

Strategies for Community Engagement with Autistic Adults and Caregivers in Early Intervention Autism Research

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See <https://www.eicollab.northwestern.edu/> for more information about the project through which this tool was developed.

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Section 1: Introduction

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What is this tool?

Many autistic people and their caregivers express dissatisfaction with therapies provided for autistic children in early childhood. Research efforts to improve autism therapies are critical to driving clinical change. However, there is substantial evidence to suggest that research largely excludes many people in the autism and autistic communities such as autistic girls, children of color, and multilingual children (and those at the intersection). This has created and exacerbated disparities in access to effective and equitable therapies for autistic children from these populations.

Community-engaged research is posited as a solution to making research more relevant to the needs of community members affected by the research. Autistic people and family members of autistic people have been found to have a great deal of empirical knowledge about autism which, in combination with their personal experiences of autism, makes them valuable partners in the research process.¹ However, autistic people and family members of autistic people have reported dissatisfying experiences participating in the research process.² Furthermore, researchers often hold ableist beliefs (either implicitly or explicitly) or use ableist language to describe autism,³ potentially contributing to distrust of researchers (and clinicians) by members of the autistic and autism communities.

This tool is intended to teach early childhood autism researchers how to conduct community-engaged research with autistic people and caregivers in inclusive, satisfying ways.

We hope that this tool will encourage researchers to use community-engaged approaches in their future research, and to use research frameworks that result in the production of knowledge that is more meaningful for the community. Community-engaged research is vital for autism research throughout the lifespan, and we believe that this tool is also valuable for those conducting research with older children and adults. This is especially important given the dearth of research about ways to support autistic adults. However, the focus of this tool will largely be on research affecting therapies and supports that may be provided for autistic children and families in the Early Intervention (EI) system in the United States (see below for an explanation). For those outside of the US, this equates to therapies provided between birth and up to 5 years of age.

Furthermore, we recommend that community-engaged methods be used in conducting **comparative effectiveness research**. Comparative Effectiveness Research refers to research studies that compare the benefits and harms of two or more therapy approaches. Such research frameworks are crucial for providing caregivers with the information they need to make decisions about their child's care. We will provide more information about the importance of community-engaged methods and comparative effectiveness research below.

What is Community-Engaged Research?

Community-engaged research refers to research that is conducted with participation of people from communities affected by the research. The term “participatory research” is also used to describe this kind of research. Community-engaged research can take many different forms. Some popular frameworks of community-engaged research include “participatory-action research” and “community-based participatory research.” **There is no single correct way to do community-engaged research, but there are many ways to do it wrong.** In the additional resources, we’ve included links to guidelines for participatory autism research created through researcher-community collaborations. These resources outline principles for engaging with autistic community partners in inclusive and satisfying ways and will help you understand what it looks like to do this work in a way that maximizes impact. But your specific approach will vary based on the research topic and resources available to you. This tool will provide you with information about different engagement methods so you can design a project that best fits your resources while satisfying the needs and expectations of community partners.

There are some very helpful tools to encourage participatory autism research, such as the AASPIRE Network’s [participatory toolkit](#) for engaging with autistic adults in adult-focused autism research at high levels of community engagement (see Recommended Resources for Further Learning in Section 2 for more examples). We hope our tool builds on efforts such as these by providing additional guidance for engaging with autistic people and caregivers (both autistic and non-autistic) in childhood autism research. We also hope that this tool is helpful for maximizing community participation at different levels of community engagement.

Why use community-engaged research methods for Early Intervention autism research?

At its core, community-engaged research is an important way to ensure that you are researching therapies, outcomes, and models that are practical to implement, relevant to the community, and embraced by autistic people— especially autistic people who are multiply marginalized. Autism research has a history of bias that has resulted in misalignment between research standards, clinical expectations, and the preferences of autistic people and caregivers (see Section 2 for a further description of these problems in research). Partnering with community members throughout the research process helps to make research more relevant to the real needs of diverse members of the autism and autistic communities. Furthermore, engaging with autistic adults and caregivers with older autistic children may help to embed a lifespan approach to EI research; designing and studying therapies given consideration of potential long-term consequences will help to maximize *positive* cascading impacts of EI therapies as autistic children age. It may even minimize negative impacts of various therapies and contextual factors (e.g., prevent the need for mental health supports stemming from negative childhood therapy experiences).

Why comparative effectiveness research?

We believe that increasing the extent to which EI therapies are embraced by autistic people and their families can have an important, positive cascading impacts on autistic children as they age. One of the cornerstones of EI is family-centered practice, which refers to a variety of practices centering the role of families in a child's development and well-being. EI clinicians are expected to individualize strategies, supports, and therapy contexts based on caregiver preferences and needs, and actively involve caregivers in their child's care. This requires that caregivers be provided with appropriate information to make informed decisions about their child's care. Not only does this make EI therapies more relevant to unique families, but it also prepares families to make important decisions for and with their child for later stages of life.

However, problems in autism research (e.g., ableism, racism, other exclusion) have resulted in limited information about best practices for all autistic children early in life. Thus, the information available from research contexts may be irrelevant or inappropriate for many families. Furthermore, the research-informed guidance families receive from clinicians and educators may conflict with community perspectives about autism (e.g., neurodiversity approaches to supporting autistic people). *Most caregivers are first learning about autism and disability through the early stages of their child's diagnostic process, potentially making this conflicting information from community and research settings even more challenging to sort through.*

We believe that **comparative effectiveness research** will facilitate the production of research that addresses questions and decisions that caregivers must make for their child in the EI system. Comparative effectiveness research compares the benefits and harms of two or more therapy approaches. This will help researchers, clinicians, caregivers, and autistic people not only understand the impact of different approaches, but to *compare* the extent to which different approaches are appropriate or inappropriate for supporting different outcomes and populations. Community-engaged approaches within CER ensure that the therapies and outcomes included in a study are relevant to the community and decisions that caregivers, clinicians, and autistic people must make.

