Inequities in Community-Engaged Autism Research: Community Member Perspectives

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What Is the Purpose of this Study/Review?

- The purpose of this qualitative research study was to gain autism stakeholders' (autistic adults, autism caregivers/parents, and service providers) viewpoints about the risks, benefits and gaps in community-engaged research (CEnR) and their suggestions on addressing the gaps related to autism research priorities and diversifying representation in CEnR.

What Is the Problem?

- A history of exclusion and significant barriers to research participation exists for individuals with autism.
- Members of the autism community with more complex medical and psychosocial needs, racial and socioeconomic diversity, women, and older adults are not well-represented in research.
- Studies have found that barriers to full community engagement have left under-engaged members of the autism community feeling isolated, frustrated, distrustful, and less informed about opportunities to participate in research and having their priorities and needs heard.

What Are the Findings?

- There is a lack of diversity in autistic individuals who participate in autism CEnR and who are included in the planning and implementation of CEnR.
- It was suggested that an approach to community engagement that creates shared ownership in the decision-making process and a trusted platform for the autism community across different demographic characteristics and support needs is important for understanding how to translate that information into effective and inclusive approaches.
- Autism stakeholders value research inclusivity and are interested in research participation. Many have the ability to make their own participation decisions with and without support from others (dependent on their preferences), and believe that research about adults with autism is important and beneficial towards addressing complex problems related to type of and access to care.

Who Should Care Most?

- Autistic people.
- Parents/caregivers of autistic people.
- Health care professionals.
- Public health professionals and researchers interested in autism.
- Organizations working with autistic people.

Recommendations for Action

- To engage autism communities in CEnR, research has to be made accessible to autistics in ways that also consider diverse characteristics, support needs, sensory sensitivities, and individual communication preferences.
- Suggestions include partnering with trusted people in the autistic community, researchers conducting preliminary research to be better informed of potential support needs of autistic individuals, involving the autistic community early in the process, and offering flexible options for participating in research.
- Autism researchers should consider the development of institutional guidelines at the level of professional and funding organizations to support effective and ethical inclusion of autistic people in CEnR across diverse characteristics and needs.