

Participatory Research with People with Developmental Disabilities

Katherine McDonald - May, 2019

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Table 1. Ethical Challenges and Responses in Public Health Research

Ethical Challenges	Responses	Recommendations for Action
<p>People with developmental disabilities have been exploited in and outside of research. The disability rights movement challenges the ethics of using exclusion and autonomy-restricting practices as a means of protection.</p>	<p>Find ways to safely and respectfully include people with developmental disabilities in public research.</p>	<ul style="list-style-type: none"> • Learn about the disability rights movement. • Include people with developmental disabilities as direct respondents in public health research.
<p>Experiences with exploitation contribute to feelings of suspicion and distrust among people with developmental disabilities.</p>	<p>Use human rights frameworks to inform decision-making about ethical public health research practices and the treatment of people with developmental disabilities in research by respecting dignity and autonomy, and promoting direct benefits associated with research participation.</p>	<ul style="list-style-type: none"> • Demonstrate respect for people with developmental disabilities. • Provide people with developmental disabilities opportunities to get the know researchers prior to research participation decisions. • Solicit and respond to participant needs and preferences. • Teach participants desired skills. • Share findings with participants. • Produce findings or policy briefs for use in advocacy efforts. • Create dissemination materials that promote respect and reduce negative stereotypes. • Use respectful language in research materials and dissemination products. • Be responsive to community priorities.
<p>Coercion and comprehension challenges test foundational concepts of research ethics and require population-specific responses.</p>	<p>Modify materials, processes, and contexts to promote comprehension and accessibility and reduce power imbalances.</p>	<ul style="list-style-type: none"> • Simplify language. • Make language more concrete and/or specific. • Use visuals. • Modify instrument delivery formats (e.g., oral instead of written administration). • Provide materials in alternative formats such as Braille, text-to-speech, and electronic formats that interface with participants' assistive technology • Provide ASL translation. • Work collaboratively with people with developmental disabilities, including working with self-advocacy groups. • Allow individuals to consult with a trusted other in making research participation decisions. • Educate people in the lives of people with developmental disabilities about the value of self-determination. • Establish protocols for being alert to and addressing coercion to participate. • Train research staff on power issues. • Find ways to avoid or strengthen mandatory reporting of abuse. • Maintain confidentiality of data. • Allow more time for consent processes • Check in during data collection to make sure the participant still consents
<p>Deficits-based models of disability linger in science, restricting ideas on the interests and abilities of people with developmental disabilities to contribute to research and the framing of</p>	<p>Apply disability rights principles to public health research.</p>	<ul style="list-style-type: none"> • Critically assess underlying assumptions of research aims and protocols, including whether people with developmental disabilities can lead healthy and fulfilling lives. • Pursue research that illuminates the strengths and voices of people with developmental disabilities. • Develop genuine, mutual relationships with people with developmental disabilities.

