Disability Representation and Inclusivity in Research
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[Janice]: “Now it's my pleasure to introduce Doctor Anjali Forber-Pratt. We're incredibly honored to have her here today. She is the director of the National Institute on Disability, Independent Living, and Rehabilitation and Research, but better known as NIDILRR.

As a wheelchair user herself for 35 years and a two-time Paralympian and medalist, Anjali is known nationally and internationally as a disability activist, a leader, and a mentor. She has really dedicated her life to helping others to really recognize their potential and what they can do. Globally, she's involved in a wide range of disability advocacy efforts related to employment, education, and sport. In 2020, she was honored by the American Psychological Association with the inaugural Citizen Psychologist Award for her work advancing disability as a human rights and social justice issue. She was also honored by the White House as a Champion of Change in 2013 and had an opportunity to participate in a roundtable discussion with President Obama about disability policy issues. So, Anjali, thank you so much for joining us this morning. We greatly appreciate it.”

[Anjali Forber-Pratt]: "Thank you so much, Janice. I appreciate that. And good morning, everybody. I'm so honored to be here with you all this morning.

As you heard, my name is Dr. Anjali Forber-Pratt, and I am part of the Administration for Community Living, serving as the director of the National Institute on Disability, Independent Living, and Rehabilitation Research, also known as NIDILRR. I also serve as the chair of the Interagency Committee on Disability Research across the federal government.

I'm thrilled to share some of my story and some remarks about one of my all-time favorite topics, disability inclusivity and representation in research.

Today, I'm wearing a pink shirt and a black suit, and I have long black hair that's up in a ponytail and I am actually sitting in my manual wheelchair, you just can't see it behind this table. My adorable service dog by my side is Colton, and he is sporting a nice plaid tie as well as his working vest. And my pronouns are she, her, hers.

For those who don't know us at NIDILRR, we are the federal government's main applied research organization and our main purpose is to fund research grants that help to generate new knowledge and promote its effective use to improve the abilities of individuals with disabilities to perform activities of choice in the community, and to expand society's capacity to provide full opportunities and accommodations for people with disabilities.

We are a part of the ACL, as Allison shared, whose mission is to support people with disabilities and older Americans to be able to live where they want to with the people that they want to, and also to participate fully in all aspects of society. In alignment with this mission and goal, we are so grateful to fund the Rehabilitation Engineering Research Center, the RERC on AAC, that carries on this mission by supporting the right of every individual’s self-expression and full participation in society as AAC users. RERC on AAC also really advances our research with this gathering here today, as well as really pushing for the latest and greatest new technologies and very, very importantly, works hand in hand with incredible disabled advocates from organizations like CommunicationFIRST.

One of my favorite quotes is from the late Judy Heumann, who is a powerhouse and a personal mentor and friend of mine, and who would be so proud that I was here addressing this group today and the fact that this summit is happening. Judy said, I want to see feisty disabled people change the world. What better advice is there than that? Especially for those of us in this room.

I think about her legacy and this quote so often in my role as I'm working hard to transform the research enterprise to be more inclusive of people with disabilities, including AAC users throughout all of its processes. This is no easy task. 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 more so in the broader disability and rehabilitation world, like clinical programs and policies and health care systems. They've been built based on the majority, not the minority. It takes leaders, like every single one of us in this room, to challenge that status quo.

In the vein of challenging the status quo, it's also important to be transparent about one's identities. You heard some of the wonderful identities that I hold in the wonderful introduction. I also, in addition to being a Paralympic medalist, am an Indian adoptee, a disabled woman of color, a researcher, an activist. Prior to this role, I was on faculty where I primarily studied disability identity development. But even before that, and 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 to communicate for them and helping them to trial different AAC options and to really find that right fit. And I also think that this has just always been something that's near and dear to me.

I acquired my disability when I was only four and a half months old because of transverse myelitis, and as a young child, I actually thought everybody in the whole world had a disability, and that it was just a phase I was one day going to outgrow. I didn't realize that disabled children grow up to become disabled adults. Spoiler alert, we do. But I held this assumption that in order to grow up and to go to college and to have a job, have a family, live on my own, that I first had to learn how to walk. Why was that? It was because every adult that I knew could walk. In my mind, as a child, I held this assumption that in order to gain access to these types of opportunities, I had to make my disability disappear. Boy, did that feel really invisible in terms of that lack of representation that was around me, which is what led to that assumption.

