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Presidential Address, 2022—Dismantling Systemic Barriers: Re-Envisioning Equity and Inclusion

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It is my privilege to deliver this presidential address and to learn and grow with you during the 146th American Association on Intellectual and Developmental Disabilities Annual Meeting and Conference. I am particularly grateful to have the opportunity to connect through our two conference venues—in-person and virtual. Each of us has been impacted in profound ways by the COVID-19 pandemic, and the impacts of the pandemic continue to reverberate throughout society. There is no question that the impacts of the pandemic have differentially impacted marginalized communities (Magesh et al., 2021), including people with intellectual and developmental disabilities (Gleason et al., 2021; Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020; Lunsky et al., 2022), exacerbating existing disparities and pushing to the forefront the need to address issues of equity and inclusion (Sabatello et al., 2020). Hosting our conference in two venues represents one small step and a recognition, I hope, of the need to respect, value, and promote access and inclusion in ways that recognize different needs related to health and wellness and to build systems of supports that start from a position of centering the voices and needs of those that are marginalized in our existing systems.

Alongside the pandemic, we have as a society been further confronted by the pervasive and ongoing impacts of intersecting systems of oppression rooted in ableism, racism, and sexism, that create barriers to equity and inclusion and cause substantial harm to marginalized, particularly multiply marginalized, communities that experience intersectionality (Crenshaw, 1989, 2017). We have witnessed systemic police brutality and the deep rooting and impacts of the carceral state. We have witnessed regressive policies advancing misogyny and misogynoir and devaluing basic human rights. We have seen certain social identities privileged over others. These intersecting systems of oppression limit equity and inclusion for all, but particularly impact efforts to advance disability, racial, and cultural justice as they sustain the deeply rooted biases in our systems, policies, and practices. Further, they fail to recognize, celebrate, and elevate the contributions of *all* members of our society, including disabled leaders that are multiply marginalized. Dismantling systemic barriers is critical to advancing equity and inclusion. As a field and organization of leaders in intellectual and developmental disabilities, I believe we are at a critical juncture. I believe we must begin to take steps to interrogate power and privilege and think and act with a critical lens to center the voices and experiences of people with intellectual and developmental disabilities who are multiply marginalized.

Naming systemic barriers is only a first step in interrogating the role they play in the long-standing and pervasive inequities experienced by people with intellectual and developmental disabilities, particularly people with intellectual and developmental disabilities who are multiply marginalized—a term I will use throughout this presentation to refer to people with intellectual and developmental disabilities impacted by intersecting systems of oppression; that is, people with intellectual and developmental disabilities who are Black, indigenous, and people of color; people with intellectual and developmental disabilities who are lesbian, gay, bisexual, transgender, and queer or questioning; people with intellectual and developmental disabilities who are immigrants; and people with intellectual and developmental disabilities who speak multiple languages and communicate in diverse ways. Naming must be followed with actions that break down systems of oppression and advance equity and justice. The importance of naming systems of oppression and centering the voices of people with intellectual and developmental disabilities in re-envisioning equity and inclusion is what led me to choose the theme for our conference this year. I want to use this space to issue a call for all of us, particularly those of us that have privilege and power in current societal and professional structures, to take steps to re-envision how we partner to remove inequities, injustices, and marginalization across all aspects of society, including in our individual and collective research, policy, and practice.

As I reflected on my work and the theme for this year's conference, this would not necessarily have been the theme that I would have guessed would drive my conference when I first became engaged with AAIDD, almost 2 decades ago. Throughout my career, I have been extensively engaged in self-determination research (Shogren & Raley, 2022), as well as work seeking to advance strengths-based, social-ecological understanding of intellectual disability that attempt to examine how the contexts we exist within shape our individual and collective outcomes and experiences (Shogren et al., 2017; Shogren et al., 2021). I value all the current and past collaborations and mentorship with and from AAIDD leaders, as well as with the broader community of people with intellectual and developmental disabilities. However, this work has not pushed the field forward as far as I had hoped when I first began my training to become a self-determination researcher. My shift to studying self-determination during my graduate training was highly personal, shaped by my sudden and jarring loss of personal self-determination when I was an undergraduate student, even though I had never heard the term self-determination at that point. I had to suddenly begin engaging with medical systems because of the emergence of my disability. And, during this time, I experienced, for myself, what the loss of a sense of personal agency felt like and how it diminished my quality of life. I realized that it was the loss of agency that better explained my "challenging behavior" during this time (often referred to in my medical charts as noncompliance, which I often referred to as substandard care). I recognized at some level—even though I did not fully understand it at that time—my privilege in avoiding the consequences that many people with intellectual disability, particularly those that are multiply marginalized, experience when they rebel against their loss of agency (e.g., additional segregation, isolation, and further external control). I wanted to make sure that no one else felt that loss of agency. Through my graduate training, I found a pathway, with support from AAIDD leaders and mentors, to begin to address individual barriers to self-determination that people with intellectual disability encountered, focusing my research on developing assessments and interventions that enhanced personal self-determination in school and community contexts.