Community-engaged approaches to comparative effectiveness research will allow you to answer questions that are foundational to conceptualizing your studies. For example:

- What kinds of decisions do caregivers need to make for their child's EI care?
- What factors do caregivers have in mind when making decisions that may impact the effectiveness, accessibility, and feasibility of different therapies? And how do these factors differ for families with different positionalities and experiences?
- What are the benefits and harms that caregivers balance when deciding if an approach is right for them?
- What kind of information might caregivers *wish* they had when making decisions for their child when they were in EI (e.g., retrospective)
- What are the benefits and harms that autistic people experienced with different therapy approaches?
- What skills and experiences do autistic adults wish they had in early childhood?
- What outcomes might be foundational for supporting skills autistic people prioritize as they age?

- What adaptations to existing approaches might increase the extent to which these therapies are embraced by the community? And for different communities/populations?

Community members can also help you after the conceptualization phase to ensure your comparative effectiveness research study is acceptable to the community. For example, community members may:

- Provide insight and help forge connections that will be helpful for participant recruitment and retention
- Oversee decision-making to ensure studies are aligned with the ethical principles of research and the autism/autistic communities
- Guide the creation of effective survey measures that are understandable and easy to complete by your community of interest
- Contribute to designing observational measures such that you capture behaviors of interest to the community in a valid and reliable way
- Guide data interpretation to better understand the clinical significance and balance of pros and cons of the approaches included in your study

Who is involved in community-engaged research?

We use the terms “**community member**” or “**community partners**” to describe individuals from the community who are engaged in the research process. In the case of EI autism research, this can include autistic people, caregivers, EI providers/clinicians, family members, EI policymakers, among others. You may involve different community members depending on the scope of your project. For example, it may be more important to involve EI policymakers in implementation-focused research than in efficacy research. But we believe it is *always* important to involve autistic people and caregivers (as well as autistic caregivers) in EI autism research.

Throughout this tool, we include information about ways to design your community-engaged projects to ensure that members from these communities have a satisfying and meaningful experience that maximizes our ability to answer research questions that are important to them, with a primary focus on autistic adults and caregivers of autistic children.

Many people use the term “stakeholder” (and stakeholder-engaged research) instead of the term “community member,” but there is a shift away from using this term due to problematic usage in the past.

When should community-engaged research be used?

Community-engaged approaches should be used at all stages of the “research-to-practice pipeline.” It is most common to see researchers partner with community groups at implementation phases of research, but biases in research have made current therapies irrelevant or unacceptable for some community members, as we will later describe. Thus,

researchers should not wait until later stages of the translational research continuum to ensure their outcomes and practices of interest are acceptable and important to the community.

Who is this tool for?

This tool is intended for autism researchers, and is particularly geared towards the Early Intervention (EI) age range. However, the basic principles apply to research throughout the lifespan. It is intended for researchers across settings (e.g., not just R1 research institutions), at various stages of their careers, of all neurotypes and cultural backgrounds. One does not need to be a member of their community of interest in order to use community-engaged methods. Furthermore, many of the examples and frameworks we describe may be more relevant to the “WEIRD” (Western, Educated, Industrialized, Rich, Democratic) countries and institutions from which the majority of autism research stems. Community engagement is an essential component of *all* research, and regardless of the setting, you should evaluate the contextual factors affecting relationships and power dynamics between research/academic institutions and the local community in your specific, local setting.

Some of the language and suggestions included in this tool are most relevant to neurotypical researchers and researchers with other privileges within academia (e.g., researchers with tenure, English-speaking researchers, White researchers) who may not yet be well-versed in engaging with the communities their research is meant to impact, but the methods and principles of engagement are potentially applicable to all researchers.

Letter to Autism Researchers, from our Advisory Board

We are a group of autistic people, autistic caregivers, and non-autistic caregivers of autistic children who have received services through the Early Intervention (EI) system. Some of us have been involved in research on advisory boards, on research teams, and as participants. We believe that community-engaged research is *critical* for the future of autism research and clinical practice. In this letter, we will explain why we think it's important and some things you should keep in mind when doing community-engaged research to develop therapies and supports for autistic people in the future.

Why do community-engaged research?

Community engagement makes clinical practice more effective and acceptable to the community.

Researchers often treat autistic people like a mystery to be solved. They rely on their perceptions of our behaviors to find ways to help or even “fix” us. This has resulted in therapies that are uncomfortable to experience, that target goals that some of us don't think are important, and that have had some negative long-lasting impacts that have been disregarded because of “favorable” short-term outcomes. Partnering with us will help you understand how your therapies are experienced by autistic people, and the actual effects of these therapies on our *whole* selves—not just the goals you measure—in short- and long-term capacities. It will also ensure that the methods, therapeutic approaches, and goals targeted in research are important to the community. Including community members at every stage (including the initial stage where the project goals are still being decided) would be a way to ensure that the time, energy, and dedication of the research community becomes a force for good by focusing on the most important issues facing autistic people and caregivers.

Caregivers also play an important role in developing effective therapies for young autistic children. Research and clinical practice tends to treat all caregivers in the same way. But we all have different priorities and preferred ways of interacting with our children, and we have our own strengths and challenges as well. A lot of us face judgment from our child's clinicians and from the other people in our lives and communities. Many of us are learning about autism for the first time. Some of the things we're told to do for our child may be uncomfortable. In some cases, this may be healthy discomfort which is part of the process of learning about autism. But in other cases, the discomfort occurs because the therapies and supports we're told are best for our child are not realistic for us to use in our daily lives, or because they are misaligned with our cultural background, needs, values, or other aspects of our lives. The insistence on using these uncomfortable or impractical therapies can create additional guilt or stress. Researchers need to work with caregivers of diverse perspectives and experiences to develop therapies we will actually be able to use with our child.

Researchers should also include autistic caregivers of autistic children, who have insight into their own personal experiences as well as the experiences of their child. Autistic caregivers may have unique needs that are not met by supports created for non-autistic caregivers. And, they may have valuable perspectives that non-autistic caregivers would benefit from knowing more about.

Community engagement makes research more efficient and satisfying for participants.