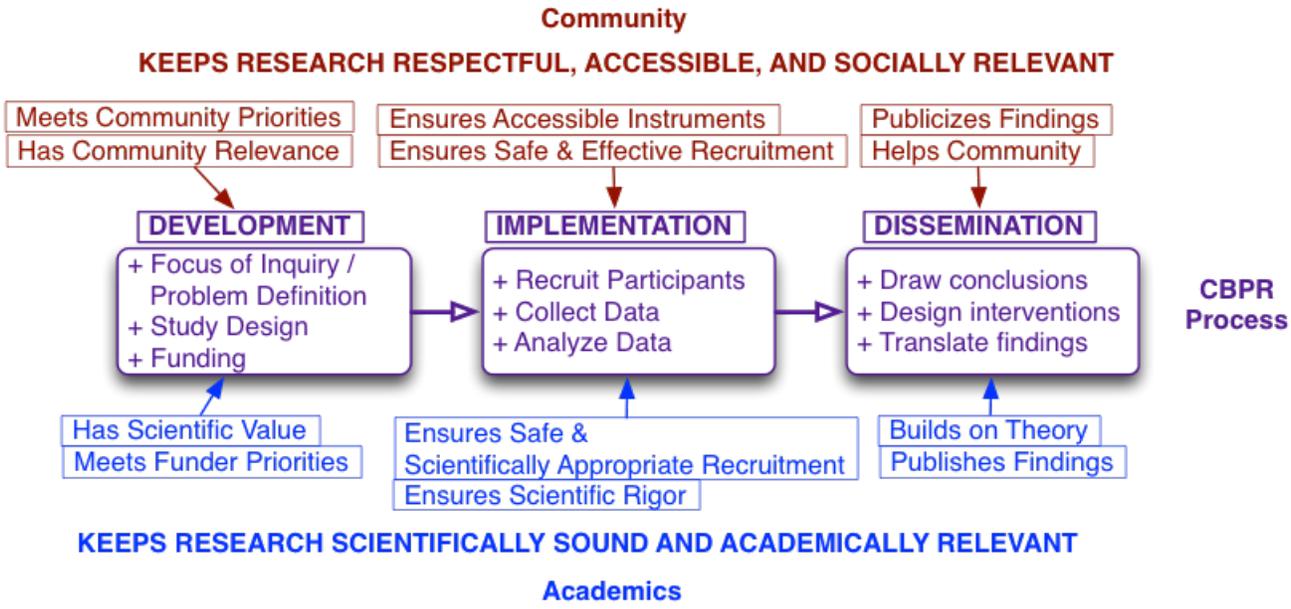
Ethical Challenges	Responses	Recommendations for Action
appropriate research questions.		
Research practice and policy largely ignores accommodating functional limitations and enabling environmental access to public health research for people with developmental disabilities.	Modify measures, materials, practices and policies to make them accessible to people with developmental disabilities without compromising, and possibly even improving, study reliability and validity.	<ul style="list-style-type: none"> • Make only changes necessary for accessibility, not for individual preference. • Make minor modifications such as to the instructions or by adding comment boxes that do not affect constructs. • Make modifications that better present constructs to the population (similar to cultural tailoring or language translation). • Offer instruments in alternative formats. • Make physical modifications to the research environment, or meet with participants in the environment of their choosing • Pilot test instruments and protocols.
	Establish policies that enable greater support for developing accessible public health research projects.	<ul style="list-style-type: none"> • Advocate in universities and at state and national levels for increased funding for projects to allow the resources and time required to include the input of people with developmental disabilities. • Revise academic expectations to reflect the timeline required to make public health research accessible to people with developmental disabilities. • Establish university and IRB policies and practices that allow for the involvement and compensation of people with developmental disabilities.
People with developmental disabilities are marginalized from the broader context of public health knowledge production. As a result, public health research agendas may not include research perceived as worthwhile by people with developmental disabilities.	Increase the influence of people with developmental disabilities on public health-related science.	<ul style="list-style-type: none"> • Establish policies to include people with developmental disabilities on research teams, IRBs, advisory boards, and grant review boards and in peer-review processes, academic and scientific occupations, policy positions, and other stakeholder settings. • Create procedures for making inclusion in these bodies and roles accessible to people with developmental disabilities.
	Pursue public health-related research that meets the priorities and needs of people with developmental disabilities.	<ul style="list-style-type: none"> • Address research aims people with developmental disabilities perceive as relevant. • Question whether interventions could risk further harming people with developmental disabilities, including because they may lead to efforts to prevent the birth of people with developmental disabilities or because they convey negative perceptions of people with developmental disabilities.
	Pursue community-engaged public health research.	<ul style="list-style-type: none"> • Include members of the developmental disabilities community as members of the research team. • Learn what people with developmental disabilities feel is important by communicating with them directly. • Listen to what people with developmental disabilities feel are priorities in public health research and develop projects around community-identified needs. • Work with people with developmental disabilities to improve their quality of life by supplying them with data or interventions they desire to live healthy lives.

