

Intellectual and Developmental Disabilities

The Right to Science: Centering People with Intellectual Disability

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Corresponding Author:	Karrie A Shogren University of Kansas LAWRENCE, Kansas UNITED STATES
First Author:	Karrie A Shogren
Order of Authors:	Karrie A Shogren
Manuscript Region of Origin:	UNITED STATES
Abstract:	<p>The right to science has been identified in multiple human rights treaties; however, there has not been a clear framework for how governments or research organizations can advance this right particularly ensuring equitable engagement of people with intellectual disability in the process of scientific research. While, the feasibility and impacts of engaging people with intellectual disability in the process of science have been repeatedly demonstrated there remain systemic barriers including ableism, racism and other systems of oppression that sustain inequities. Researchers in the intellectual disability field must take steps to dismantle systemic barriers and advance participatory approaches that advance equity in the process and outcomes of science.</p>

Abstract

The right to science has been identified in multiple human rights treaties; however, there has not been a clear framework for how governments or research organizations can advance this right particularly ensuring equitable engagement of people with intellectual disability in the *process* of scientific research. While the feasibility and impacts of engaging people with intellectual disability in the *process* of science have been repeatedly demonstrated there remain systemic barriers including ableism, racism and other systems of oppression that sustain inequities. Researchers in the intellectual disability field must take steps to dismantle systemic barriers and advance participatory approaches that advance equity in the *process* and *outcomes* of science.

The Right to Science: Centering People with Intellectual Disability in the Process and Outcomes of Science

The Universal Declaration of Human Rights in 1948, in Article 27, introduced the right of all people to “share in scientific advancement and its benefits.” This *right to science* has been recognized and acknowledged in multiple additional human rights treaties. For example, the International Covenant on Economic, Social, and Cultural Rights (1966) in Article 15 states that all people have the right to “enjoy the benefits of scientific progress and its applications.” It further obliges States Parties to “conserve, develop, and diffuse science” and to “respect the freedom indispensable for scientific research.” Specific to the disability community, the United Nations Convention on the Rights of Persons with Disabilities (CRPD; 2006) states in Article 32 that state parties should recognize the importance of “facilitating cooperation in research and access to scientific and technical knowledge.”

These treaties advance a human rights perspective on equitably distributing the benefits of science throughout the world (Chapman & Wyndham, 2013). The inclusion of the concept in CRPD reflects the explicit recognition that the right to science extends to people with disabilities and can and should be used to advance disability justice. However, there remain persistent inequities in actualizing the right to science. There has not been a clear definition or framework for how governments or research organizations can advance the right to science (Chapman & Wyndham, 2013). Further, much of the focus of efforts have targeted equitable access to the *benefits* of scientific progress, which while critical, does not ensure equitable engagement in the *process* of scientific research. But, a lack of engagement in the process of science can contribute to scientific advances that are not meaningful or usable by the communities which scientific research is purported to benefit, further perpetuating inequities in accessing the benefits of

science (see Pellicano & den Houting, 2022 for a review in autism research).

It has been stated that advancing a recognition of the right to science has the power and potential for “empowering individuals, strengthening communities, and improving the quality of life” (Wyndham & Vitullo, 2018). The United Nations highlighted core components of the right to science, including “opportunities for all to contribute to the scientific enterprise” and “participation of individuals and communities in decision-making about science” (United Nations, 2012). The disability community, including people with intellectual disability, have long advocated for their right to be involved decisions about their lives. Participatory and inclusive research approaches have been developed and adopted in the intellectual disability field to advance engagement in the process of science (Ahlers et al., 2021; Barnes, 2002; Bigby et al., 2014; Powers, 2017; Schwartz et al., 2019). In the autistic research community, there is a growing push to create space for autistic researchers and advocates to co-define, co-lead, and fully participate in the process of research (Jivraj et al., 2014; Nicolaidis et al., 2019). Such efforts center the voices of disabled people in the process of science, advancing outcomes that have meaning for the community. Yet, such approaches remain the exception rather than the rule, particularly in intellectual disability research. Further, limited work has addressed issues of intersectionality in intellectual disability research (Johnson et al., 2021) and impacts on engagement in the process of science.