You can engage with community members for insight on your study procedures like participant recruitment, survey creation, assessments and more. Autistic people and caregivers can help you create methods that are inclusive of diverse experiences (e.g., sensory differences) that could impact the satisfaction of autistic children and family members participating in your study. Community members can also contribute new and important interpretations of your results. We may have insight into alternative ways to make meaning of expected or unexpected patterns in the data that are only apparent given our personal experiences.

What should you keep in mind when working with community members?

Here are some things you should always remember when doing community-engaged research. Check out the rest of the tool for specific strategies to help you integrate these principles in your work. You can see a full list of topics in the Table of Contents.

Make sure your research doesn't perpetuate ableism, racism, sexism, and other forms of bias and discrimination.

Research and clinical practice are rooted in its social-cultural context, meaning they may also perpetuate biases present in the culture (and it may contribute to these biases, too). It's important that your research actively combats these biases. Efforts to overcome these biases not only make your research better, but they also help your community partners feel safer contributing. You should make sure that your community partners are also aligned in these goals.

Ask yourself why you're in this field and why you want to do community-engaged research.

Research in this field should have an application that will help our community in the way we want help. You should only be in the field to genuinely understand autism and create enriching, meaningful supports for autistic people. You may have entered this field to fix "problems" that you've been told exist, and there are indeed many barriers and challenges that do need to be addressed by research. But many of the problems centered in autism research don't reflect the actual priorities of autistic people and families. For example, some repetitive movements were once considered a nonfunctional behavior to be eliminated, but many autistic people find these movements to be beneficial and calming. Engaging meaningfully with the autistic community, and the diversity of experiences and perspectives within the community, is critical for understanding what challenges are actually prioritized by the community. If you have not

meaningfully engaged with people from the community to understand the challenges we actually experience, that's a sign that your research may not be aligned with community perspectives. Similarly, you should want to partner with us to make your research more applicable and relevant to our lives. You should not engage with us if you only want to use our experiences to further your own agenda, make your own studies more effective (e.g., using our community relationships for recruitment), or to fulfill some sort of grant or publication guideline.

Proactively make your community engagement procedures inclusive of a wide variety of needs (communication, sensory, executive functioning, etc.).

Taking efforts to make projects inclusive from the beginning, instead of putting accommodations into place after the project begins, can make your community partners more comfortable. It shows that you're dedicated to including our whole community. It may also make us more comfortable asking for additional accommodations if needed. You should also take time to ensure that all your community partners understand the value of accommodations to ensure mutual respect between your partners. For example, providing basic education to your community partners about stimming and sensory processing may help non-autistic partners understand why an autistic community partner may wear noise reduction headphones, use vocal or motor stims, communicate and/or participate in less conventional ways, etc. These accommodations will not only spread a message of respect and acceptance but may open the doors for participation to people who are often excluded from the research process, such as those with disabilities, medical disorders, and mental health challenges.

Be patient.

Many of us haven't been part of the research process before, so it may take us some time to get used to it. Researchers have treated many people in our community poorly in the past, so it can take some time to build trust. Additionally, some of us may require support to navigate some social situations or situations that cause anxiety and stress. If you do not have the tools to communicate with autistic and neurodivergent community partners, this will make us much less comfortable contributing to the research process.

Teach us about how research works.

We can't be equal partners in the research process if we don't know how research works. Teach us about the methods in a research study, the grant-writing process, and the politics and logistics that underlie research so we understand the limitations and areas for growth in research.

Look at a full range of perspectives.

No two autistic people are the same, and no two families with an autistic child are the same. It's important that you don't only collaborate with people who share the same beliefs and background as you, and also keep in mind how to combat beliefs and practices that may actively cause harm to autistic people of all identities (as will be explained later in the tool). Community engagement is critical to expanding research to be more inclusive. There are many members of our community who are excluded from research more than others (for example, autistic people with intellectual disabilities). Take special attention to include people with multiple marginalized identities in the research process and know that this could mean using different methods of engagement for different people.

Be open to opinions that challenge your own.

Community partners may not always agree with you, or with each other. It's important that you don't get too defensive if someone challenges your opinion, especially if that challenge is in an area in which you are relatively privileged. You should take time to reflect on why your opinions differ. Reflecting on the underlying worldviews and social-cultural contexts influencing people's perspectives can help you navigate disagreements and find a solution that helps you set and achieve shared goals. Being open to new opinions and perspectives will 1) reduce prejudices and disparities perpetuated by current research and 2) open the door to new avenues for research that may result in innovative methods for addressing a wide range of priorities. You should also have processes in place to handle disagreements between community partners to ensure everyone is comfortable sharing their opinions and has space to contribute to the project.

Respect our knowledge and personal experiences as a different type of expertise than you may have.

You may know more about autism from a research perspective, but there have been many problems in autism research that have led to skewed and incomplete pictures of autism. Autistic adults should be a primary source of knowledge about the experience of being autistic because we live it every day. Caregivers of autistic children should be a primary source of knowledge about the experiences of raising autistic children as we live it every day. Acknowledge and respect our realities as we express them and use this to create therapies and supports that address these realities.

Respect autistic children.

Our children are not problems to be fixed. They are not just your sources of data; they are people who can be affected by the procedures of your research study, and it's important to prioritize their well-being over the fidelity and validity of your study procedures. We must appreciate the inherent rights of autistic children as human beings and understand that even if their experiences and preferences are different than what we would expect as adults, they are worthy of respect. Additionally, their happiness and well-being are affected by a lot more than their proficiency in the skills you measure in your studies. Supporting autistic children is therefore more than just helping them develop skills by whatever means necessary. There are no skills worth acquiring if it is going to compromise mental health and well-being. Additionally, presume that all children can think, learn, and feel, even if their ways of doing so look different than other children (whether autistic or not). Also, you should take caregivers seriously in our judgment of what our child can do or understand.

Autistic children also have important experiences that should be considered when developing and testing therapies. Although autistic toddlers may not have the skills to express the nuances of their experiences, you can look for indicators of distress/happiness/assent/etc. You can make efforts to engage with older autistic children to understand the impacts of therapies as well.

Mistakes are inevitable.