I remember the day in preschool where I was crying in the bushes, watching my classmates running around on the playground and in the swing set. There was something about that moment. I don't know what it was, but it was when I realized that this disability thing was here to stay. I realized in that low moment that I could let society's expectations, or really lack of expectations for me, dictate my life. I knew that wasn't going to get me anywhere. Fortunately, I grew up just outside of Boston, Massachusetts, whereas a young girl, I saw wheelchair racers who were competing in the Boston Marathon go flying by. I learned through the power of example that people with disabilities could thrive, work, succeed in life and athletically. I latched on to those role models from that moment on.

Around the 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 predetermined age range. It all started off initially as a place where I went for a few hours so my mother could run errands and do some grocery shopping.

Well, let me tell you about my friend Timmy. Timmy was my age about 4 or 5 at the time, and he used a power wheelchair, and we were just instant friends- laughing and having a good old time. But I was really, really confused why Timmy's dad came to camp with him. My mom dropped me off, and Timmy just wanted to be at camp without his dad, too. I knew that.

In my determined four-year-old brain, I went straight to the director to find out why this was happening. They very nicely explained to me that Timmy isn't able to speak or to communicate, and that they needed his dad to be there so that they would know what Timmy needed or what he liked or didn't like. I told them they were ridiculous, that of course Timmy could communicate, that I knew exactly what he liked and didn't like. In fact, his favorite book was No More Elephants. His favorite color was yellow and well, let me tell you, that this just confused all of the adults. They asked me how I knew, and I said his eyes tell me! So, they decided to see if I was right and his dad was like, of course she's right. He looks to make his choices and directs where to go and what to do. Nobody had taken the time to figure that out. This was in the 80s, long before things like the Tobii Eye Tracker and other such wonderful high-tech devices existed. I sure hope he has a better device today than his dad going with him everywhere.

In the end, Timmy's dad did a trial of being on the property, but not right there with him. Then eventually he was dropped off at camp and his dad left, and he came back later just like my mother. That early experience really planted the seed and the spark in me to be curious about language and communication. What we know now, and what I've been able to implement with other kids is, of course, that early adoption and use 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 to the use of sign language for those in the deaf community. This positive impact is life changing, and it helps to set the tone for self-determination, agency and meaningful full participation in society. I'm so proud to now be a disabled person leading NIDILRR and to be that representation for others and to ensure that this representation carries forward to the work that we fund and its relevance to the communities that we care about. We must constantly, as others have said, as Jordyn said, think about who is not being represented, who is not at the table, but then change our policies and approaches, especially in research, to ensure that all voices are heard.

For me, growing up, those visible representations of disability, as I shared, were initially hard to find in the media, and in advertisements and toys and books. I'm so thankful that this is getting a lot better. I remember when wheelchair-using Becky Barbie first hit the market, and then a couple years later, there was even a Paralympic Barbie who was a wheelchair racer. I love that there's many more disability representations, including inclusive dinosaur stickers that are AAC users. If you don't know about those, they're really cool.

And this has become such a part of my life's work to both research this power of representation, to be that representation for others and to help empower and educate about disability representation. So, to increase disability representation in research in and across society, we also must be aware of the forces that are at play. There's this thing in research and in the community, that's called the disability hierarchy. Disability hierarchy is a social construct that makes certain kinds of disabilities more acceptable than others.

And as I said, it happens both within the disability community and among people outside the disability community who make judgments about who is or is not valued most. At the top of the hierarchy is physical disability, and then it goes down from there, followed by chronic illness, learning disability, sensory disability, cognitive disability, communication disabilities, neurodevelopmental disabilities, intellectual and psychiatric disabilities. The ones at the bottom, and we'll make sure that you get the slides afterwards, are the most highly stigmatized, both from within the disability community itself and by society. We need more research to show the impacts of this disability hierarchy as it relates to AAC users.

