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Anjali J. Forber-Pratt

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DISCUSSION

A personal commentary about disability inclusion, and representation in research

Anjali J. Forber-Pratt

American Association on Health & Disability, Rockville, USA

ABSTRACT

This paper is a personal commentary about disability inclusion and representation in research that was based on remarks given in person at the Future of AAC Research Summit on May 13, 2024. Drawing upon her experiences as a Paralympic medalist, disabled woman, person of color, researcher, and activist, the author describes the critical need for (1) diverse researchers as the generators of the science; (2) diverse individuals as study participants; and (3) diverse representation in the knowledge translation materials we produce and disseminate about the research. We need all of these, and we are stronger for them. Our science is better with this intentionality; it makes people feel seen by the research we are doing and signals its relevancy.

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A personal commentary about disability inclusion & representation in research

In May 2024, the Future of AAC Research Summit was held in Arlington, VA in the United States, and I was honored and thrilled to be a part of the event. I am now the Director of Research with the American Association on Health and Disability, and previously served as the Director of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the United States. As I reflect on the importance of the AAC Research Summit, I believe it is imperative to ensure greater and enhanced disability inclusivity and representation in rehabilitation research and to underscore the importance of intentionally including AAC users in this broadening national conversation. Many researchers and attendees at the AAC Research Summit embodied the mission to support the right of every individual to self-expression and full participation in today's society as AAC users. Further, this inaugural gathering also pushed the field to advance our research, newest technologies and—very importantly—work hand in hand with the incredible disabled advocates from organizations like CommunicationFIRST. This commentary highlights my perspective on the value of inclusive research and disability representation.

One of my favorite quotes is from the late Judy Heumann, who was a powerhouse, a personal mentor and friend of mine. Judy said, “I wanna see feisty disabled people change the world” (*Crip Camp*; LeBrecht & Newnham, 2020). What better advice is there than that? I think about both her legacy and this quote often in my past and current role, as I am working hard to transform the research enterprise to be more inclusive of people with disabilities, including those

who are AAC users, throughout all processes. This is no easy task. But for far too long, the world of research has been dominated by predominantly white cisgender non-disabled male voices and researchers. Even beyond the focus of the research world, much in the broader disability and rehabilitation world—like clinical programs and policies and health-care systems—have been built based on the majority not the minority, and it takes leaders like all of us to challenge the status quo.

In the vein of challenging the status quo, it is important to be transparent about one's identities. My identities I wear proudly include: Paralympic medalist (Indian adoptee), disabled (wheelchair) woman, person of color, researcher and activist. Prior to this role, I was on faculty where I primarily studied disability identity development. But even before that, also relevant to this group, is that I have two degrees in speech language pathology, where I was drawn to helping individuals figure out the best ways for them to communicate and helping to trial different AAC options to find that right fit. I also think this has just always been something near and dear to me.

I acquired my disability when I was only 4.5 months old, because of transverse myelitis. As a young child, I thought everybody in the world had a disability and that it was a phase I would outgrow. I never realized that disabled children grew up into disabled adults; spoiler alert, they do. I also thought in order to grow up and go to college, have a job, start a family, live on my own—I first had to learn how to walk. Why? Nearly every adult I knew could walk. Therefore, in my mind, I held this assumption that in order to gain access to these opportunities I had to make my disability

disappear. I felt invisible and this lack of representation around me is what led to this assumption.

I remember the day crying in the bushes at preschool when I was watching my classmates on the playground and the swings and monkey bars, and there was something about that moment when I realized this disability thing was here to stay. I realized in that low moment, I could let society's expectations, or really lack of expectations for myself, dictate my life, but I knew that wasn't going to get me anywhere. Fortunately, I grew up just outside of Boston MA in the United States where as a young girl I saw wheelchair racers from the Boston Marathon go flying by and I learned through the power of example that people with disabilities could thrive, work, and succeed, both athletically and in life. I latched onto the role models from that moment on!