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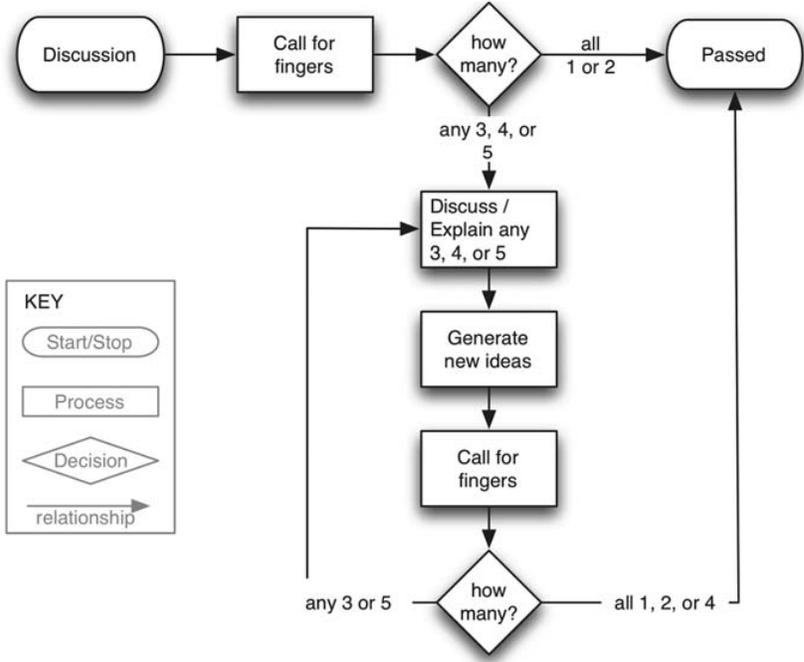
Box 1. Guidelines to promote the successful inclusion of autistic adults as co-researchers.

1. Be transparent about partnership goals and choose an appropriate approach to match those goals.
 - Match the level of engagement best suited to your project (e.g. equal partnership vs. authentic engagement/collaboration vs. consultation) to the participatory approach (e.g. community-based participatory research, patient and stakeholder engagement, emancipatory research, other forms of community-engaged research).
 - Explicitly communicate what type of engagement community partners can expect from the approach being used.
 - Create an infrastructure that supports the type of collaboration you and your community partners have agreed best meets the project goals.
2. Clearly define community partner roles, consider who needs to be included on the team, and partner with people who are likely to help the project succeed.
 - Clearly describe roles and expectations, and select partners who can commit to them.
 - Consider the expertise the project needs based on different types of lived experience.
 - Create a balance between autistic community leaders and other autistic adults.
 - Identify partners who have a shared long-term vision and who will prioritize achieving collaborative goals over individual gain.
 - If including non-autistic partners (e.g. family members, service providers, other academics) identify people who are willing to share power with autistic partners.
3. Create processes for effective communication and power-sharing.
 - Jointly create collaboration processes and guidelines.
 - Agree on a structured process for making decisions.
 - Individually assess accommodation needs, discuss as a group, and re-assess regularly.
 - Discuss and address competing accommodations.
 - Consider the effects different meeting formats will have on partners' abilities to engage, and consider offering multiple methods for participation (in-person, teleconference, video conference, text-based chat).
 - Present concepts and information using accessible language and formats so partners can make truly informed decisions.
 - Allow adequate time and space for partners to process information.
 - If using email, provide a structured format to improve clarity (e.g. Purpose, Actions, Deadline, Compensation, Details).
 - Provide materials in advance of meetings.
 - During meetings, provide strong facilitation, with clear delineation of agenda items, time to catch up, cues to transitioning, and an etiquette for handling digressions.
 - Regularly consider the role that power and privilege may play in tensions between academic and community partners and actively work to equalize power.
 - Avoid pathologizing autistic partners when trying to understand and address collaboration challenges.
4. Regularly focus on building and maintaining trust.
 - Engage in a visioning exercise to clarify and solidify shared goals.
 - Include exercises to help team members get to know each other. Consider asking community partners to choose and lead such exercises.
 - Actively listen to community partners' views and demonstrate that you value the expertise that comes from lived experience.
 - Follow through and implement the group's decisions, and regularly report back on progress.
 - Celebrate success and make space for humor and fun.
 - Regularly evaluate and improve the collaboration.
5. Collaboratively disseminate findings.
 - Collaboratively decide on ways to present findings to minimize stigma or harm.
 - Include community partners as co-authors on scientific papers. Doing so may require review and discussion of lay language or annotated versions of manuscripts.
 - Co-create lay language briefs that can be shared in non-academic venues.
 - Jointly find ways to use findings to advance community priorities or goals.
 - Encourage community members to find creative venues for dissemination.
6. Actively encourage community capacitation.
 - Offer opportunities for autistic individuals to pursue education, participate in internships, and serve as research staff.
 - Be aware of the inherent power differentials between faculty and students, trainees, and staff members, and do not assume that such individuals can substitute for collaborations with autistic organizations or leaders.
7. Fairly compensate community partners for their work.
 - Be transparent about project funding.
 - Find ways to pay community partners, especially when academic staff or study participants receive payment.