Everyone makes mistakes, even those with a lot of experience in community engagement or who are completely dedicated to transforming autism research. Continuously gathering feedback from your partners, incorporating that feedback, and being transparent about your mistakes will help to maintain your relationships with community partners even when you make a mistake. Also understand that many of us have been wronged by researchers in the past, so we may need a bit more time or effort to regain trust that was potentially lost. We would rather you try in earnest to work with us and grow from mistakes, than to continue to exclude us from the research that impacts our community.

We believe that research, when done in genuine collaboration with the autistic community, has the potential to make a significant positive difference and to pave a way for increased acceptance and quality of life for autistic individuals. Keep reading this tool for more information about the importance of community-engaged autism research and practical strategies to use it in your research.

Signed,
[EIRG Advisory Board](#)

Terminology

Overarching terminology:

Community member: A person who is directly impacted by the research in question. For early childhood autism therapy research, this can mean autistic children, autistic adults, caregivers (both autistic and non-autistic), clinicians, and EI policy-makers. We will focus on autistic adults and caregivers (both autistic and non-autistic) as our primary “community members” in this tool.

Autistic community: The community of individuals who are autistic. We use identity-first language due to community preferences, but understand that many also use and prefer person-first language (e.g., person with autism).

Autism community: The community of people who care about and care for autistic people. While this includes autistic individuals, it also includes others such as caregivers, family members, clinicians, and others.

Caregiver: someone involved in caring for an autistic child who has decision-making capacity for that child. This could mean parents, legal guardians, aunts and uncles, grandparents, or other adults who care for the child and make choices to support the child’s development.

Community-engaged research: Research that is designed and/or conducted with participation of people from communities affected by the research (also called “participatory research” or “stakeholder-engaged research,” though we avoid using the term stakeholder here due to problematic usage in the past).

Section 2:

Ableism: prejudice and discrimination against people perceived to be disabled and have characteristics associated with disability.

Medical Models of Disability: Models for thinking about disability that positions disability (and disabled people’s challenges) as being primarily caused by the characteristics of a person’s condition, without consideration of the complex and varied social contexts in which disabled people live. Applied to autism, medical models view autistic people’s challenges as being caused by autism traits (“deficits”).

Social Models of Disability: Models of disability that positions disability as a result of an individual being in an unaccommodating social or physical environment that was not designed with disabled people in mind. Applied to autism, autistic people face challenges because their environment does not support impairments associated with autism.

Characteristics of autism: An umbrella term including *all* traits related to autism. These traits can be strengths, challenges, or neutral differences. (often depending on the situation and degree of support or acceptance).

Differences: characteristics of autism that are different from assumptions about normative behavior. We will use this term to describe characteristics that may be strengths or have no noticeable or differential impact on autistic people..

Disabling: When the social or physical environment and structures pose barriers to participation for individuals based on their impairments.

Impairments: Characteristics of autism that may pose challenges to an autistic person's development, learning, functioning, and/or well-being. Under the social model of disability, impairments may or may not be disabling depending on the social/physical environment. This term is not used as an inherently negative term, as may be suggested by its colloquial usage.

Neurodiversity: a term that describes neurodevelopmental disabilities like autism as part of the natural variability in the ways that people think, learn, feel, and function. It puts a *neutral value* on autism characteristics (and characteristics of other neurodevelopmental disabilities); some characteristics may be strengths, and some may impair functioning, but even impairments should not be treated with shame or stigma. Specific definitions and applications vary between scholars and community members.

Neurodiversity movement: An advocacy movement related to the disability rights movement that is built upon the scholarship and community discussion surrounding neurodiversity. Broadly, this movement advocates for increased understanding of neurodiversity and use of neurodiversity-aligned approaches, and for the rights of neurodivergent people.

Neurodiversity-aligned therapy approaches: Approaches to therapies and supports that focus on removing barriers to participation for autistic people, and when these contextual changes are not sufficient, suggest utilizing methods to support remaining impairments to increase the health, safety, and quality of life of autistic people. The use of biomedical interventions is limited to impairments that affect physical well-being such as chronic medical conditions (e.g., seizure disorders, gastrointestinal disorders)

Strengths-based/additive approaches: Approaches for supporting autistic people and their families across cultures by building on the existing practices and values in their community, rather than solely supporting families in ways that center the practices of dominant groups (e.g., White, middle-upper class English-speaking families). These approaches examine the successful practices and routines used by families from minoritized communities and support development in those contexts. They will also examine and dismantle structural barriers that influence the use of different practices, rather than place the blame on individual families for not implementing "ideal" standard practices.

Levels of Engagement (borrowed from Goodman and Thompson [2017]):

Non-Participation: The level of community engagement in which researchers learn how to reach community members and educate them about research topics. This level of engagement usually refers to outreach and education opportunities.

Symbolic Participation: The level of community engagement in which researchers ask community members for feedback and help with their research studies. At this level, you may consult with community members to understand their perspectives on a topic.

Engaged Participation: The level of community engagement in which researchers and community members work together to co-create research focused on community preferences (e.g., collaboration, community-based participatory research, participatory action research).



Section 2: Equitable, Inclusive Community Engagement

In this section of the tool, we will describe concepts that will help you get in the appropriate mindset for conducting community-engaged autism research. It is intended to help you establish meaningful community partnerships and considers the ways that research, and the therapies resulting from research, have benefited and harmed people in the autism and autistic communities. This will provide a foundation for community-centered comparative effectiveness research (and research foundational to such studies) in the field of EI autism research. The information described here is just a starting point; we encourage you to reflect on the material, utilize the additional resources provided, and continue learning about these dynamic concepts.

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Autism Research - A History of Discrimination, Disparities, Ableism, Racism, and Exclusion

The ultimate goal of autism research should be to support the well-being and quality of life of autistic people, according to how autistic people themselves define these constructs. But current therapies and supports for autistic people and their families assume a small range of outcomes and methods are appropriate and relevant for all autistic people. They may even use methods that autistic people find to be disrespectful, that violate their autonomy and preferences, and that contribute to long-term negative consequences due to a narrow focus on short-term outcomes. These problems have been influenced by bias in autism research, and therefore, overcoming these biases is crucial to developing equitable and acceptable supports for autistic people and their families.

