: AAC users, my name is Rob Stone. I am 23 years old. I am an emerging AAC user.

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When I get frustrated because I can't say all I want to say, what's your advice for keeping my spirits up?

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[LAUGHTER]

When I get frustrated because I can't say all I want to say, what's your advice for keeping my spirits up?

My name is Rob Stone. I am 23 years old.

>>TAUNA: OK.

>>JUDY: OK. So Rob, did I meet you?

>>ROB: Yes.

>>JUDY: Yeah. So nice to see you again.

I don't know. I think, actually, I'll give you my thought. But then Bob and Hari should give their comments also, because I'm not an AAC user, so I'll talk about it from another vantage point.

You know, when we're learning to use anything new, it takes time to adjust. And when we do things slower, it can be very frustrating. And certainly when you're using AAC, which is for communication purposes, you have a lot of thoughts in your mind and getting the– can be very frustrating.

So Bob and Hari– but one of my other comments would be, it likely will get better as you use it more, as you learn how to use the technology. And yeah, I think always trying to have friends who may be experiencing similar things so that you can also talk with them about your frustrations. So Bob, Hari?

>>ROB: Yes.

>>BOB: I think what I and others have found helpful is to brainstorm with other AAC users on how to manage the frustrations because they come and go.

>>JUDY: Hari, do you have something to say? How do you deal with frustrations with your AAC device? Do you have anything you want to say? Are you typing?

>>TAUNA: Hari, we can also move to the next question, if you'd like– introduce the next questioner, if you wish.

>>HARI: Keep looking for alternative paths. The regular solution probably won't work.

>>JUDY: Good. Do you have examples? Maybe we can go to the next question then. Hari, if you've got suggestions, you can–

>>HARI: For example, charter school versus district.

>>JUDY: Which one do you go for?

>>HARI: Charter school.

>>JUDY: OK. I wouldn't necessarily do that, but depends on the school.

>>TAUNA: Hari, in the interest of time, do you want to introduce the next questioner? Thank you, Rob.

>>HARI: Our next question is from Ben McGann of Virginia, who is a fellow board member of the Autistic Self Advocacy Network. Like Judy, Ben also attended the Sundance Film Festival this year, as he was featured in another documentary film there, *The Reason I Jump*. You are on video, Ben.

>>TAUNA: Ben, you're going to have to turn on your video and unmute yourself. I'm sorry, Ben. You're still on mute.

>>JUDY: Would it be OK if we read your question, Ben? OK, got it. There you go.

>>FEMALE VOICE OFF-CAMERA, FOR **BEN MCGANN:** So his question– it's in the interest of time– he's just typed– What can we do to increase— increase (inaudible)–

So his question was, what can we do to increase collaboration within the disability community– and then I will just add– between those with physical disabilities with those with intellectual disabilities?

>>JUDY: Again, I think we need to create opportunities. And I think some of the Centers for Independent Living have people not just with physical disabilities and IDD but people with many different types of disabilities. I think there's been real separation of people with intellectual disabilities, so we need to create opportunities. And we need to really work on destigmatizing people who have intellectual and developmental disabilities, and do the work that we all are talking about, getting people to be able to live in communities out of institutions so we're becoming friends and colleagues.

>>INTERPRETER: Thank you, Judy.

>>TAUNA: Thank you, Ben. Our next question comes from 11-year-old LJ Seiff, also of Virginia. LJ? Are you on? There you are.

>>LJ SEIFF: I am an 11-year-old boy with brown hair, I wear glasses, and [am] wearing a green polo shirt. I'm sitting in my wheelchair. In the background is our kitchen. Would your parents have sent you to Camp Jened, if they'd known the shenanigans that had happened while you went there, do you think?

>>JUDY: Yeah, probably. Some of what was being discussed– some of the campers were older. I think it's fair to realize that some of the things that were being discussed weren't happening with kids who were 11 and 12 years old. You had older teenagers who were going to camp there. 15, 16, 17, 18. At the time, I was 21 years old. I did go to camp, as I mentioned earlier. I went to another camp called Oakhurst, and there I was like 9 years old until I was 12 or so and then went to Jened. And really a lot of what was going on at Jened was what I would call age-appropriate behavior.

Kids, if they didn't have disabilities and were living in the cities or the rural communities, they would be experimenting and doing things that non-disabled kids do. I think because we were in a more accessible environment and because the administration of the camp was not restrictive, I think we had opportunities to explore and discuss and do things that we didn't have when we were living in the cities.

Doe that answer your question? I guess I have a question of you. Do you have other friends who are AAC users, Ben? Oh, wait. No. LJ?

>>LJ: Yes.

>>JUDY: OK. And what are some of the things you discuss around your technology?

>>LJ: Being together and emergency planning.

>>JUDY: OK. And do you like being together?

>>LJ: Yes.

>>JUDY: Are you in regular classes in school?

>>LJ: Yes.

>>JUDY: So you like a combination of being in the regular classes but also being able to be friends with kids who use technology.

>>LJ: Yes.

>>JUDY: Do you have enough opportunities to do that?

>>LJ: Yes.

>>JUDY: OK. Do you have an opportunity to talk to other kids your age who may need AAC– augmentative communication devices to help them?

>>LJ: Yes.

>>JUDY: Do your parents help also?

>>LJ: Yes, and they know you from the state of– Yes, and they know you from the state of Utah.

>>JUDY: OK.

>>LJ: Yes, and they know you from the state of Utah.

>>JUDY: OK. [LAUGHTER]

>>MOTHER OF LJ: Hi, we met at your *Crip Camp*.

>>JUDY: OK. Nice to see you again. Sorry.

>>MOTHER OF LJ: Nice to see you too.

>>TAUNA: Thank you so much, LJ. Looking at a time, we technically have one minute left. So I am– just to keep on schedule, it looks like we might have to cut out the remaining questioners. I'm terribly sorry about that. The discussion was so rich and just carried on, so I'm thrilled about that. So I would like to thank you, Judy, Hari, and Bob, and everyone who submitted questions for today's event. I've really enjoyed the discussion. We are planning similar events in the future to give our community similar opportunities to engage with other prominent people who are helping to lead the way on disability rights, policy, and advocacy. To make sure you hear about those events, we encourage you to sign up for our newsletter on our website, so you won't miss these opportunities.

And finally, as an executive director of a small startup non-profit, I'd be remiss in not mentioning that if you appreciated this event and the work we're doing overall to help build the nation's first civil rights organization dedicated to people who can't rely on speech to communicate, we encourage you to become a sustaining member and to make a tax-deductible monthly contribution on our website CommunicationFIRST.org. You can also support our mission by ordering and using CommunicationFIRST face masks, tote bags, and t-shirts. You can get those also on our webpage, CommunicationFIRST.org, by clicking on "Shop" in the upper right-hand corner.

In the next few days, we'll send a follow-up email to everyone who registered with a link to the recording, assuming that all went off without a hitch. And thank you once again, and we hope you enjoyed today's event, and hope you have a safe and relaxing weekend. Thanks to everyone.

>>JUDY: Thank you