However, although I recognized the impacts of the othering and dehumanization that permeated so many of the disability and health service systems that I was experiencing, personally and professionally, I could not yet fully name the impact and role of systems of oppression and marginalization in limiting opportunities and agency. I did not have the language to challenge the deeply rooted ableism and sexism inside these systems that were shaping my experiences as a newly disabled, female, first-generation college student. I did not fully recognize all the social identities that each of us experience, and how all of these identities jointly shape our experiences of the world, with certain identities privileged over others in our current systems (Annamma et al., 2013). But, as we know from the social model of disability (Davis, 2016; Oliver, 1983), the systemic barriers often had a more profound impact on my quality of life than my health condition, even with my significant privilege as a White, cisgender female. These barriers are even more pervasive for people with intellectual and developmental disabilities, particularly for people with intellectual and developmental disabilities that are multiply marginalized. I do not think I fully realized how much these intersecting systems of oppression created power and privilege and how these systems and this power and privilege became self-sustaining. And, as some of my trusted colleagues have justly pointed out to me, much of my research in education systems has been situated in a system that privileges White, middle-class identities. Thus, although not my intent, my work failed to center the experiences, resources, and funds of knowledge of people that are unjustly marginalized in our current systems.

Although I talked about systems in my research and recognized their power in shaping outcomes, because I did not have the language and understanding, I was unable to articulate and critically examine the systems of oppression that were limiting my work and its impacts, as well as my personal health and well-being. In many ways, as I have spent time reflecting, I became complacent as a White, middle class, female, cisgendered researcher, working in ways and in systems that were familiar and comfortable for me, and not fully recognizing and acknowledging the broader issues or the broader community I was not partnering with. The focus of my research became about supporting each person as they interacted in systems, but I was not acknowledging the inherent inequities in those interactions given the biases that were so deeply rooted in systems. And, although I still value and believe there is a critical need for work focused on supporting each person, I also believe there is a need to challenge myself to better recognize how systems of oppression fundamentally shape this work and our broader research, policy, and practice in intellectual and developmental disabilities.

I am becoming increasingly aware—as are many in our society and community—of the need to listen more to those with lived experiences and center these experiences to support action to advance equity and inclusion. This will require critical self-reflection, as well as critical collective reflection on our research, policy, and practice. It will require that we examine our current theories and approaches and how they have been shaped by systems of oppression, and it will require engaging with work broader than our own. It will require building new coalitions, and creating more spaces for inclusive research, policy, and practice that critically analyzes and re-envisions how to approach *all* the factors that impact outcomes, from the perspective of those that are impacted. This work must recognize and collectively engage with leaders and scholars who have long been tackling these issues (including many of the invited plenary, preconference, and conference speakers at this 146th AAIDD Annual Meeting and Conference and other leaders in the field).

Naming and taking action to identify and dismantle systemic barriers, including interrogating our complacency with these barriers, is not intended to minimize the work that has been done. But, as a researcher, data on the ongoing disparities across multiple outcome domains (e.g., inclusive education, employment, community participation) highlights the need for different pathways forward and the need for new coalitions, voices, and perspectives to be centered throughout all the systems that shape research, policy, and practice to enable deeper change. I believe this can lead to new and even more impactful personal and systemic interventions, policies, and practices that re-envision equity and inclusion and center the voices and funds of knowledge of people with lived experience.

