



NIH Community Roundtable Panel Discussion

11/7/2024

1. What are the primary scientific opportunities and challenges in disability research that should be addressed by NIH? How can the NIH mission statement most accurately reflect NIH's disability research priorities?

Individuals with Down syndrome are living longer than ever. The average lifespan is now 60 years, opening up a whole portion of older adult life that has not been studied before. By focusing on aging in individuals with disabilities, we have an opportunity to better understand the new challenges facing this older adult population, such as Alzheimer's disease.

Mission statement: NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

The mission to "reduce disability" can be interpreted as ableist. The focus on nature and behavior of living systems heavily emphasizes the medical model at the organism level. As we are expanding our understanding of health to incorporate structural and social determinants of health, the mission of NIH may also need to expand.

2. How can NIH encourage new investigators to enter the field of disability research, support existing researchers, and promote disability inclusion in the scientific workforce?

Funding of community engagement is critical. Community engagement in disability communities is difficult because of mistrust and geographic diversity. NIH-funded community engagement grants help provide the time and resources investigators need.

Creating more accessible and inclusive training programs for individuals with lived experience as well as examining requirements for funding co-investigator and leadership status on grants that include community partners and content experts outside of academia would promote disability inclusion in the scientific workforce.

3. How can NIH improve the inclusion of individuals with disabilities in research and clinical trials, including the development of research topics, and foster collaboration with advocacy groups and professional associations?

The NIH can improve the inclusion of individuals with disabilities in research and foster



collaboration with advocacy groups by:

- Creating specific RFAs targeting community engagement and recruitment in collaboration with advocacy groups to raise awareness of research opportunities.
- Having more representatives of people with disabilities and from advocacy organizations participating in the research process.
- Not assuming that individuals with developmental and intellectual disabilities cannot or will not participate in the research process. NDSS serves on countless advisory boards for studies along with individuals with Down syndrome and other disabilities who provide invaluable insights to the research team.
- Having less stringent inclusion and exclusion criteria as well as more inclusive assessment tools would allow even more individuals with disabilities to participate.

Advocacy organizations can be great connectors between the research world and those with lived experience. In addition to serving on advisory boards, NDSS shares recruiting research studies with the community via our newsletter, website, social media, webinars, and conferences. We want to be the bridge that closes the gap that exists between our community and researchers so that the two groups can work together to answer questions and improve quality of life for individuals with Down syndrome.