Community engagement is critical to aligning research with the preferences and needs of the community. Research created with active participation of community members will intentionally consider the challenges and systemic barriers experienced by diverse members of the autism and autistic communities, resulting in therapies and supports that are less likely to perpetuate biases, and that may even combat them.

Having a deep understanding of the biases in autism research not only makes research stronger, but can also help researchers build trust with their community partners. By understanding the reasons why community members may mistrust researchers, we can take steps to address these concerns and design community-engaged projects that facilitate meaningful partnerships. This will empower community members to shape the production of knowledge that will be used to support autistic children and families.

Here we will briefly describe two main problems with autism research that both reflect and perpetuate bias in therapies, supports, and the broader social-cultural context:

***Problem 1:** Research reflects and perpetuates ableism when it is underpinned by assumptions that autistic people are of less value than non-autistic people. These assumptions can be built into medical models of disability.*

***Problem 2:** Research reflects and perpetuates racism, sexism, and other forms of bias, which is further exacerbated by the exclusion of multiply-marginalized communities and identities from the research process.*

The consequences of these research biases may change over time with systemic and sociocultural changes, and with advances in our understanding of autism. Furthermore, each individual has unique preferences and viewpoints regarding their relationship with autism. It is

vital to continually check in with your community partners (and members of groups with which you are *not* engaged) to understand the diversity of opinions, and to evaluate how your research intersects with (or may diverge from) different concerns and priorities. In addition to understanding the “research-specific” biases we describe below, we also encourage you to examine additional biases inherent to the systems in which autistic people and their families interact (e.g., educational and medical systems), and how these may influence the ways your work is experienced by autistic people and their families.

Problem 1: Ableism reflecting and perpetuating Medical Models of Disability

Ableism refers to prejudice and forms of discrimination against people perceived to be disabled and characteristics associated with disability. Ableism assumes that there is a standard “norm” for functioning, and sees deviations from this “norm” as inferior. This results in a variety of disrespectful, oppressive, and stigmatizing attitudes and behaviors towards people with disabilities (or disability characteristics), and structural barriers towards their well-being and participation in desired activities. Ableism is a complex phenomenon that takes many different forms, and these manifestations may vary based on the social-cultural context and disability characteristics in question.

Autistic people of all ages are affected by ableism, and prevailing attitudes and practices in autism research reflect this ableism. For example:

- Characteristics associated with autism are assumed to be inherently inferior to “non-autistic” characteristics. For example, researchers have assumed that when autistic people perform better than non-autistic people on cognitive tasks such as the embedded figures test (a task requiring the identification of a figure from a complex background), this is actually a sign of a deficit; even though these same attributes would likely be interpreted as strengths if they occurred in non-autistic people (see Gernsbacher, Dawson, and Mottron, 2006⁴ for a discussion of these instances).
- Autistic people are viewed as burdens on their families, communities and society, as manifest by outcome measures of “family burden” and analyses framing autism as a financial burden
- Infantilization of autistic adults leading to dismissal and/or distrust of autistic adults’ experiences, and the assumption that non-autistic researchers, clinicians, and caregivers know what is best for autistic people. This is especially true of autistic people who were diagnosed in adulthood, which is especially problematic given the inequities in early diagnosis for girls and children of color.
- Dismissal or downplaying of autistic adults’ concerns around therapeutic approaches that may violate the autonomy and mental health of autistic people because these therapies are working towards “the greater good.”
- Viewing autistic children as an amalgamation of discrete traits and deficits to be fixed in order to improve long-term well-being, rather than seeing them as “whole people” who will have unique preferences and experiences as they age.

- Autistic traits that are seen as helpful for meeting productivity standards of the workplace (e.g., hyperfocus, pattern-seeking skills) are idealized, and individuals with these traits may be mistreated or taken advantage of in the workplace. For example, their concerns about their treatment by co-workers may not be taken seriously because it is assumed they will be loyal to the company. In contrast, autistic individuals who do not have these traits may be seen as less “valuable” to society and are not given the opportunity (or necessary supports) to work.
- The traits and strengths of autistic people from minoritized groups (e.g., autistic women, autistic people of color) are poorly understood, ignored, or may even be vilified to a greater extent than autistic men.

Ableism can also affect the nature of community-engaged projects in EI autism research. For example:

- Researchers may be hesitant to partner with autistic people in their community-engaged projects for many reasons rooted in ableism. For example:
 - They may assume that autistic people are too “concrete” and cannot understand nuances in experiences
 - They may believe that autistic people are unable to introspect or report about their own lives and experiences
 - They may worry that autistic people will demand that their ideas be implemented in the project and will not be flexible in accommodating other perspectives or restrictions to allowable changes due to resources/guidelines of a project or grant.
 - They may believe that autistic adults who “have the ability” to advocate and participate in the research process could not have once been autistic children with higher support needs (or adults who currently have high support needs despite advocacy abilities), and thus are categorically unable to provide insight into the experiences of children with higher support needs.
- Researchers may believe that community engagement is only possible with autistic adults who can participate in standard engagement methods without accommodation, and therefore do not use methods for engaging with autistic adults who are nonspeaking, who have intellectual disabilities, or who have other significant support needs.
- Researchers may use inaccessible or upsetting methods and terminology when engaging with autistic adults, making autistic people uncomfortable sharing their honest opinions and experiences
- Researchers may inherently value the perspectives of neurotypical caregivers more than the perspectives of autistic adults or autistic caregivers, and believe that the perspectives of these communities will inherently be different.

Effective and appropriate community engagement will require you to understand ableism experienced by the community, and to actively and continuously examine your own beliefs that are influenced by ableism. This will help you design studies that intentionally combat ableism, and will help you design community-engagement methods that facilitate the comfortable and equitable inclusion of all community partners.

Reflecting society at large, autism research is rooted in ableist attitudes, beliefs, and practices, and the continued use of some foundational methods and mindsets also perpetuates ableism. Much of the ableism in autism research is manifested in the models of disability that researchers have historically used to conceptualize autism: medical models of disability.