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- One Finger -- Yay, I approve! Do it!
- Two Fingers -- Meh, I'm not thrilled, but I'll approve.
- Three Fingers -- I am not sure, I need more information or discussion.
- Four Fingers -- I don't like it, I won't approve it, but I can live with it.
- Five Fingers -- I hate this so much that I can't live with having my name associated with it.



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Project ETHICS Expert Panel Member
Roles and Responsibilities

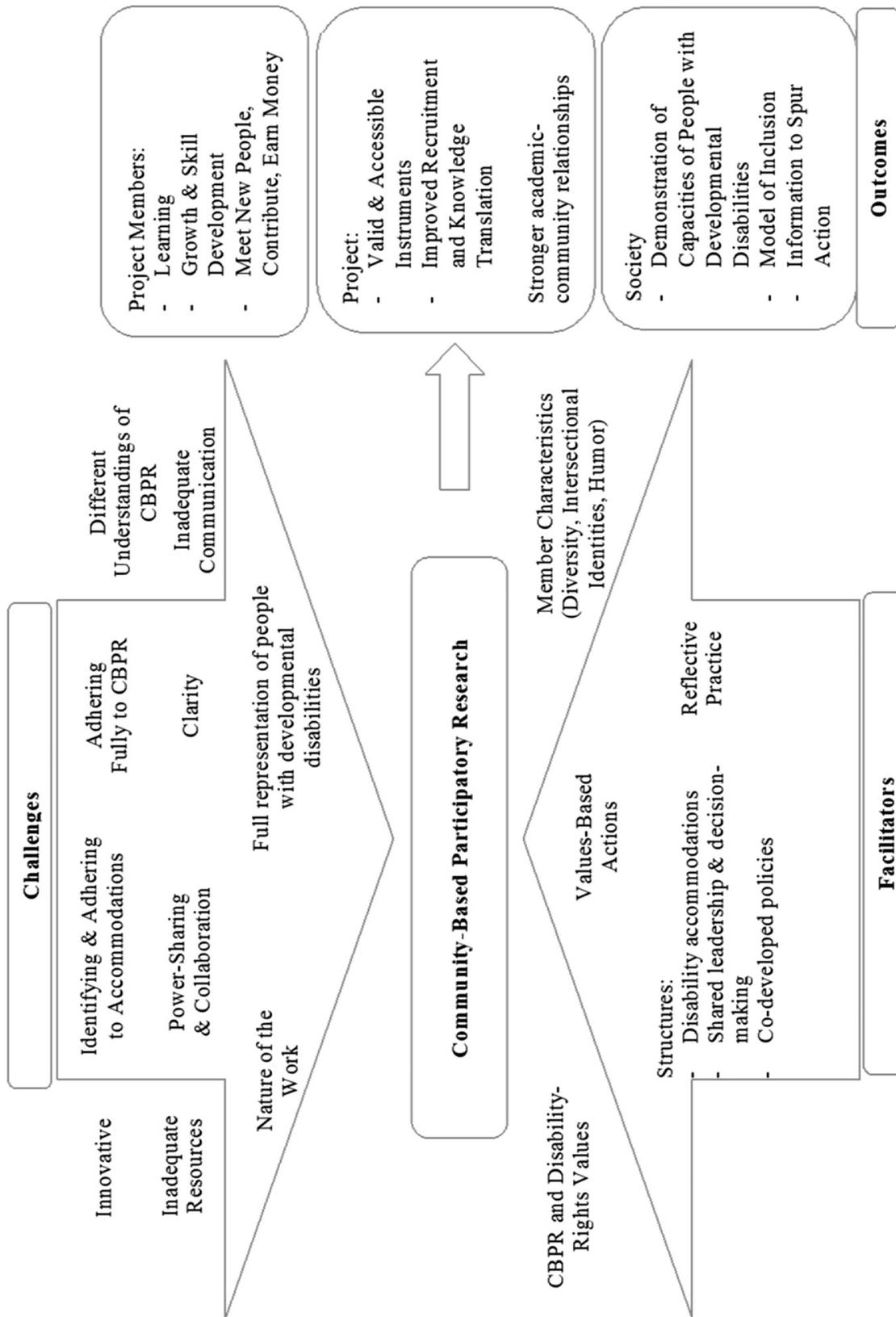
What will my role on the Expert Panel be?

