Strengthening Autism Research and Neurotechnology Development through Adapted Community Based Participatory Research Methods

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INTRODUCTION

- Neuroscience is pivotal in our constructions of health and disability. How we conduct and frame research has major impacts on communities of interests[1]
- As competing frameworks of understanding autism arise[2,3], critical engagement with stakeholders becomes essential in research and technology
- The use of CBPR based methods could be employed to better include autistic voices within neuroscience and aligns with calls from advocates[4,5]

THE ISSUES

Philosophical concerns: How do we appropriately delineate categories of brain health, diversity, and disorder? What values underpin current nosology?

Justice: How does neuroscience understand autistic differences? Do these models respond to and reflect autistic perspectives? How can we ensure the benefits and access to new research is shared?

Beneficence: What resources, treatments, and research questions do autistic people think are of the most importance? How do we quantify and maximize well-being for those on the spectrum?

Autonomy: How do we promote self-determination and capacity building in our research, evaluation, and medical support for those on the spectrum? How can we ensure access to new technology and research for all?

Non-maleficence: With our research are we empowering or further stigmatizing autistic people? How can we avoid unintended stigmatization and harm to autistic people? How can we measure the relative benefits and harms of interventions?

COMMUNITY BASED PARTICIPATORY AUTISM RESEARCH

WHY

- May improve support and research relevance[4,6]
- Provides novel methods and questions for inquiry[4,7] and improves validity of methods used with autistic people[4,6,7]
- Address health disparities[9,10] and address researcher biases[11]

HOW

- Work with existing networks: Autistic Self-Advocacy Network (ASAN), Autistica, Autistic Woman and Non-binary network, Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
- Utilize and build on pre-existing guidelines for CBPR with autistic people by AASPIRE[4]

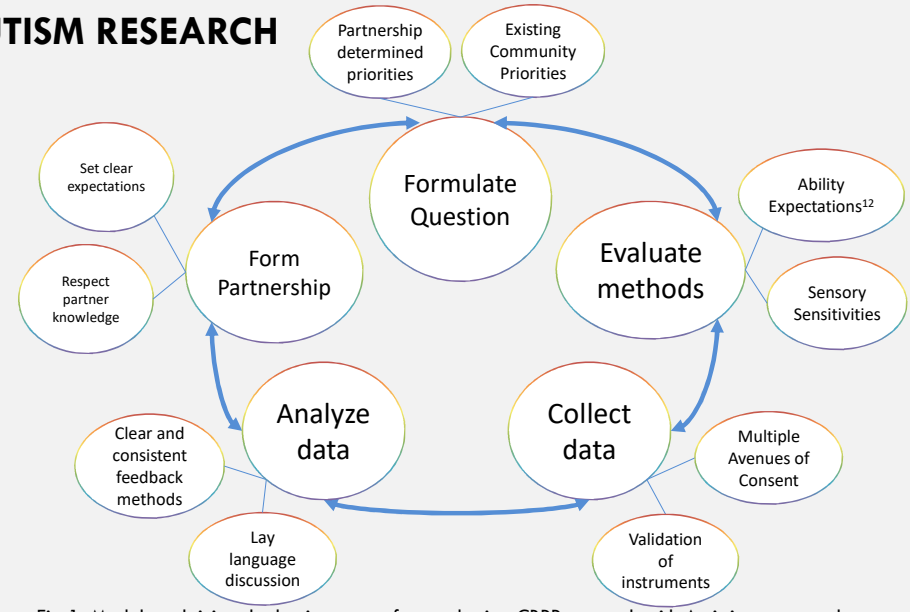

Fig 1. Model explaining the basic process for conducting CBPR research with Autistic co-researchers based on source 3 unless otherwise specified. This process is iterative with room to move flexibly between all points.

CONSIDERATIONS

- Reflect on positionality and implicit ableism to enable effective power-sharing[4,5]
- Remember that these communities are not separate; autistic researchers may function as both community members and academic researchers[13]
- Engage with the community through other approaches if resources, funding, and commitment make CBPR infeasible[14]

CONCLUSIONS

- Engaging with self-advocates is both possible and of great potential benefit to researchers and the Autistic community
- Using CBPR methods improve research relevance and tailor research outcomes and neurotechnology development towards community determined needs
- These methods should not be seen as an impediment to progress in this field but rather an exciting opportunity to catalyze effective research and neurotechnology development for these communities

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest for this work.