Note: The ways we conceptualize disability and autism change over time. Here, we describe some fundamental principles of various frameworks and models, but it is important to note that there is diversity of opinion even amongst adherents of different frameworks. We have provided additional resources describing some of these different perspectives.

What are medical models of disability?

Medical models of disability position disability (and disabled people's challenges) as being primarily caused by the characteristics of a person's condition, without consideration of the complex and varied social contexts in which disabled people live. According to these models, autistic people face challenges because their autistic traits are impairments which are inherently negative. Conversely, the assumed norm for how people think, develop, and experience the world is generally perceived of as the ideal outcome. Thus, the goal of autism therapy research has been to eliminate autistic children's impairments to help them develop and learn, or to facilitate development according to non-autistic norms and developmental trajectories. Supports created under medical models of disability often prioritize the comfort of non-autistic people over the preferences and needs of autistic people (e.g., social skills therapies that teach autistic people to suppress autistic characteristics so that non-autistic people will like them more).

Viewing autism purely through a medical model creates many limitations for ways to develop supports for autistic people. Medical models of disability consider *all* autism characteristics as impairments to be fixed (with the occasional exception of some traits that are valued for increasing productivity, as described above). This is manifested in common research methods, like targeting a reduction in "diagnostic characteristics of autism" as an ideal outcome of a study.⁵ This deficit-based view of autism ignores the unique ways in which autistic children develop and learn, or sees this uniqueness as an impairment in itself. Moreover, this view also ignores the role of environmental and social factors in causing disablement for autistic people. Therapies and supports developed under medical models aim to eliminate differences between autistic and neurotypical children (i.e., children with no developmental disabilities) so that autistic children function more like neurotypical children. Similarly, changes to the environment are made with the goal of making the autistic child act like neurotypical children. This can look like training caregivers to interact with their child in a way that promotes skills that are regarded as typical for non-autistic children, without consideration of autistic preferences, needs, or developmental trajectories.

Beyond the negative effects that medical models can have on autistic people, they can also negatively affect their families. Society may treat autistic people poorly because there is an understanding that autistic characteristics are "undesirable" or "bad". Autistic people may feel pressure to act "normal" (i.e., like neurotypical people) to hide their differences and impairments.

Caregivers may also feel pressure to make their child act less autistic, which could influence their relationship with their child and their own self-concept as a caregiver.

Placing the blame of an autistic person's challenges on their autistic characteristics paints an incomplete picture of autism and how it manifests. Autistic people have embraced different ways of conceptualizing autism and disability that should be considered by clinical and research communities: social models of disability and neurodiversity.

A potential solution: Social models of disability

Social models of disability position disability as a result of an individual with impairments being in an unaccommodating social or physical environment that was not designed with disabled people in mind. According to the social model, autistic people face challenges because their environment does not support impairments associated with autism. The goal of therapies created under the social model will be to change society and the built environment to remove barriers to participation, and create appropriate accommodations to support autistic people's impairments and better facilitate their unique development and learning.

Terminology Check: Describing Autism

Characteristics of autism: An umbrella term including *all* traits related to autism. These traits can be strengths, challenges, or neutral differences (often depending on the situation and degree of support or acceptance).

Differences: characteristics of autism that are different from assumptions about normative behavior. We will use this term to describe characteristics that may be strengths or have no noticeable or differential impact on autistic people.

Disabling: When the social or physical environment and structures pose barriers to participation for individuals based on their impairments.

Impairments: characteristics of autism that may pose challenges to an autistic person's development, learning, functioning, and/or well-being. Under the social model of disability, impairments may or may not be disabling depending on the social/physical environment. This term is not used as an inherently negative term, as may be suggested by its colloquial usage.

A *purely* social model may not be sufficient to develop adequate ways to support autistic children's development and challenges; there are some conditions that autistic people find to be inherently challenging or distressing regardless of the environment, and that caregivers have difficulty learning how to manage or understand even with support (e.g., common co-occurring conditions such as gastrointestinal distress, seizure disorders, significant sensory sensitivities). But incorporating a social model of disability into autism research encourages us to examine ways that autism characteristics and co-occurring conditions can be accepted and supported. It also encourages us to investigate the way that social, cultural, and other contexts influence the success and happiness of autistic people.

Integrated Models of Disability: Neurodiversity

There are many frameworks for disability that integrate components of the social and medical models of disability to provide well-rounded support for people with disabilities. This includes models like the biopsychosocial model of disability, the World Health Organization's International Classification of Functioning, Disability, and Health (ICF)⁶, and—of particular relevance to autism research—**Neurodiversity** (described below). According to these models of disability, people with a condition experience challenges based on the interaction between their condition and contextual factors (e.g., environmental and personal factors), but there are some impairments or conditions that are still disabling regardless of the context. We will focus on neurodiversity given its relevance to autism, but it is notable that such conceptualizations of disability are commonplace across health and disability domains.

Neurodiversity is a framework spanning multiple disciplines that is discussed and developed in the autism, autistic, therapeutic, and research communities (and across other health, education, and disability communities). Specific definitions vary between scholars and community members,^{7,8} but in general, neurodiversity frameworks describe neurodevelopmental disabilities like autism as part of the natural variability in the ways that people think, learn, feel, and function. It puts a *neutral value* on characteristics associated with autism and other neurodevelopmental disabilities. Some characteristics may be strengths, and some may impair functioning, but even impairments should not be treated with shame or stigma. Everyone has strengths and challenges and should be treated with respect. And importantly, neurodiversity extends to *everyone*, regardless of their unique impairments, extent of supports, co-occurring disabilities, or methods of communication (see “Common Criticisms of Neurodiversity” below for more information). There are a variety of perspectives about neurodiversity within this area of scholarship and community conversation; we recommend you read the additional resources provided below, and continue to educate yourself about this framework as it evolves to inform future research.

