TRUST

USC Chan Division of Occupational Science and Occupational Therapy

Transforming Research:
Understanding Experiences in
ASD, Stakeholders Working
Together

About This Tool

This document is intended to be used as a resource for anyone looking to engage autistic self-advocates, clinicians, family members and caregivers, and researchers in all phases of research to support the autism community. Mitigating identified barriers and implementing facilitators may promote optimal participation, representation, and inclusion of all stakeholders.

The barriers and facilitators identified in this document were generated by the Autistic Self-Advocate, Clinician, Researcher, and Family Member and Caregiver groups. Several ideas identified by these groups were similar and several members in these groups held multiple identities. For these reasons, the ideas of all four groups were integrated in this tool.

Thematic headings were used to organize the information. Under each heading, there is a list of barriers and facilitators related to the overarching topic. Whenever possible, the language used by the stakeholders is retained. However, in some instances, language had to be edited for clarity. Thematic headings include: Perceived Value of the Topic of Study, Logistics of the Study, Communication During Recruitment and Enrollment, The Study Environment, Communication & Participation During the Study, Representation, and Compensation & Recognition.

It should be noted that this list is not all-encompassing, and it is not intended to be prescriptive. Every stakeholder presents with unique expertise and needs. The individuality of participants should be respected and supports should be adapted and customized as needed.

Perceived Value of the Topic of Study

Barriers	Facilitators
• The topic of study does not align with what individuals feel would be most beneficial or salient for one or multiple stakeholder groups. • The topic of study does not appear to be relevant to clinical practice or daily life.	• The topic of study is relevant and could make a meaningful difference in the lives of stakeholders. • Stakeholders identify with the topic or problem and perceive a potential for significant impact.

Logistics of the Study

Barriers	Facilitators
• Study designs which include interacting with the child in a space where the parent is unable to visibly observe • Not providing enough time for clinicians to engage in collecting data and navigating across systems • Requiring participants to dedicate a large amount of time to the study • Location of the study site in relation to family home • When parents are not permitted to bring their other children, or a babysitting option is not provided • When study participants have to complete multiple steps to participate • Overall inflexibility of researchers • Difficulty retaining study participants	• Providing opportunities to participate virtually • Offering the ability to complete study related tasks on the participant's own time • Opportunities for anonymity • Allowing parents to bring their other children and offering babysitting • Providing support to individuals when they are completing registration paperwork and collecting documents needed to participate • Providing the participating individual or family transportation to and from the study • Offering a preparatory session where the individual can participate in a tour of the research space and get to know the research team

Communication During Recruitment and Enrollment

Barriers	Facilitators
• The study recruiter cannot efficiently and clearly articulate the purpose of the study • The study recruiter cannot clearly explain what will be expected of individuals who participate • When people who are asked to help with recruitment do not have enough	• Sending a knowledgeable member of the research team to the settings where recruitment is taking place • Maintaining communication with recruitment site and offering support • Providing an explanation of the study and what is required of participants in jargon-free language

information about the purpose, expectations, or logistics, they don't feel comfortable recruiting families they work with	

The Study Environment

Barriers	Facilitators
• Busy sensory environment (i.e., auditory, visual, tactile features of the environment) • The logistics of using specific types of physiological measures makes collecting data in community settings very difficult	• Reducing sensory stimuli in the environment • Designating a quiet space for breaks that can be used by all age groups (i.e., parents and children) • Willingness to accommodate needs as they arise

Communication & Participation During the Study

Barriers	Facilitators
• Engaging participants without providing a structure and clear expectations • Participating within a large group • Feeling as though you must be outspoken or extraverted in order to contribute to the discussion • Navigating social expectations • Limited time provided for processing the information provided (i.e. speaking quickly • Communication styles that may not fit that of the participants • Underestimating the experience of family members, caregivers, and self-advocates • Disregarding that being interviewed about negative past experiences can be emotionally challenging • Failing to consider the expertise that clinicians may possess as research partners	• Implementing "rules of engagement" or strong ground rules that are well understood • Reminders and follow-up communication with participants of the study • Making it clear that everyone will have the opportunity to participate • Discouraging people from interrupting one another • Allowing participants to have extra time for processing the information and asking questions • Supporting all means of participation (i.e., drawing, typing, writing, speech) • Supplementing information with pictures to support understanding of topics being discussed • Creating a safe space where people can share their personal views without judgement • Encouraging all participants to be supportive and respectful of all members of the research project • Responding non-judgmentally to all questions • Fostering a sense of community

Representation

Barriers	Facilitators
- Feeling that there is a lack of diversity across participants - Lacking racial and ethnic diversity amongst the research team - Difficulty recruiting diverse research participants - Using invasive research measures and foundational skills participants must have when engaging with that measure limit who can participate (Example: to participate in an fMRI study you have to be still for an extended period of time)	- Promoting diversity within the research group - Including autistic people and autistic organizations - Supporting participation of diverse participants

Compensation & Recognition

Barriers	Facilitators
- Not being given the option to be recognized in the publication of findings - Being paid an insufficient amount for participation - Receiving funding that is not enough to conduct a longitudinal study or recruit a large number of individuals.	- Being paid an adequate amount for the participant's time - Providing the participants a copy of the study once it is published (electronic or hard copy)