McLeod and colleagues in 2023 have a very interesting chapter that illustrates the right to communicate should occur without the distinction of language, meaning we shouldn't be privileging certain modalities over another, or verbal spoken language with voice over, say, AAC. Their work looked at this intersection of this concept of disability hierarchies and communication from a human rights lens with insights from Australia, Fiji, Iceland and Vietnam. I encourage you to think about this in your own work and profession and life too and in the field of disability research, we historically have really focused and valued mostly those with just a physical disability, which likely contributes to maintaining that hierarchy of disability, something that I believe we must work hard to intentionally dismantle.

During my time as director, and as is reflected in NIDILRR’s newly launched long-range plan, we are committed to increasing the representation of disabled researchers and disabled researchers of color from other underrepresented backgrounds across the entire research enterprise. This means not just our investigators, but our research participants, our project officers, our peer reviewers, our partners, our funders, and also our own staff. As I said, academia and research have a long history of systematic exclusion of certain voices, and we’re working really hard to really chip away at these issues.

It’s important to talk about this from three different perspectives: diverse researchers, as researchers or as the generators of the science, diverse individuals as study participants and diverse representation in the knowledge translation materials that we produce and share about our research.

We need all of these and are stronger for all of them. Our science is better with this intentionality, and it makes people be seen by the research we are doing and signals its relevancy. 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 really important nuances within the field of AAC research. We also need to make sure that AAC users are not being systematically excluded from general research studies too. We need AAC users in broader disability research and broader general research, whether that’s social science research or biomedical research.

Too often, due to these embedded elements of ableism and disability hierarchy in action, sometimes because of gatekeeping of institutional review boards, AAC users are excluded from these really important studies. This is a very important area where continued advocacy and push for research inclusion is greatly needed. It also means that we need data to show how we are doing on all of this, and that we have this disability representation across the research pipeline.

Here is data from the National Science Foundation on the Stem workforce from 2011 to 2021. The piece that I want to point out is the light blue bar that shows that when we look at disability, only 3% of the STEM research workforce identifies with one or more disabilities, and this has remained unchanged over this ten-year period.

And so, I call on us, the disability field, to do something about this. Additional data from the Women, Minorities and Persons with Disabilities and Science and Engineering 2021 report indicates that disability representation in the scientific workforce decreases throughout the career path. So even if we're doing a better job at getting disabled people into the door of the scientific workforce, we aren't keeping them or supporting them to grow in their careers. And so we see the percentage of individuals with disabilities greatly declining as we go through that career path, that traditional research and academic career path. At NIDILRR, we really do track these data through our annual performance reporting system that grantees are required to share with us. We actually use this data, so thank you to our grantees for sharing this.

So many NIDILRR projects do include staff members with disabilities in 2023, 500 staff members on NIDILRR funded projects identify as disabled. And this slide shows the number of NIDILRR grants where the main principal investigator identifies as having a disability in fiscal year 23. That's 51 of NIDILRR grants out of 261 grants were led by a main principal investigator with a disability. We are really glad to see this upward trend here, but there's still more work to do. I also want to underscore the opportunity that exists for us all to be a part of research teams. Even if you aren't pursuing a formal higher education degree, 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 to our communities and that it's answering actual problems or gaps that we encounter in our lives. At NIDILRR we are trying to make improvements to all of this. As I said, across the entire research enterprise and are committed to deepening this disability inclusion expectations and fostering discussions about disability identity and creating inclusive research spaces.

So, for example, at NIDILRR all applicants are required to describe how the input of people with disabilities and other key stakeholders is used to shape the work that's being proposed. We also updated our peer review criteria for our project staff to more directly evaluate and score the extent to which applicants describe their outreach practices and encourage applications for employment among people with disabilities.

In our postdoctoral training mechanism, our Advanced Rehabilitation Research Training (A.R.R.T.). In that notice of funding opportunity, applicants are required to share specific plans for recruiting individuals with disabilities. These are some of the many ways that we're really trying to combat those dismal statistics that were on the previous slides. As another example, for all peer review panels starting this year in 2024, we are collecting optional demographic information, including disability status, about those that are evaluating and scoring our applications.

And grantees must report demographic information, including disability status, of their principal investigators, project directors, fellows and project staff, which is how we're able to generate those slides that were on the previous slide. And so, to include people with disabilities across this research enterprise, it also means talking about and encouraging, talking about the disability identity of individuals and building inclusive research spaces where investigators and staff with and without disabilities are integral members and full members of the research team.