We must also acknowledge the struggles and anxieties that such work can bring. I am still working to learn, name, and act, and I know this will be an ongoing process. Actively critiquing my own work and positionality is not always comfortable and I know that I will make mistakes. I also know that terminology will continue to evolve and change. But, this work is necessary and does not compare to the struggles others experience in continuously navigating intersecting systems of oppression. And, I like to believe that, if any of us are to grow and have the collective impact we seek, growth, change, and vulnerability must be how we approach our work. Just as my lived experiences shaped my initial drive to support self-determined lives for people that are "othered" in our society, my ongoing learning and experiences in systems that privilege certain ways of knowing and being have raised my awareness of deeply rooted systemic barriers and the importance of not letting fear be a justification for not pushing for change, personally and collectively. We must ensure that we instantiate what is learned, act to support the work that is necessary, embed this work everywhere, and do not expect marginalized communities to solve the problems alone. Instead, we must engage in new collaborations and allyships. It cannot be okay to say any longer that this does not affect me or my work in "x," because it affects all of us.

Naming the Deeper Issues

There has long been discussion in the intellectual disability field and within AAIDD of the pervasive, negative impacts and harms of deficit-based conceptions of disability that define intellectual disability and other developmental disabilities, including autism, as pathological or something to be fixed or eliminated (Wehmeyer, 2013). We have seen recent efforts to acknowledge the impacts of racism in the intellectual disability field and take steps toward antiracist research, policy, and practice in in our work (American Association on Intellectual and Developmental Disabilities [AAIDD], 2020; Johnson et al., 2021). We have also seen the push back on these efforts throughout society. For these reasons, it is a particularly important time to name the deeper issues and re-envision equity and inclusion. Although we cannot just stop operating inside of existing systems and structures in society, I believe we can more critically analyze the beliefs in which these systems and structures are rooted and use this to re-envision these systems and our collective work—collaborating in work that is already being led by key leaders and thinkers in AAIDD and beyond. My hope in this presidential address and in the theme of the 146th AAIDD Annual Meeting and Conference is to call all of us to collective action that centers the voices and funds of knowledge of people with intellectual and developmental disabilities who are multiply marginalized in guiding broad, systemic changes in systems of supports.

For example, in my own scholarship and teaching I have frequently discussed deficit- vs. strengths-based models of disability (Shogren et al., 2017); however, this work has centered the discussion on disability and disability systems, including policies and practices in the disability field (Shogren et al., 2020). I have rarely, however, called out the broader ways that conceptions of ability undergird all systems in our society. I have not specifically named ableism as a systemic bias that shapes the process, impacts, and outcomes of my research until very recently. But, the discussion of ableism must be part of our broader conversations. We must follow and learn from the established leadership of disabled researchers, advocates, authors, and creators. This creates an opportunity for us to increase our focus on integrating critical theory, understandings of intersecting systems of oppression, and, perhaps most importantly, centering the voices of multiply marginalized communities throughout all phases of research, policy, and practice (Disabiity Visability Project, n.d.; Wong, 2020).

Bogart and Dunn (2019), in a special issue on ableism, define ableism as "stereotyping, prejudice, discrimination, and social oppression toward people with disabilities" (p. 651). They describe this as a "broad definition of ableism, intended to parallel social psychological definitions of other 'isms' in order to spur social science research in this area." They recognize the pervasiveness of ableism in the lives of people with disabilities and highlight the need to explore structural factors that marginalize people with disabilities. Disabled leaders are increasingly pushing us to name and support the dismantling of this marginalization throughout society. And, once we begin to name it, it becomes easier to identify systematic ableism and all systems of oppression and impacts in our research, policy, and practice, even research, policy, and practice developed with positive intentions. For example, the Individuals With Disabilities Education Act fails to mandate inclusion and, instead, accepts a continuum of placement options that enables segregation based on ableist assumptions (Cornett & Knackstedt, 2020). Placement data for students with intellectual disability highlights the persistent use of segregated placements (Brock, 2018; Sauer & Jorgensen, 2016) and the impacts of interacting systems of oppression. For example, Black students with disabilities are more likely to experience segregated, restricted placements than their White peers (U.S. Department of Education, 2021). Long-term services and supports (LTSS) through Medicaid were originally provided only through institutional care, reflecting ableist assumptions that continue to undergird contemporary uses of waivers to provide home and community-based services (HCBS). The ongoing impacts of systemic ableism (Friedman & VanPuymbrouck, 2019) and racism (Shippee et al., 2021) continue to impact spending and the quality and outcomes of LTSS. Plenary guardianship remains the default option for people with intellectual disability, despite its roots in ableist, racist, and sexist policies and established alternatives (Shogren et al., 2019).