Around this same time, I also started going to a summer camp for kids and adults with disabilities, even though I was technically too young based on their pre-determined age range. It started off as a place where I went for a few hours so my mother could run errands and do grocery shopping. Well, let me tell you about my friend Jimmy (pseudonym). Jimmy was my age, 4 or 5 at the time, and used a power wheelchair, and we just were instant friends, laughing and having a great time at camp. But, I was very confused why Jimmy's dad came to camp with him but my mom dropped me off, and Jimmy wanted to just be at camp without his dad, too. So, in my determined 4-year old brain, I went straight to the director to find out why this was happening. They nicely explained to me that Jimmy (pseudonym) wasn't able to speak or to communicate and that they needed his dad to be there so that they would know what Jimmy needed or what he liked and didn't like. I told them they were ridiculous—that *of course* Jimmy could communicate, and that I knew exactly what he liked and didn't like—his favorite book was *No More Elephants*, his favorite color was yellow. Well, that confused all the adults. They then asked me how I knew, and I said, his eyes tell me! So they decided to see if I was right, and of course his dad was like, she's absolutely right, he looks to make his choices and to direct where to go and what to do—but nobody had taken the time to figure that out—and this was long before things like eye-tracking technology (Hoopmann et al., 2024) existed. I sure hope he has a better device today than his dad going with him everywhere. In the end, Jimmy's dad did a trial of being on the property but not right there with him, and then eventually he was dropped off at camp and his dad left and came back later, just like my mother!

This early experience planted the spark in me to be curious about language and communication. What we know now, and what I have been able to implement with other kids, is that early use and adoption of AAC enhances language development, improves communication, and reduces frustration for those who cannot rely on speech to be heard and understood—this is not dissimilar to early exposure and use of sign language for those in the Deaf community! This positive impact is life changing—it helps set the tone for self-determination, agency and meaningful participation in society.

I am proud to be a disabled person leading the research efforts at the American Association on Health and Disability

and to be representation for others, and to encourage funders to honor this important lived experience representation which helps to ensure research being funded is relevant to the communities we care about. We must constantly not just think about who is not being represented or at the table, but then change our policies and approaches, especially in research, to ensure all voices are heard. For me, growing up, visible representations of disability were hard to find in the media and in advertisements and toys and books; I'm so thankful that this is getting a lot better. There are now inclusive dinosaur stickers that showcase AAC devices—things are getting better! This has become such a part of my life's work to both research this power of representation, be that representation for others, and to help empower and educate about disability representation.

Disability hierarchy

In order to increase disability representation in research and in and across society, we also must be aware of the forces at play—there is a thing called *disability hierarchy*. Disability hierarchy is “a social construct that makes certain kinds of disabilities more acceptable than others” (Sauder, 2015). This happens both within the disability community, and among people outside the disability community, making judgements about who is or is not valued most within the broad spectrum of disability, and who is or is not accepted most. At the top of this hierarchy is physical disability, followed by chronic illness, and then learning, sensory, cognitive, neurodevelopmental, intellectual and psychiatric disabilities (Chan et al., 2009; Deal, 2003; Gordon et al., 2004; Huskin et al., 2018; Morin et al., 2013; Westbrook et al., 1993). The ones at the bottom are the most highly stigmatized, again both within the disability community and by society itself.

We need more research to show the impacts of this disability hierarchy as it relates to AAC users. McLeod and McLeod (2023) have an interesting chapter illustrating the right to communication should occur without the distinction of language—meaning we should not be privileging a certain modality over another, or verbal spoken language over, say, AAC, and their work looked at the intersection of this concept of disability hierarchies and communication using insights from Australia, Fiji, Iceland, and Vietnam. I encourage you to think about this in your own work and profession, too. The field of disability research has historically really focused on and valued mostly just those with physical disability. This likely contributes to maintaining the hierarchy of disability—something that I believe we must work hard and intentionally to dismantle.

