

Community Engagement in Deafness and Autism Research (CEDAR): Challenges and promises

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Research increasingly aims to include autistic people not just as data-generators, but as key contributors in developing and executing research. Community engagement is particularly complex when the very nature of human interaction is under investigation, with studies centered on the emergence and use of communication skills. Being a scientist requires training and expertise; how can science better reflect the needs and interests of stakeholders (Milton, 2014; Grinker, 2015)? What is the role of researchers who are not members of the community they research? Shifting demographics of the scientific community help: Researchers who study neurodiverse populations are increasingly themselves members of those communities.

Scientific research with deaf people provides useful parallels. Research on sign languages and Deaf culture has advanced our understanding of human language; Deaf researchers have helped overcome the medical model of deafness, as a deficit that must be fixed. These changes arose primarily because members of the Deaf community became partners in research.

In October 2018, scientist and non-scientist Deaf, Autistic, and neurotypical people gathered to discuss this issue. Steve Silberman, author of Neurotribes, was an invited speaker. Organizing the meeting was difficult; the meeting was originally planned for May 2018. Organizers (primarily faculty and grad students) planned to solicit contributions from autistic and Deaf people with the goal of establishing an open forum for discussion. However, the invited speakers (Silberman, and a discussant with expertise on dialogue in conflictual settings) and organizing committee were not representative of the Deaf and autistic communities, and the meeting was canceled. After a more representative committee was constituted, we grappled with difficulties in communication, differing expectations about how to accommodate individual needs, and shifting and differing goals.

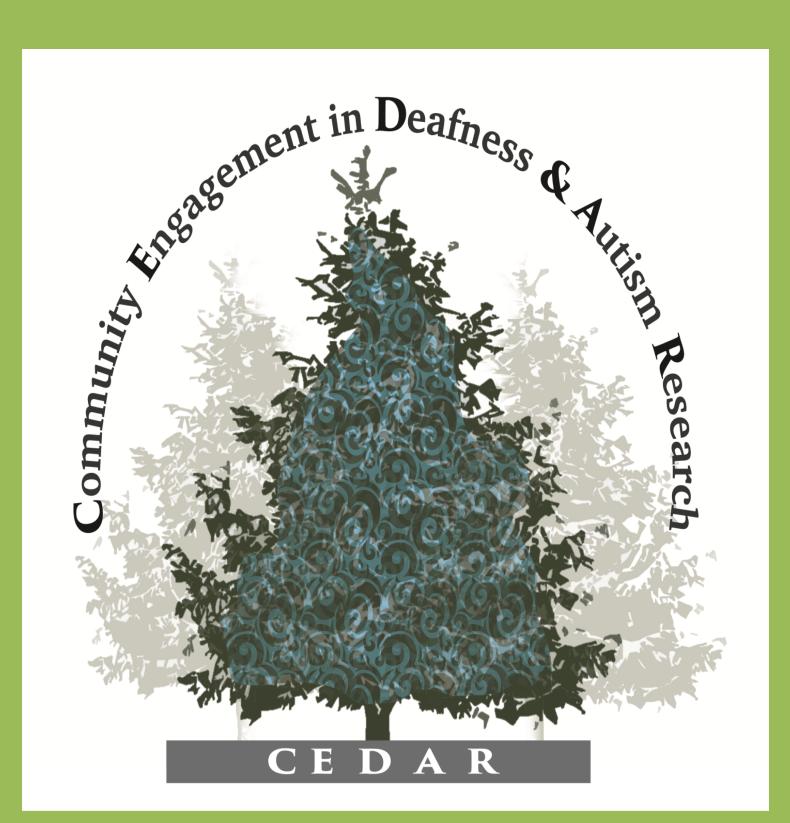
• There are useful parallels in the history and experiences of Deaf and autistic communities. • Deaf individuals with autism are underserved, with limited access to services, research, and community (Van Naarden Braun et al., 2015) Appearances matter: who is on the "masthead" • Include community members EARLY in planning. Meaningful engagement, even by highly invested parties, requires significant time and planning. • Tech tools (e.g., Google Drive) can help address communication challenges in the planning process access. • Preferences for/against various communication options should be considered: face-to-face spoken/sign communication; text chat; email

process.



• Common ground is possible, but inclusion is more than an ETHOS, it is an active, reflective and humble







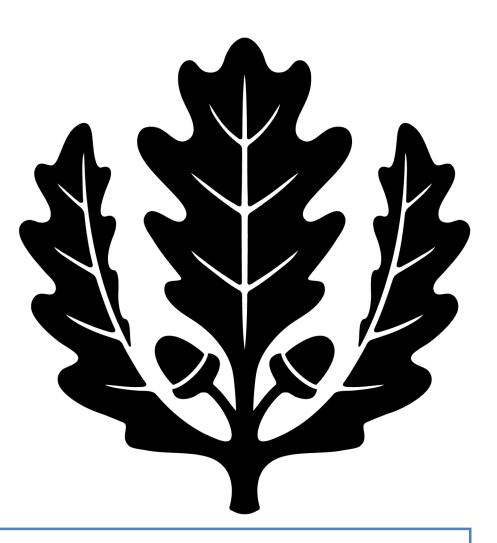
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This poster format is unconventional; it uses the Better Poster Movement format: https://tinyurl.com/y5fud2np

Further info and examples: https://osf.io/ef53g/



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