Going back to this data in terms of that gross underrepresentation of people with disabilities in the scientific workforce, I believe it's reflective of two things, both the exclusion of people with disabilities throughout that research pipeline, but also the stigma attached to revealing a disability. I believe that some of those numbers are probably a little bit off, simply because some individuals might not have felt comfortable disclosing that disability.

But across the government, efforts are ongoing to increase the inclusion of people with disabilities, both in the research supported by these agencies and by the people conducting them. And I'm thrilled that many more are deeply engaged in these conversations across universities, across the National Academies of science, engineering and medicine, and even in spaces like this. I also think that we need to plant the seed and encourage everyone to be brave enough to include positionality statements in written work about your and your team's disability status.

This helps to make the less apparent, more apparent, and give confidence to others who may not realize that research could be a career path for them. This is far more common in qualitative research, but if we really want to move the needle on disability representation and to transform that research enterprise, we must boldly claim our identities loud and proud, as they say in the disability community. This signals so much to future generations, and to the consumers of our work, and to the populations in our studies, too. And it humanizes the work.

Research must include all of us. The diversity of the disability community is a tremendous asset, and our work must be inclusive of all people with disabilities. As researchers, we may be unintentionally excluding a person who is an AAC user and a wheelchair user in a spinal cord injury study by ignoring the accommodation needs in study design and recruitment. It's far easier to design studies with diverse populations and the needs of people with disabilities in mind upfront. It's way easier than retrofitting, and that value of inclusive research just simply cannot be underestimated.

Inclusive research allows for traditionally silenced voices to be raised up, and to help to shape the research being conducted. By inviting and encouraging these voices throughout the processes, it adds depth, relevancy, and nuances that could otherwise be missed. 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’s imperative for us within the disability community to echo what was shared earlier in our mantra: nothing about us without us. This must include research. We don't want the involvement of AAC users to just be a checkbox or the afterthought. Too often that's what it is. While this is an exceedingly complicated issue to tackle, this is why we're gathered here today in spaces like this, to have these conversations and for us to all be a part of the solution.

We need disabled individuals, AAC users and non, to commit to the future of our field and to help us diversify that research workforce. With this intentionality in mind. And lastly, we also must ensure that the diverse representation in the materials that we create and disseminate are accurate and relevant to our community.

This means ensuring that the imagery that we use is as diverse across racial and ethnic groups, across disability, like for example, are you only using images of people in wheelchairs? Okay, maybe if your study is only about wheelchair users, but if you're studying cerebral palsy, there's a lot who ambulate with cerebral palsy who often aren't seen in imagery. Do your images show the diversity of the types of AAC devices and tools that exist, or are you only showcasing one type of AAC device in the images that you're using?

There's also a lot of bad stock images out there that do not reflect the accurate portrayals of disability. Thankfully, there are more resources now with inclusive and diverse representation of disability, and these are some of my free favorites, and I encourage you to think about the process of selecting images, too. Some NIDILRR grantees have a formal approval process that across project directors, others use paid community advisory board members of people with disabilities who are connected to projects, who approve materials, and who are asking these questions to ensure that that representation really is carried forward in the work that is produced.

So, as I begin to wrap up, what does it mean to achieve disability inclusivity and representation in research? It means that we are not an afterthought, that we can participate in research studies without being perceived as a burden or an inconvenience. That we are helping to co-create the research questions being asked and answered. 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, our study participants, and ensuring that the representation is carried forward into the materials that we produce.

To make this a reality, we must go back to Judy's words and be feisty ourselves and support each other, amplify each other's messages, dialog with one another, and hold ourselves accountable on this journey.

Please feel free to take note of the ways to stay engaged and to connect with NIDILRR about funding opportunities, serve as a peer reviewer, or to learn about currently funded work in our portfolio. In closing, you can help to make our society and the field of disability research 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 that you'll join me too. Thank you.”