Disability representation in research

I am beyond thrilled to see more and more federal agencies, universities, and professional associations showing commitment to increase the representation of disabled researchers and disabled researchers of color and from other underrepresented backgrounds across the entire research enterprise. This means not just our investigators, but also our research participants, our project officers, our peer reviewers, our

partners and our funding agencies. Academia and the field of research has a long history of systemic exclusion of certain voices and we are working to chip away at that because people with disabilities experience disparities and so we need people with disabilities in the workforce studying these issues.

It is important to talk about this from three perspectives: (1) diverse researchers as researchers or as the generators of the science, (2) diverse individuals as study participants, and (3) diverse representation in the knowledge translation materials we produce and disseminate about the research. We need all of these, and we are stronger for them. Our science is better with this intentionality, and it makes people feel seen by the research we are doing, and signals its relevancy.

Disability representation as study participants

In terms of who our study participants are, this means both having and supporting AAC-specific studies where participants are AAC users. This gives us depth and important nuances within the field of AAC research, but we also need to make sure that AAC users are not being systematically excluded from general research studies too! We need AAC users as participants in broader disability-related research and broader general research too—whether that’s social science research or biomedical research. Too often, due to embedded ableism and disability hierarchy in action, and sometimes because of gatekeeping of institutional review boards, AAC users are excluded from these important studies—this is an important area where continued advocacy and push for research inclusion is needed.

It also means we need data to show how we are doing on this, and, that we have representation across this entire pipeline in and out of government. Data from the National Science Foundation (NSF) in the United States on the science, technology, engineering, and mathematics (STEM) workforce suggest that we’ve made some slight improvements in terms of gender and racial gaps, but when we look at disability only 3% of the STEM workforce identifies with one or more disability, and this has remained unchanged from 2011 to 2021 (National Center for Science and Engineering Statistics, 2023). I call on us, as the disability field, to do something about this. Data from the Women, Minorities, and Persons with Disabilities in Science and Engineering 2021 report indicate that disability representation in the scientific workforce decreases throughout the career path (Hamrick, 2021). More specifically, this report looks at disability representation across the typical academic trajectory and reports that 19% of undergraduate students, 9% of doctoral students, 8% of postdoctoral students, 8% of assistant professors, 10% of associate and full professors, 8% of department directors, chairs, and chancellors, and 8% of university presidents and provosts identify as disabled. Related data from other studies indicate that just under 5% of medical students (Meeks et al., 2020) and approximately 3% of practicing physicians report disability (Nouri et al., 2021).

So, even if we are getting disabled people in the door to the scientific workforce, we aren’t keeping them or supporting them to grow in their careers. There is a real opportunity here. Also, I want to underscore the opportunity that exists for all to be a part of research teams, even if not pursuing

formal higher education degrees—your voice matters and you should be providing input and participating on research teams to help to ensure that the research being conducted is relevant to us and our communities and that it is answering actual problems or gaps that we encounter in our lives.

Disability representation on research teams

To include people with disabilities across the research enterprise also means talking about (and encouraging the talking about) the disability identity of individuals, and building inclusive research spaces where investigators and staff with disabilities are integral members of the research team and serve as funding agency project officers and research administrators. For a more detailed review and suggestions of inclusive research design, see Forber-Pratt (2024). Going back to the data, the gross underrepresentation of people with disabilities in the scientific research workforce is either reflective of the exclusion of people with disability throughout the research pipeline or reflective of the stigma attached to revealing a disability. I believe it is both. Regardless, low representation of people with disabilities in research careers remains a barrier. Across the government, efforts are ongoing to increase the inclusion of people with disabilities in both the research supported by these agencies and the people conducting them. I’m thrilled that many more are deeply engaged in this conversation, including many more universities too.

I also want to plant the seed and encourage everyone to be brave enough to include positionality statements in your written academic work about your own and your team’s disability status—this will help to make the less apparent more apparent and give confidence to students/trainees who might not realize this could be a career path for them. This is far more common in qualitative research, but if we want to really move the needle on representation and transform the research enterprise, we must boldly claim our identities—loud and proud—as we say in the disability community. This signals so much to future generations, to the consumers of your work, to the populations in your studies, too. It humanizes the work.