*Note: Neurodiversity refers to a framework developed in community and scholarly circles. This is different than the **neurodiversity movement**, which is an advocacy movement related to the disability rights movement that is built upon the scholarship of neurodiversity. Broadly, proponents of the neurodiversity movement advocate for increased understanding of neurodiversity and use of neurodiversity-aligned approaches, and for the rights of neurodivergent people.*

Neurodiversity-aligned approaches to autism can combat ableism by reducing stigma attached to autistic characteristics and by encouraging the full inclusion of characteristics from diverse neurotypes. These approaches suggest removing barriers to participation for autistic people, and when these contextual changes are not sufficient, suggest utilizing methods to support remaining impairments to increase the health, safety, and quality of life of autistic people. Crucially, autistic people guide the conversation about characteristics that they see as strengths, neutral, or impairments, and the environmental factors they see as barriers to their quality of life and participation in desired activities. Some autistic people may find that these conceptualizations of autism and approaches to developing supports reflect their experiences while treating them as a well-rounded person worthy of respect, allowing for individualization and nuance in describing autistic experiences.

Common Criticisms of Neurodiversity

Critics of neurodiversity (both the framework and the movement) often believe that neurodiversity paints all characteristics as strengths and denies people's challenges, and therefore view the framework as being unhelpful or exclusionary to people with higher support needs. However, as described above, neurodiversity views characteristics *neutrally*; it proposes to unpack the ways in which society creates or exacerbates challenges that people face. And, even for individuals with impairments that are not currently well-supported, we must continue developing supports that do not focus on "normative functioning" as the end goal of therapy.

Therefore, for impairments that do not yet have an apparent social or environmental change that is effective in supporting those impairments, we should expand our ideas of what participation and functioning can look like, and support people to reach those goals without reinforcing a standard ideal outcome. In this way, neurodiversity-aligned therapies are not "only relevant to some people," as critics may argue. Instead, more work is required to ensure that neurodiversity-aligned supports are effective for a wider range of people.

For example, the advent of current Augmentative and Alternative Communication (AAC) methods have facilitated robust communication for numerous autistic people without requiring them to use speech, therefore reducing barriers to communication for some people whose impairments make speech (the assumed "norm" for communication) challenging. But there are many people for whom current AAC approaches are not yet effective. Neurodiversity-aligned approaches are still relevant to these individuals; such approaches will investigate new or adapted forms of AAC that will support communication without focusing on access to speech as the ultimate goal of therapy.

Some critics also believe that neurodiversity asserts that there is no place for medically-based interventions. This is also untrue; however, the place for medically-based intervention is more limited in Neurodiversity frameworks than under the medical model. Many proponents of neurodiversity frameworks view medical interventions as primarily being helpful to support characteristics associated with chronic or co-occurring disabilities such as seizure disorders or gastrointestinal disorders. Understanding and developing genetic or biologically-based interventions for things like social communication impairments would not be supported under Neurodiversity frameworks (e.g., oxytocin nasal sprays for social skills); they should not be used to enforce a standard, normative way of being.

See Table 1 below for a comparison of autism across medical models, social models, and neurodiversity frameworks.

Table 1. Comparing Medical Models, Social Models, and Neurodiversity

Here, we compare definitions of autism across medical models, social models, and neurodiversity. We will use the most “extreme” definitions of these models to better highlight differences, but it is important to note that these concepts change over time. In particular, newer social models of disability view autism in an increasingly similar way as neurodiversity frameworks.

	Medical Model	Social Model	Neurodiversity
What is autism?	Autism is a disorder, and all autism characteristics are deficits that inherently cause challenges for autistic people regardless of the context.	Autism characteristics may be neutral differences, strengths, or impairments that may be disabling in an unaccommodating environment.	Autism characteristics may be neutral differences, strengths, or impairments that may be disabling in an unaccommodating environment. Some impairments may remain disabling regardless of the context.
<i>EXAMPLE: An autistic child engages in self-stimulatory behavior, "flapping" (e.g., waving their arms up and down), to regulate their sensory needs.</i>			
What is flapping?	Flapping is a problematic behavior that non-autistic children do not do with the same frequency or intensity (if at all), and it may even inhibit autistic children’s learning and development	Flapping is a behavior that helps the child regulate their sensory needs and express emotions. Heightened sensory sensitivities are an impairment.	Flapping is a behavior that helps the child regulate their sensory needs and express emotions. Heightened sensory sensitivities are an impairment.
What supports are needed?	Therapies or strategies to stop the child from flapping, perhaps regardless of their underlying self-regulation needs.	Increase social understanding of flapping to reduce stigma while allowing the child to self-regulate with flapping. If flapping results from a need to regulate a negative sensory experience, consider ways to reduce these dysregulating environments.	Increase social understanding of flapping to reduce stigma while allowing the child to self-regulate with flapping. If flapping results from a need to regulate a negative sensory experience, consider ways to reduce these dysregulating environments. If flapping and environmental changes are insufficient in helping a child regulate their sensory needs, consider supports to support the underlying sensory sensitivity.

We encourage you to critically examine the models of disability that influence your own beliefs about autism, and how these beliefs in turn influence how you frame and position your work. Here are just a few ways to begin incorporating neurodiversity and social models of disability into your research:

1. Learn more about characteristics that autistic people and caregivers find to be challenging, and how they think the social/physical environment contributes to these challenges, without making assumptions about their experiences. This may require a variety of methods. For example: some autistic children and adults may require capacity-building around self-advocacy to accurately and comfortably report about their experiences; researchers may also consider using a variety of survey or observational techniques for those with interoception challenges.
2. Investigate ways in which impairments that are thought to inhibit development along neurotypical trajectories may not be disabling in the right environment, and may even support development outside of neurotypical developmental norms.
3. Consider ways to support autistic children without centering neurotypical standards. This can look like building on autistic children's strengths and supporting them in ways that are natural for them, rather than comparing them to 'typically developing' children.
4. Consider how changing the physical and social environment (e.g., caregiver understanding, communication style and expectations) can contribute to learning, well-being, and relationship-building. Consider what your role in this change could look like (e.g., educating your research team and collaborators, educating caregivers, etc.).