Toys and Books Referenced

The Girl Who Figured It Out by Minda Dentler

Tenacious by Patricia Cisneros

We Move Together by Kelly Fritsch & Anne McGuire

Braille Hot Wheels

Remote Control Hot Wheels: Aaron ‘Wheelz’ Fotheringham

Wheelchair Barbie

Inclusive Dino Stickers

References and Recommended Readings

Andrews, E. E., Forber-Pratt, A. J., Mona, L. R., Lund, E. M., & Balter, R. (2019). #SaytheWord: A disability culture commentary on the erasure of ‘disability’. *Rehabilitation Psychology.* Advance online publication. https://doi.org/10.1037/rep0000258

Chan, F., Cardoso, E. D. S., & Chronister, J. (2009). Understanding psychosocial adjustment to chronic illness and disability: A handbook for evidence-based practitioners in rehabilitation. Springer Publishing Company.

Deal, M. (2003). Disabled people's attitudes toward other impairment groups: A hierarchy of impairments. *Disability & Society, 18*(7), 897–910. https://doi.org/10.1080/0968759032000127317

Dunn, D. S., & Burcaw, S. (2013). Disability identity: Exploring narrative accounts of disability. *Rehabilitation Psychology, 58*(2), 148–157. https://doi.org/10.1037/a0031691

Forber-Pratt, A. J., & Zape, M. P. (2017). Disability identity development model: Voices from the ADA-generation. *Disability and Health Journal, 10*(2), 350–355. https://doi.org/10.1016/j.dhjo.2016.12.013

Forber-Pratt, A. J., Mueller, C. O., & Andrews, E. E. (2019). Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up. *Rehabilitation Psychology.* https://doi.org/10.1037/rep0000256

Forber-Pratt, A. J. (in press). Advancing and expecting inclusive research. Inclusion.

Gordon, P. A., Tantillo, J. C., Feldman, D., & Perrone, K. (2004). Attitudes regarding interpersonal relationships with persons with mental illness and mental retardation. *Journal of Rehabilitation, 70*(1), 50–56.

Huskin, P. R., Reiser-Robbins, C., & Kwon, S. (2018). Attitudes of undergraduate students toward persons with disabilities: Exploring effects of contact experience on social distance across ten disability types. *Rehabilitation Counseling Bulletin, 62*(1), 53–63. https://doi.org/10.1177/0034355217730355

McKee, A., & Gomez, A. S. (2020). The voices of typers: Examining the educational experiences of individuals who use facilitated communication.

McLeod, S., & McLeod, J. (2023). Communication rights moderated through hierarchies of disability and childhood. In *The Routledge International Handbook of Disability Human Rights Hierarchies* (pp. 362–381). Routledge.

Meeks, L. M., Case, B., Plegue, M., Moreland, C. J., Jain, S., & Taylor, N. (2020). National prevalence of disability and clinical accommodations in medical education. *Journal of Medical Education and Curricular Development, 7,* 2382120520965249. https://doi.org/10.1177/2382120520965249

Morin, D., Rivard, M. C. A. G., Crocker, A. G., Boursier, C. P., & Caron, J. (2013). Public attitudes towards intellectual disability: A multidimensional perspective. *Journal of Intellectual Disability Research, 57*(3), 279–292. https://doi.org/10.1111/j.1365-2788.2012.01559.x

National Center for Science and Engineering Statistics. (2023). *The STEM workforce*. Retrieved from https://ncses.nsf.gov/pubs/nsf23315/report/the-stem-workforce

Nouri, Z., Dill, M. J., Conrad, S. S., Moreland, C. J., & Meeks, L. M. (2021). Estimated prevalence of US physicians with disabilities. *JAMA Network Open, 4*(3), e211254–e211254. https://doi.org/10.1001/jamanetworkopen.2021.1254

Sins Invalid. (2017). *Skin, tooth, and bone–the basis of movement is our people: A disability justice primer*.

Westbrook, M. T., Legge, V., & Pennay, M. (1993). Men's reactions to becoming disabled: A comparison of six communities in a multicultural society. *Journal of Applied Rehabilitation Counseling*, *24*(1), 35–40.

Varadaraj, V., Deal, J. A., Campanile, J., Reed, N. S., & Swenor, B. K. (2021). National prevalence of disability and disability types among adults in the US, 2019. *JAMA Network Open*, *4*(10), e2130358–e2130358. https://doi.org/10.1001/jamanetworkopen.2021.30358