Research must include *all of us*. The diversity of the disability community is an asset, and our work must be inclusive of all people with disabilities—as participants, we may be unintentionally excluding a person who is an AAC user and a wheelchair user in a spinal cord injury (SCI) study by ignoring these accommodation needs in study design and recruitment. It is far easier to design studies with diverse populations and the needs of participants with disabilities in mind upfront.

The value of inclusive research cannot be overestimated. Inclusive research allows for traditionally silenced voices to be raised and to help shape the research being conducted (Forber-Pratt, 2024). Inviting and encouraging these voices throughout the processes adds depth, relevancy, and nuances that could be missed otherwise. All research—regardless of whether the topic relates to disability—benefits from inclusive research team design. And, as disability researchers, this should be the norm, not the exception.

It is imperative to remember the disability community mantra of Nothing About Us Without Us (Charlton, 1998). I do not want the involvement of people with disabilities to be just a check box or an afterthought—too often people with disabilities are the afterthought. While this is an exceedingly complex issue to tackle, it is so important that we are gathering here today in spaces like this to have these conversations. We all are a part of the solution, and we need disabled and non-disabled people to commit to the future of our field, and to help us diversify the research workforce with intentionality and inclusion in mind.

Disability representation in knowledge translation materials

Lastly, we must ensure diverse representation in the knowledge translation materials we produce and disseminate both in terms of study findings and recruitment materials. This means, ensuring the imagery you use is diverse across racial and ethnic groups, cross-disability. For example, are you only using images of people in wheelchairs? This may be okay if your study is only about wheelchair users, but if you are studying cerebral palsy, there are a lot who ambulate with cerebral palsy who often don't feel seen in imagery. Do your images show the diversity of the types of AAC devices and tools that exist? Also, please, especially as disability researchers: Are the images you're using actually accurate representations of disability? There are a lot of bad, or misinformed stock images out there that do not reflect accurate portrayals of disability. Thankfully, there are more resources now with inclusive and diverse representation of disability and other elements of diversity.

I encourage research teams to be more mindful about the process of selecting images, too. Some federal grantees in the US have a formal approval process across project directors, others use a paid community advisory board of disability community members connected to the project who approve materials and are asking these questions. This helps to ensure that different genders are represented, races, types of disability, religions and so forth.

Conclusions

What does it mean to achieve disability inclusivity and representation in research? It means that we are not an afterthought, and that we can participate in research studies without being perceived as a burden or an inconvenience. It means that we see ourselves represented in the questions being asked, and in the identities of the people conducting the research. It means diversifying our own project teams, our co-investigators, and our study participants, and ensuring that representation is carried forward in the materials we produce. It means expecting this equity in our own work and in the work of others. To make this a reality, we must be feisty ourselves, support each other, amplify each other's messages, dialogue with one another, and hold ourselves accountable on this journey.

We all can play an integral part in helping to make our society and disability research field more inclusive. As I reflect

back on Judy Heumann's words, I am so proud and honored to be a feisty disabled person changing the world, and I sure hope you will join me too!

Author note

This commentary is based on remarks given in person at the Future of AAC Research Summit. The Summit was organized through the equitable, shared leadership of people who use AAC, a community advocate, and university-based researchers; it was co-sponsored by the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (The RERC on AAC, funded by the National Institute on Disability, Independent Living, and Rehabilitation Research) in the United States (US) in collaboration with Communication FIRST, a US-based, nonprofit organization run by AAC users to protect and advance the civil rights of people who cannot rely on speech alone to be heard and understood.

At the time of the Future of AAC Research Summit, Dr. Forber-Pratt was serving as the Director of the National Institute on Disability, Independent Living, and Rehabilitation Research. She is now the Director of Research at the American Association on Health and Disability. The opinions and assertions contained herein are the private views of the author and are not to be construed as official or as reflecting the views of the National Institute on Disability, Independent Living, and Rehabilitation Research, the Administration for Community Living, Department of Health and Human Services or the United States Government.

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