All of us at the 146th AAIDD Annual Meeting and Conference are aware of and fight to challenge the barriers to equity, inclusion, and self-determination through our individual and collective work, and advance policies, like the Convention on the Rights of Persons with Disabilities (United Nations, 2006), that establish inclusion as a human right and an expectation in all systems and practices. But, could we do more to critically examine the degree to which the lack of progress toward inclusive outcomes is rooted in ableism and its interaction with other deeply rooted systems of oppression that fail to center the voices and funds of knowledge of people who are marginalized in existing systems?

Parallel Movements

The increasing calling out of ableism by disabled leaders has paralleled intersecting movements that are also increasingly pushing us and providing concrete ways to talk about other -isms (for example, racism, sexism, heterosexism, cisgenderism) and how they all influence the societal structures we exist within and concentrate power and privilege in certain dominant social group identities, while oppressing marginalized social groups (Palmer et al., 2019). For example, Ibram

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Kendi, in his work on anti-racism, highlights that importance of defining concepts to call attention to them, as a means to promote shared understanding and change. He identifies issues related to the intersection of these systems of oppression: "many Americans don't necessarily have a clear definition of racism, nor do they have a clear definition of ableism, which then prevents them from understanding their intersection" (Kendi, 2021). But, they are "roots of the same tree" (Kendi, 2021). Disability scholars have long argued that racism and ableism interact and lead to further exclusion and dehumanization of disabled people of color, necessitating theories that explore these intersecting systems of oppression, such as disability critical race theory or DisCrit (Annamma et al., 2013; Annamma et al., 2022).

Similar arguments can be made with regard to sexism; philosophers such as Kate Manne have advanced frameworks to better understand sexism and misogyny and their relationship with other systems of oppression. She defines sexism as "the branch of patriarchal ideology that justifies and rationalizes a patriarchal social order and misogyny as the system that polices and enforces its governing norms and expectations" (Manne, 2018, p. 20). Importantly, she highlights how all people can be complicit in misogynistic social systems and how systems rooted in sexist ideas act to position advancements by women as taking opportunities and privileges away from men. It is important to recognize that the focus of this work is not on individual actions, but systemic bias and enforcement processes. This framing puts in context that ableism (like racism and sexism) is not just related to disability or disability services and supports, but also encompasses the system of policies that enforce understandings of ability based on achievement, productivity, and certain ways of navigating throughout all systems in society. It focuses on the need to take action to dismantle systems that enforce oppression.

Disability and social justice advocates and leaders have elaborated on academic definitions of ableism and advanced the focus on intersectionality, recognizing how systems of oppression interact to privilege dominant social identities. For example, Lewis defines ableism as:

> A system that places value on people's bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's language, appearance, religion and/or their ability to satisfactorily [re]produce, excel, and "behave." You do not have to be disabled to experience ableism. (Lewis, 2021)

All of these leaders I am drawing on and learning from are engaged in this work across research, policy, practice, and advocacy and are articulating that racist, sexist, ableist ideas—and all ideas and systemic biases that create power and privilege for one group at the expense of others—collide to create systems of oppression that are pervasive in our society and filter down and are enforced in our research, policy, and practice in intellectual disability.

Going back to Kendi's work on antiracism, he, like Manne, introduces a series of definitions. Kendi defines racist ideas as "any idea that suggests one racial group is inferior or superior to another racial group in any way. Racist ideas argue that the inferiorities and superiorities of racial groups explain racial inequities in society." He elaborates that racist ideas can be assimilationist, "expressing the racist idea that a racial group is culturally or behaviorally inferior … supporting cultural or behavioral enrichment programs to develop that racial group," or segregationist, "expressing the racist idea that a permanently inferior racial group can never be developed … supporting policy that segregates away that racial group." Alternatively, antiracist ideas express "the idea that racial groups are equals and none needs developing" (Kendi, 2019, p. 24).

