

Disability Identity and Pride in Equity Research: Webinar Recap



Hosted by the Community Living Equity Center (CLEC) on August 18, 2023

Led by Jennifer Lee-Rambharose, CLEC Project Coordinator

Interactive audience Q&A moderated by Teresa Nguyen, CLEC Director

Guest panelists: Andy Arias, Dr. Janie Mejias, and Germán Parodi

Extended Synopsis by Mel Ptacek · September 2023

Introduction

The webinar began with an overview of the Community Living Equity Center (CLEC) and its [mission and principles](#). CLEC conducts research related to disparities in community living and in participation experienced by disabled people of color. CLEC seeks to develop interventions and recommendations for systems change related to policy and planning. From its inception, CLEC has been committed to the participation and leadership of disabled people of color within CLEC leadership and at all stages of the research process.

The webinar discussed existing barriers to disability inclusion and identity within the research process, the current lack of relevant data, and ways that researchers might better engage with disabled people of multiple, intersecting identities. Panelists were members of the CLEC [Community Advisory Committee](#), representing a wide range of disability identity, culture, and pride.

Several themes emerged in the discussion and resonated with attendees.

Moderator



Jennifer Lee-Rambharose
CLEC Project Coordinator

Panelists



Janie Mejias
Women Enabled International



Andy Arias
Self-Advocate and Policy Subject Matter Expert



Germán Parodi
The Partnership for Inclusive Disaster Strategies

Themes



Urgent need for the *meaningful* inclusion and involvement of disabled people of color throughout the research process

Panelists emphasized that disability researchers must truly understand the need for involvement by disabled people of color in the research process, starting from the very beginning with planning and design and continuing throughout, including the dissemination process. As Mejias described, disabled people of color have been “historically hurt by research.” Arias stressed that, in response, there must be accessibility and inclusion for disabled people of color “at the beginning, middle, and end” if research is to achieve equity. Parodi noted that there is a need for disability inclusion and participation to extend beyond research itself into areas of policy development and policy implementation associated with research.

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Disabled people of color must be included “at the beginning, middle, and end” if research is to achieve equity.

The panelists underscored how disability inclusion is essential to research quality, but only if inclusion is meaningful and not tokenistic, superficial, or occasional. Meaningful inclusion entails full and equitable participation in drafting research questions and protocols, designing and implementing data collection, conducting analysis, and developing conclusions and policy recommendations and it requires adequate and equitable compensation along with thoughtfulness about individual access needs during the research process.



Respect for the needs and priorities of disabled people of color too often lacking

The lived experiences and needs of disabled people, particularly disabled people of color, are neglected or suppressed when, as Arias memorably phrased it, researchers or others who are non-disabled “able-splain,” that is, inform people with disabilities “about our needs and services, about the realities of our lives and what our lives will entail, how research will be developed.” Mejias pointed out that “our voices are not being captured in a meaningful way and our priorities are being sidelined” when people with disabilities are brought into a research project only early on to generate ideas or at the end to assist with interpretation, while non-disabled researchers take the lead—and most of the credit. She also suggested that researchers should be familiar with the social and cultural model of disability in order to avoid the harmful and mistaken medicalizing of disability.



Intersectionality of multiple identities among disabled people of color

Mejias noted how hurtful it is when researchers implicitly or explicitly require people of color with disabilities and other people who are multiply marginalized to feel as if they must compromise parts of their identities. “All parts of our identity are extremely important to who we are. And we don’t want to compromise or emphasize one part of our identity over another ... [but] to claim proudly all of the identities that we have.” As Arias stated, “cookie-cutter” solutions based in the experience of mostly white and male people with disabilities won’t work for everyone, including those disabled

people of color who are queer or who are immigrants.

“ *All parts of our identity are extremely important to who we are.* ”

Moving from disability rights to disability justice

The need to distinguish between disability rights and disability justice (DJ) was stressed. “Understand that distinction well,” Mejias encouraged researchers. Whereas the disability rights movement has typically been led by white wheelchair users and has not been intersectional, the DJ movement intentionally “really takes a lot of steps to make sure that the voices of multi-marginalized people with disabilities are at the forefront,” frequently doing this from the very start. Similarly, Arias referenced the “white lens of disability,” which he said needs to be replaced with one based in equity for communities of color as well as for LGBTQ+ and other communities.

“ *Disability justice ensures that the voices of multi-marginalized people with disabilities are at the forefront.* ”

Other principles of disability justice were raised. For example, Parodi brought attention to the need for the benefits of home- and community-based services to be extended to all disabled people who need services and supports, not only Medicaid-eligible people, reflecting DJ principles of collective access and collective liberation. He added that healthcare and other services needed by disabled people should not be lost when someone relocates to a new state. Moreover, research across the range of disabilities is needed on the effects of disasters and other occurrences and best practices in response.



Researching and teaching disability pride

Parodi discussed the need to research and teach people about disability, particularly in order to reach those people with disabilities who don’t understand it well. Parodi, who works in disaster preparedness and response, was especially referring to people who are newly disabled. As he suggested, demands for meeting the needs of disabled people can be based in an understanding of disability that expresses disability pride.

Recommendations

The panelists’ discussion offered several recommendations:



Ensure meaningful participation for disabled people of color at all stages and in all parts of the research process, including dissemination of the analyses and the results

Genuine respect for people of color with disabilities and their trust of researchers can be fostered by including them throughout the research process and compensating them fully for their time and contributions. They should not be required to work as volunteers and fair and equitable compensation is imperative. Their knowledge and other contributions should be acknowledged, centered, and honored. If followed through, research participation can be empowering and can generate trust between disabled communities of color and researchers, enhancing the quality of research.




Offer visible and expansive leadership opportunities to disabled people of color

Move away from any “white-savior” thinking that would treat equity as something merely to be added in at some point. Help create

conditions in which “we do not have to have the door opened for us by anyone else but us.” In addition, the reality and visibility of the contributions of disabled people of color can be promoted by including and highlighting their participation in proposals to funders.


 **Be thoughtful about intersectionality and accessibility**

Multiple identities may bring not only diverse experiences but also specific histories of trauma and oppression, which affect disabled people’s needs and priorities in different ways. Recognize and celebrate disabled people’s intersectionality. Similarly, recognize the diversity of access needs and augment standard accommodations and accessibility according to the needs of various communities and those of individual disabled people.

 **Understand dissemination of research results as a significant accessibility issue**

Ensure that research results are available and accessible to disabled people of all communities. That would include support for open-access publication and other venues without paywalls. In addition, make sure to

publish plain-language versions of research results and analysis and to make ASL standard.

 **Disabled people of color should be included meaningfully in *all* discussions of policy and practices, not only those that explicitly pertain to disability**

Parodi touched on disaster planning as an example of how the development of policies and practices not specifically focused on people with disabilities should also consider effects of these policies and practices on the range of disabled people and their families. For any public policy or practice to be effective, disabled people (including disabled people of color) must be involved in the development.



The panelists cited CLEC as an example of a research center led by people of color with disabilities and promoting their visibility as it models the principles of equitable and collaborative research discussed during the webinar. CLEC researchers and leadership emphasized the importance of disability identity and pride to them and their work and the importance of participatory research frameworks to CLEC research projects.

Access the Webinar Recording

Access the recording: https://brandeis.mediaspace.kaltura.com/media/t/1_ekszzp9g

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