As an Expert Panel member, you will:

1. Make sure that all Expert Panel members are valued.
2. Make sure that Expert Panel activities and discussion are **accessible** to all participants. 
3. Make sure that the discussion respects and values both those in the room and the **disability community**.
4. Offer **advice and ideas** to all Expert Panel members.
5. Assist in **making decisions** throughout the Expert Panel. 
6. Make sure materials are **accessible** for all people.
7. Help us **understand findings** from Project ETHICS focus groups and other research.
8. Play an active part in **developing a survey** that will that make sense to others.
9. Help **create, review, and edit** materials for recruitment and informed consent. 

Group Guidelines – ways we want to work together

1. Meetings will start and end on time.
2. Everyone's thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
3. Everyone is included in the conversation.
4. Speak one at a time.
5. No private conversations during meetings.
6. Respect confidentiality – personal stories “stay in the room.”
7. Speak your name before talking.
8. When you are done talking, say “done” or “next.”
9. Respect everyone's time by staying on topic.
10. Be patient while learning everyone's accommodation needs.
11. Do frequent check-ins and do “round robins” to get everyone's feedback.
12. Finger counts will be taken when making decisions.



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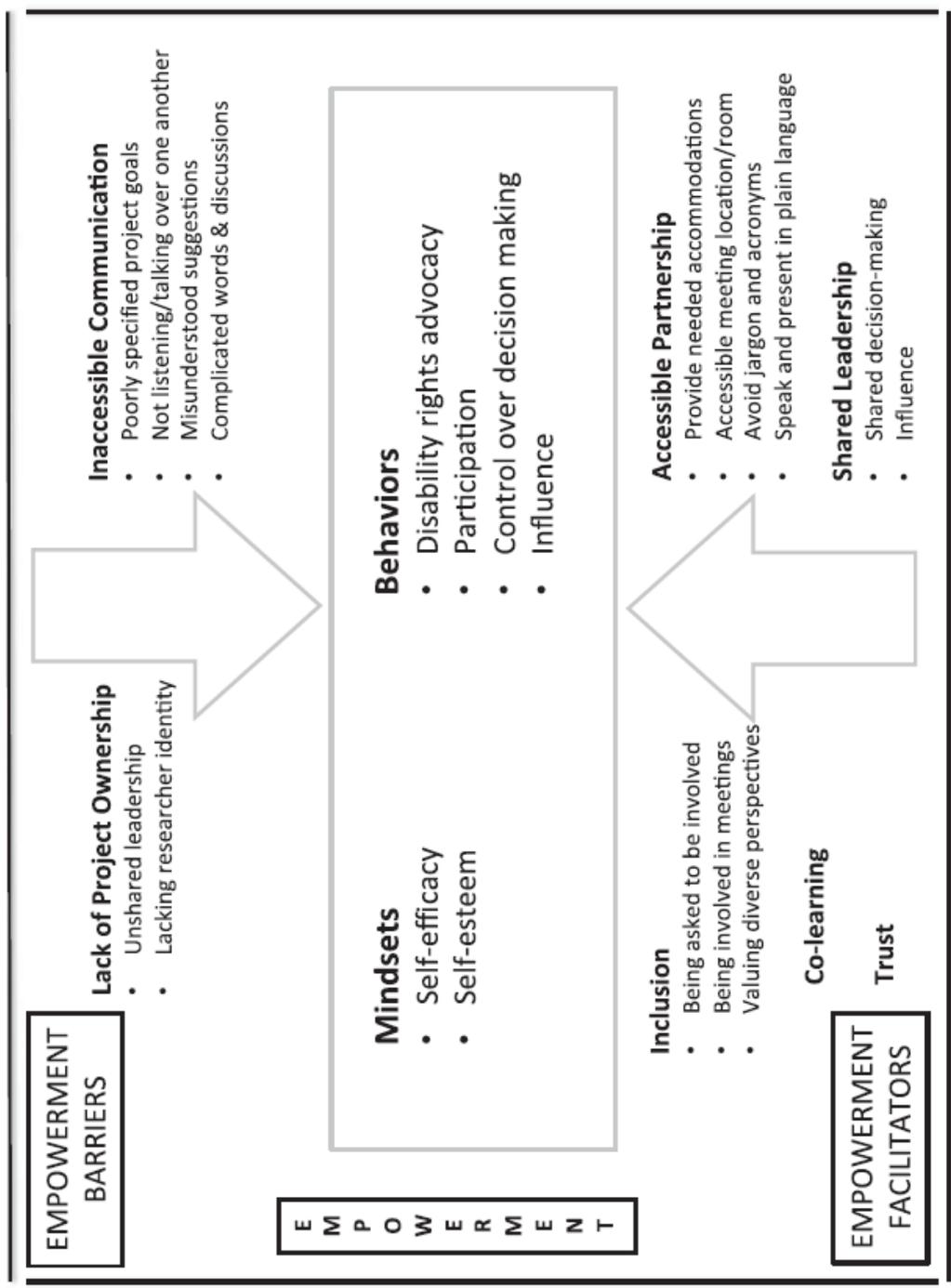


FIGURE 1
Empowerment definitions and CBPR barriers and facilitators affecting empowerment.

Box 2. Guidelines to promote the successful inclusion of autistic adults as study participants.