Think about these distinctions and the relationship to disability and ableism and the intersection of racism and ableism. Although leaders in AAIDD have taken steps to reject segregationist ideas, they still reflect a large part of the history of this organization and contemporary thought in multiple segments of society. But, as a field, have we fully named, interrogated, and rejected assimilationist ideas? Assimilationist ideas also still shape so many aspects of disability research, policy, and practice. Too much of our research remains focused on supporting disabled people to "develop"—to use Kendi's word—to fit into existing societal systems and norms and this expectation is more deeply rooted, for example, for Black youth with intellectual disability (Scott et al., 2021) or for trans people with intellectual disability (Dinwoodie et al., 2020). However, why are our existing societal systems and norms the reference point? What could our work look like if we dismantled these systems of oppression? What if we assumed that each person needs personalized supports *in inclusive systems that accept all people as fully human and equal in their contributions*? To advance an anti-ableist agenda, I believe we need to adopt new lenses through which we conceptualize and critique research, policy, practice to enhance outcomes at the individual and systemic level that breaks down the "enforcement structures"—to use Manne's term—in society and in our collective work.

Mechanisms for Change: Centering Voices

If we accept that ableism is a part of broader intersecting systems of oppression that impact all aspects of our society, I believe we can take steps toward re-envisioning. I invite all of us to learn with and actively support others who are leading this work. In my work as a researcher, an anti-ableist lens that recognizes intersecting systems of oppression can help me think about what I need to do to advance change in research, policy, and practice to centers the voices and experiences of communities that are marginalized in our current systems. I believe one way that I, speaking as a researcher, can recognize how systemic ableism and systems of oppression impacts us overtly and covertly is to better acknowledge the systemic barriers to fully centering the voice and experiences of people with intellectual disability, particularly those that are multiply marginalized, in our research. There is an increased push from disability leaders (as well as leaders in anti-racism and other social justice movements) to consider whose voice is centered—or, put another way, who has the power in defining the "problems" addressed in research as well as the methods adopted to explore "problems." We will hear about inclusive science in many of our plenaries and sessions at the 146th AAIDD Annual Meeting and Conference, and there are strong movements toward recognizing the fundamental right of people with intellectual disability to be part of the process and outcomes of science (Shogren, 2022). But, what if we expected inclusive science (and policy and practice) and did not accept anything less? What if the default in our systems was people with lived experiences being afforded their right to be an equal contributor and a driver of the science (and the policy and practice) that is intended to impact their lives? And why can't it be?

As I apply a critical lens to my work over the past 20 years focused on developing theories of self-determination and advancing personalized assessment and intervention approaches, my intent has been to enhance outcomes identified as valuable by members of the disability community (e.g., self-determination, community participation, inclusion). However, most of my research activities have not been in full partnership with people with intellectual disability across *all* phases of the research process. This leads to people with intellectual and developmental disabilities, particularly people with intellectual and developmental disabilities who also experience other marginalized identities, being excluded from the generation of ideas and implementation of methods that guide research and the process of science. The number of participatory research teams that equitably and inclusively engage members of the intellectual disability community as researchers is incredibly small, although notable exceptions exist (e.g., Hughes et al., 2020; Kramer et al., 2011; Morgan et al., 2015; Schwartz et al., 2019; St John et al., 2018), including many that will present throughout the 146th AAIDD Annual Meeting and Conference. Navigating systemic barriers related to equitable pay, inclusive participation, and recognizing multiple forms of contribution across all phases of research are challenging inside the research enterprise. Further, there is limited data on these issues, reducing the ability to advocate for equity and inclusion. This contributes to the nondisabled, White, cisgender, upper-middle-class voice driving the development of research questions, the implementation of research designs, the development of policy, and the interpretation and dissemination of outcomes (Garcia et al., 2018). In my own work advancing self-determination, who should have the power and privilege to shape this work?

Attempting to pivot to engage in fully collaborative and participatory work where all partners are equally resourced and supported across all phases of research is complex at multiple levels and will continue to take time, effort, and sharing

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of power and privilege on my (and our) part. I hope that we, as a field, can continue to challenge ourselves to ensure that research is inclusive; that theory is accessible and meaningful; that policy is driven by people with lived experience, and *that people with lived experience have equitable opportunities to be practitioners, researchers, and policy makers, if they so choose*. I believe this can support the dismantling of systemic barriers.