Ableism and The Right to Science

While, the feasibility and impacts of engaging people with intellectual disability in the *process* of science have been repeatedly demonstrated (Hughes et al., 2020; Kramer et al., 2011; Morgan et al., 2015; Schwartz et al., 2019; St John et al., 2018), there are deeply rooted systemic barriers to making this the default. There is a critical need, as a field, to name these systemic

barriers and collectively envision approaches that dismantle systemic barriers and advance the right of people with intellectual disability to engage in the process of science, particularly those who experience other marginalized identities.

Ableism has been defined as “stereotyping, prejudice, discrimination, and social oppression toward people with disabilities” (Bogart & Dunn, 2019, p. 651). Ableism is being increasingly identified and named – particularly by the disability advocacy community – to highlight systemic factors that act to maintain pervasive negative outcomes for disabled people in multiple domains (e.g., employment, education, health, participation). Ableism is closely intertwined with racism and other -isms (e.g., sexism,) and the systems of oppression that operate in society to maintain the power of the “dominant” culture, sustaining inequities (Annamma et al., 2013; Annamma et al., 2022; Johnson et al., 2021).

These interrelated systems of oppression have significant and pervasive impacts on the actualization of the right of people with intellectual disability to participate in the process of and experience the benefits of science. The systems (e.g., universities, research institutes, funding agencies) that govern the research process are deeply situated in ableist notions of ability and how contributions to science are made (Brown & Leigh, 2020; Dolmage, 2017). Just like other systems in our society, the research enterprise has developed without the input of people with intellectual disability and in many ways is structured to preserve and advance certain identities and to marginalize others. Within the research enterprise there are clear and direct impacts of ableism, including prioritization and privileging of certain ways of knowing, communicating, and engaging in the world (Brown & Leigh, 2020; Dolmage, 2017). Such issues are further perpetuated for those with intersectional identities, as there is also systemic marginalization based on race, ethnicity, and gender within the existing research enterprise. The lack of diversity

in research faculty, the exclusion of certain populations in research, and the lack of insistence on researching issues that are identified as important by the communities that are purported to be the beneficiaries of scientific advancement all contribute to the lack of uptake of research, and identified biases in services and supports across fields related to disability and race (McDonald et al., 2021; Pellicano & den Houting, 2022; Shippee et al., 2021; Vyas et al., 2020).

Further, there are often direct and indirect benefits to maintaining the status quo for those that are privileged in existing structures. Direct benefits can involve not having to change or challenge existing practices that privilege certain ways of knowing and engaging in the scientific process; disruptions to the status quo can be perceived as threatening when there is a need for personal or systemic change. Indirect benefits can involve the maintenance of power structures and recognition provided by existing structures that celebrate certain ways of knowing, communicating, and engaging in the scientific process. Participatory approaches have the potential to challenge the status quo as they require changes in the ableist approaches that dominate the generation of knowledge.

There is a need to increase the focus in the intellectual disability field on (a) engaging people with intellectual disability at all stages in research, (b) creating pathways for training and career development that creates space for people with intellectual disability to pursue research careers of their choosing and (c) actualizing the change needed in existing structures to enable this to occur. While tokenistic approaches (e.g., advisory panels with unequally resourced “volunteers” or “consultants”) have long been used and are even required for some funding in intellectual disability, they reflect an incomplete approach to advancing full and meaningful participation and centering of the experiences and voices of people with intellectual disability in the research enterprise. As Weintraub (2016) wrote: "One of the biggest ways to show that you

are treating the person as a token is to just invite them to the table without a reason, just to be nice, or just to make you or your organization look good. You or your organization need to figure out why you want the person at the table” (p. 157). Authentic membership, on the other hand, reflects equal status, recognition, and role definition that leads to meaningful individual and group contributions (Beckwith et al., 2016). Tokenistic structures may, in fact, act to preserve ableist structures by creating inequitable structures at the margins that attempt to address identified issues without making systemic change that redefine ability and participation in research and the process of science (Ahlers et al., 2021; Beckwith et al., 2016; Caldwell et al., 2009).