1. Avoid the risk of undue influence and exploitation while maximizing autonomy and inclusion.
 - Do not assume that anyone with a diagnosis of ASD needs to undergo an assessment of decisional capacity. Consider the level of risk and the types of decisions the potential participants make on a regular basis.
 - In cases where decisional capacity is unclear, consider conducting a brief comprehension assessment after the use of an accessible informed consent process.
2. Make the consent process as accessible as possible.
 - Adapt consent forms to increase accessibility (e.g. by making language simpler and more concrete, removing sections that unnecessarily hinder comprehension, adding images, and providing text-to-speech versions of online consent forms).
 - Consider partnering with autistic adults to create more accessible consent materials.
 - Consider strategies to reduce participant burden (e.g. online consent).
3. If possible, offer multiple modes of participation to maximize inclusion of autistic participants with differing strengths and needs.
 - For surveys, consider offering in-person, telephone, and online options. If the survey is only available online, consider using software with read-out-loud capability for participants with low literacy.
 - For qualitative interviews, offer both synchronous and asynchronous modes of participation and allow both oral and written communication. Examples include email (asynchronous, written), telephone or in-person (synchronous oral), and instant messenger chat (synchronous, written).
4. Do not assume that survey instruments validated with general populations, caregivers, or children are valid for use with autistic adults.
 - Assess the need for adaptations and, if needed, modify the instrument and re-test its psychometric properties.
 - Whenever possible, use a participatory process to assess, create, and/or adapt instruments.
 - Only change items that would cause significant problems.
 - If needed, add prefaces to increase precision or explain context; and modify items to simplify sentence structure, remove the passive voice, and clarify pronouns.
 - If needed, substitute difficult vocabulary words, confusing terms, or figures of speech with more straightforward terms. In cases where a substitution is not possible, add hotlinks that define the term or offer examples or clarifications.
 - When response options are problematic, consider graphics to increase clarity (e.g. cylinders filled to varying proportions; frowning/smiling faces).
5. Create accessible qualitative interview guides.
 - Offer participants the option to review materials in advance.
 - Begin with a preface that clearly explains the type of answers you wish to receive.
 - As much as possible, use concrete questions, asking for stories about specific experiences rather than answers to questions about abstract concepts.
 - Work with community partners to ensure that questions are precise enough, and provide enough context, to be answered.
 - Use probes to help anchor events and further elaborate on stories or concepts.
 - If using email to conduct the interview, include a preface and the first order of questions in the initial email message, and expect 2–4 rounds of responses to obtain complete, rich answers.
6. Use proxy reporters only if direct participation is not possible, even with accommodations and supports.
 - Distinguish a “supported participant” (i.e., autistic individual answers questions with help from a supporter) from a “proxy” (i.e., supporter answers questions with minimal input from the individual).
 - Provide a way for supporters to offer their own opinions separately from the person they are supporting.
 - Create a separate survey for use by proxies. Review and adapt all items, focusing on what the proxy can answer on behalf of the patient versus where the proxy can only provide their own perspective.

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You are invited to be in a **research study about adults with an intellectual disability being in research.**

Katherine (Katie) McDonald, PhD, at Syracuse University is in charge of this study.



You are being asked to take the survey because **you have important experiences.** We hope to have 500 people take the survey.

This form has **information about being** in this study.



It is **up to you** to decide whether you want to be in this research study.

This project is funded by a grant from the National Institute of Child Health and Human Development, a part of the National Institutes of Health (NIH).

What is the study for?



To learn what **you think** about topics such as:

- How important it is that different things happen when adults with an intellectual disability are in research studies.
- How safe adults with an intellectual disability are when people who do research do certain things.

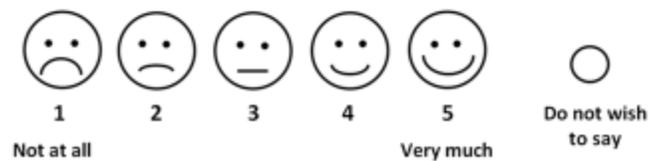
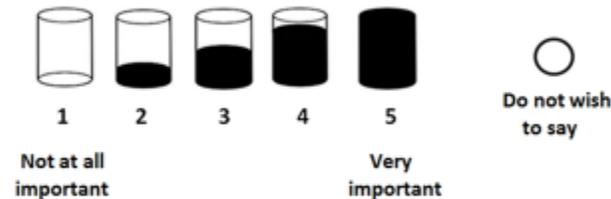


We also want to learn about your experiences being in research studies and some of your personal information, like your gender and age.