Perhaps the sustained inequities and lack of equitable engagement in research, policy, and practice is rooted in assimilationist ideas and policies and practices—as defined by Kendi—that privilege ability, as defined by our current systems. For example, we still define many specific disabilities, including intellectual disability and autism, by deficits in specific domains (e.g., intellectual functioning, social communication). And there are differences, but why are they deficits? Why is the comparison group always those that function intellectually and socially in specific ways that are considered part of dominant social identities? If people with intellectual disability and autism were leading research, theory, and practice, would we still frame these as deficits or would we be talking about differences and identifying how supports can be personalized to each person's needs? What could happen if we shifted away from assimilationist ideas and approaches to disability? What if I (and we) focused on how we *pull out the roots* and *re-envision systems* in a way that recognizes all groups as equal and all individuals as deserving of personalized supports?

The minimization of disabled experiences in research and the research enterprise have become more and more obvious to me, perhaps given my duality in my personal and professional life. I have had the privilege of being able to move between identities, although, as I mentioned, it was my identity and experiences as a newly disabled person that initially brought me to self-determination research. However, after my graduate studies, I positioned myself as a researcher and expert, not as a person with lived experiences, perhaps because I recognized at some level early in my career that I experienced "othering" when I was the only disabled person in the room. I internalized a perspective of needing to assimilate at the highest level to achieve and be valued in academic systems. And as a White, cisgender woman without an intellectual or developmental disability, I had the privilege of being able to assimilate. When I first entered academia, I had no mentors with a disability. There weren't movements like #SaytheWord (Andrews et al., 2019). I was frequently lauded as the "amazing" disabled person because I thrived "despite" my chronic pain and health issues. Even though the intent was benevolent, the outcome was me feeling the need to assimilate to the expectations for a nondisabled academic. And this became easier and easier as I experienced changes in my health needs over the past decade that made my support needs much less visible. But I also stopped being open about my disabled identity and internalized assimilationist ideas. Although I never realized the toll that would take.

Overtime, and as I have had more experiences with enforcement structures not only related to ableism but also sexism, I have realized how deeply rooted notions of performing like the default White, male, cisgender, able-bodied person were, and how much I internalized them, but also how much they drained me. This has opened my eyes to how all the -isms are so rooted in our systems and beliefs and how, without personal intent, systems of oppression lead to marginalization of diverse voices and funds of knowledge. As I have begun to reflect more on how I can survive and hopefully thrive in existing structures while acting to dismantle them, I realized that I could not unless I was true to who I was and embraced my multiple identities and sought to have cultural humility. But the work to do so is complex, personally and in existing systems. The ongoing question I now face (and I hope the collective question we will tackle together), is how to dismantle the systems that perpetuate the need to compartmentalize and conform to existing systems of oppression and instead create new systems that truly and equitably celebrate and advance all voices.

Moving Forward

So, what do we do? Given the intersectionality of disability, race, ethnicity, gender identity, sexual orientation, multilingualism, etc. in shaping systemic barriers and biases there are so many opportunities to work together in solidarity to promote systemic change and recenter the "problem" on systemic barriers, systems of oppression, and exclusion and disempowerment. What is the potential if we start to call out the roots of ableism and all systems of oppression and our forced complicity in existing enforcement structures? Can we take small and hopefully larger and larger steps to be anti-ableist and to situate all of our work in this value? If we openly confront these issues, can we support and empower the next generation of leaders to disrupt systems of oppression and advance a radically different way to advance equity and inclusion?

I cannot and will not propose today, a "solution" —that is not my place nor is there a simple solution. This is something I have discovered through my ongoing learning and, hopefully, growth. Instead, I want to invite all of us to explore how to engage in work on a daily basis to create more anti-ableist spaces, elevate disabled voices, and instantiate these efforts throughout our research, policy, and practice. I invite all of us in this room, listening virtually, or reading this address, to think about how we center marginalized voices, experiences, and funds of knowledge and create space and pathways to shift systems of power and privilege to enable equity and inclusion for all.

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