However, these systemic issues, including intersectionality, are rarely named by intellectual disability researchers, by funders, and by professional organizations, with notable exceptions (Forsythe et al., 2018; Johnson et al., 2021; McDonald & Stack, 2016; Stack & McDonald, 2014). Interrogation of the systems of oppression that continue to make participatory approaches the exception rather than the rule is necessary to (a) define the systemic factors that lead to the inequitable access of people with intellectual disability, particularly people with intellectual disability who experience other marginalized identities, to the process of research (b) continue to build an anti-ableist agenda that creates pathways for participation in research that centers the voices and experiences of people with intellectual disability, and (c) dismantle current systems so that they can be rebuilt with the necessary structures and supports for full and meaningful participation in all aspects of life, including the research enterprise. Necessary to such efforts will be those that have power in current systems taking steps to actively share their power, act as allies to support the advancement of anti-ableist approaches, and advocate for systemic changes needed to create spaces for co-leadership and self-direction in the research

process by people with intellectual disability.

This will necessitate new and different ways of thinking for a majority of those engaged in the research enterprise. Those of us that have power and privilege in current structures must challenge ourselves to explore our complicity in ongoing inequities and reenvision our roles. We must advocate within the broader research enterprise for concrete actions to be taken that dismantle ableist structures and advance career pathways that are equitable and inclusive. As a field, we must also engage with opportunities throughout society focused on dismantling systemic barriers and advancing cultural justice.

Call to Action

The time has come to more clearly acknowledge that the generation of knowledge that shapes policy, practice, and ongoing research in the intellectual disability field is influenced by systemic biases and begin naming these deeply rooted issues. As a field, we must engage in collective work to define systemic factors that lead to inequitable access to the process of science and build an anti-ableist agenda with action steps to implement this agenda. We must strive to engage with and elevate work already being done by researchers, including those with intellectual disability, to reenvision how the process of research can be used to advance anti-ableism, anti-racism, and challenge systems of oppression (Johnson et al., 2021; McDonald et al., 2021). And we must challenge ourselves – particularly when we are aligned or perceived to align with identities that have power in current structures – to support reenvisioning that allows for the identification of systemic barriers and their dismantling, with a focus on ways to promote access to the *benefits* as well as the *process* of science by people with intellectual disability. We must recognize we will take missteps and that there will be ongoing change and challenges. But, unless we create pathways for people with intellectual disability with intersectional

identities to co-develop and co-lead the *process* of science that impacts their lives, there will always be tokenism in our approaches and benefits that do not align with the needs of the community. Given the almost non-existent changes in outcome data over the past 30 years across multiple domains (e.g., integrated employment, inclusive education) for people with intellectual disability, it seems clear that new approaches are needed to fundamentally change the process and outcomes of science, and advance equity and social justice and create authentic career pathways for people with intellectual disability with intersectional identities in research.

An anti-ableist agenda that centers people with intellectual disability in the research process and its outcomes must drive the future of intellectual disability research. Such an approach must draw upon and align and partner with other approaches to challenge systemic bias and fundamentally reenvision equity, inclusion and belonging in all aspects of society, such as work to advance anti-racism, challenge misogyny, and reduce other forms of systemic bias and oppression. Ongoing advocacy will be needed to change the supports available and the skills prioritized in research and university settings and break down barriers to authentic participation, including actions that seek to create career pathways, equalize compensation structures, and elevate the importance of lived experiences in the process and outcomes of science. This work must be participatory and emancipatory, with those of us that have had power and the privilege in current research spaces recognizing this, shifting to acting as supporters and allies, and reenvisioning what we do with our power and privilege with the goal of advancing equity in the *process* and *outcomes* of science. We must draw from successful examples of inclusive, participatory research while also creating spaces to address broader, systemic issues and develop a collective agenda that changes the structures that prevent this approach from becoming the status quo, reducing inequities both in the process and outcomes of science.

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