We hope to learn about what different people think about these topics.

Response Scales



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Visual Communication Examples



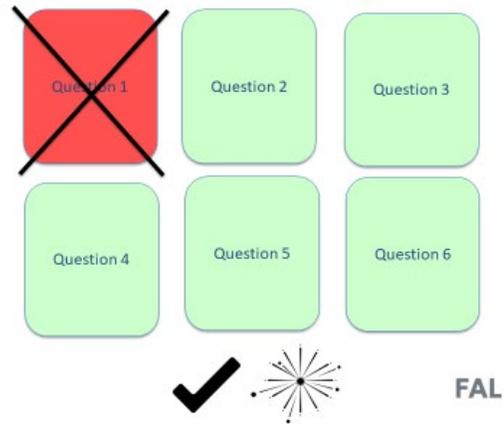
Interview Guide Progress (cont.)



2. BAD things about ...?



Interview Guide Progress



AASPIRE Web Accessibility Guideline: This guideline is a summary of the accessibility features we identified and implemented during the course of our study. None of these items were difficult or expensive for us to implement. They did not require special expertise beyond basic web programming and technical communications skills. We recommend that anyone seeking to create accessible websites for autistic users follow the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Web Accessibility Guideline in addition to broader web and communications standards and principles.

Physical accessibility:

- Provide at least one low-contrast neutral color palette option to accommodate sensitive vision.
- Provide a selection of color palettes, including one with a dark background and one with a light background, again to accommodate color and contrast sensitivity.
- Provide a no-style option (i.e., no cascading style sheets (CSS) to accommodate browser customization and users who prefer no stylistic formatting.
- Provide simple consistent navigation and highly consistent site behavior for increased ease of operation.
- Avoid textured backgrounds, moving images, decorative elements that do not convey information, and other visual and/or sonic “clutter”; these types of elements may make the site difficult or impossible to comprehend.
- Provide smaller font sizes in addition to larger ones; large font sizes may make the page appear cluttered and difficult to read.
- Use a plain accessible sans-serif font (e.g., Arial) for ease of readability.

Intellectual accessibility:

- Use the simplest interface possible for ease of understanding.
- Use simple concrete icons or images to communicate redundant information with text, and accommodate multiple ways of understanding information.
- Clearly label site elements with their purpose everywhere on the site, even if it seems redundant, to make navigation and site functionality easier to follow.
- Provide concrete examples where applicable to accommodate difficulties in understanding abstractions or generalizations.
- Minimize scrolling so the user does not need to rely on assumptions about content to guess what might be on the page.
- Show all important features and site navigation (as opposed to within combo box drop-down areas) so the user does not need to rely on assumptions to guess whether the item exists and how to access it. For example, completely visible list boxes or radio buttons can be used instead of combo boxes.
- Make content as short as possible without sacrificing precision and specificity, to reduce cognitive burden.

Social accessibility:

- Be specific and precise in language use; avoid colloquialisms, idioms, and ambiguity to accommodate difficulties with language pragmatics.
- Explain the reason behind any nonstandard instructions or unusual information; provide additional pragmatic context to accommodate difficulties with language pragmatics.
- Provide alternatives to definitive response items on surveys and forms, for example, “do not know,” “do not wish to say,” or “not applicable,” to reduce frustration for not being able to produce an exact answer.
- Use FAQ formats to organize complex information to enhance clarity as to why the information might be useful to the user and how it connects to their life.
- Define terms that might have different meanings depending on social context, or which might be jargon related to a specialized field (e.g., “drug interactions” and “health care providers”), to accommodate difficulties with language pragmatics.
- Be mindful of autistic culture and community preferences, including the language used to describe autism and how community-based symbols and history might influence content and perception of site credibility.