Problem 2: Research reflects and perpetuates racism, sexism, and other forms of bias due to the exclusion of marginalized communities and identities from the research process

Autism researchers have excluded autistic people and families of many populations from the research process, including:

- Black, Brown, and Indigenous people, and other people of color⁹
- Girls, women, non-binary and transgender people⁵
- Autistic people with co-occurring medical conditions and intellectual disabilities¹⁰
- Poor and working-class families
- Single parent families and other under-represented family structures
- Multilingual families and speakers of languages other than English
- People from the global south
- Autistic adults, especially older autistic adults

It is critical to acknowledge that no community is a monolith; there will be great variability in norms, preferences, and values within members of a community. Furthermore, a family's norms, preferences, and values are informed by a wide range of factors (e.g., culture, language use, social-cultural context, disability, geographic location, socioeconomic status, knowledge about development). Intentionally considering the influence of these facets of identity on development and caregiving preferences (rather than making assumptions based on any single factor or group of factors) is critical to designing and disseminating equitable EI autism therapies. Another critical consideration is intersectionality within the communities we engage with and how different dimensions of a person's or a community's identity may have been oppressed or excluded.

Many people may believe that autistic people are usually white, monolingual, middle/upper class boys because research has historically centered the experiences of these autistic people and their families. Our current understanding of autism is based on the experiences and preferences of those centered in autism research, which limits understanding of diverse presentations of autism and how best to support autistic people across different social-cultural contexts. But developmental characteristics and trajectories are influenced by cultural norms, caregiving practices, and the social-cultural context in which a child is raised. This means that autism characteristics may differ for different children, and that “ideal” supports may also vary to fit each family's needs and caregiving styles.

The exclusion of autistic children and families from the aforementioned communities has contributed to problems in Early Intervention care for autistic children and families, such as:

- Delayed autism diagnosis or misdiagnosis for children of color, girls, children with some co-occurring conditions (e.g., ADHD¹¹), or children who do not meet the “traditional” profile that is centered in autism research. For example, even the way clinicians define “stimming” or repetitive movements often overlooks repetitive movements such as repeated fidgeting with jewelry (which may be more common in autistic girls and women)
- Incompatibility of some therapy strategies for caregiving preferences across cultures (e.g., for Latine families^{12,13})
- Encouraging caregivers who are bilingual or who speak minority languages to only speak in English with their child,^{14,15} and a dearth of information about ways to support language development for bilingual autistic children due to their exclusion from research
- Lack of knowledge and access to information about autism in Latine¹⁶ and Black¹⁷ communities, and immigrant communities.¹⁸
- Experiences of racism with their child's EI service providers or team for Black families¹⁹
- Reduced therapy hours and increased unmet needs for families with limited English proficiency²⁰
- Lack of options for sliding scale or affordable therapies, cost of diagnosis
- Logistical challenges scheduling or accessing appointments that may be more challenging for families who are working multiple jobs or less flexible jobs to navigate (which disproportionately impacts working class families)

- Deficit-oriented views of language input provided to children from families that are bilingual, of low socioeconomic status, and/or are from marginalized cultural backgrounds, which may perpetuate stigmatizing beliefs about these communities (e.g., research and policy initiatives about the “word/language gap,”²¹ disparities in inclusion for “quality of language”²² research)

In summary, diagnostic processes and therapy approaches may be ineffective, inappropriate, or irrelevant for many children and families due to their exclusion from the research process (as participants and as researchers). This creates and further exacerbates inequities in access to services for many people from these underserved and excluded groups. Furthermore, we apply assumptions about those who have been centered in autism research to *all* autistic people; in addition to impacting those from minoritized communities, this may even have negative consequences on people from dominant cultural groups who do not fit these narrow profiles of autism. There are many assumptions underlying commonly researched approaches to therapies that are inappropriate for many families (see Table 2 below for some common examples).

Common Therapeutic Approach or Research Method	Assumptions underlying the approach/method	Potential incompatibilities*
Caregiver-implemented interventions	<ul style="list-style-type: none"> • There is a single primary caregiver who is available and wants to learn strategies to teach their child new skills 	<ul style="list-style-type: none"> • Families with multiple “primary” caregivers • Caregivers who are not available to learn or attend sessions • Caregivers who do not view themselves as their child’s “teacher”
Child-led interactions	<ul style="list-style-type: none"> • Encouraging adults to follow the child’s lead in interactions supports the child’s independence • The parent will generally be able to follow the child’s approach 	<ul style="list-style-type: none"> • Cultural or familial preferences for child cooperation or interdependence • Conflicting access needs (e.g. child wants to bang on a toy drum together and parent has noise sensitivity)
Communication temptations/wait time	<ul style="list-style-type: none"> • Encourages the use of spontaneous language from the child 	<ul style="list-style-type: none"> • Cultural or familial preferences to avoid frustrating the child
<p>There is great variability within cultural groups, and the context of autism/disability also influences caregiving practices and preferences. Researchers and clinicians must avoid making assumptions about the fit of a therapeutic approach for a family based on their cultural background alone. Community engagement can lead to productive conversations about the compatibility of current and adapted approaches on the nuanced caregiving preferences of unique families.</p>		

Improving Equity through Increased Inclusion

Engaging community members from historically excluded groups can help research become more relevant and useful for these members of the autism and autistic communities. Participatory research approaches center these community members and put them in positions of authority over the design and implementation of services and supports. Engaging with diverse community members about their preferences can also lead to the development of new approaches *and* adaptations of existing approaches that better address the nuances in caregiving practices across cultures. This may also allow researchers to fully examine the underlying mechanisms of differences in caregiving practices and preferences, rather than simply painting people from a demographic group to have certain preferences due to their identity. This will ensure that these approaches avoid stereotyping; that they account for diverse caregiving practices; that they support diverse developmental competencies and outcomes; and that they are compatible with diverse family structures, relationships, and cultural orientations. Elevating Researchers of Color and dismantling structural barriers preventing them from joining the field is also critical to making research more reflective of the wide-ranging experiences of the autism and autistic communities.

However, *solely* increasing the inclusion of individuals from excluded and underserved communities in the research process is insufficient for improving equity in Early Intervention autism therapies. Using methods and frameworks that embed an equity lens is critical to designing equitable research and clinical innovations.

Using Health Equity and Culturally-Informed Frameworks of Development

Autism researchers should utilize health equity and culturally-informed frameworks of development to encourage the design of EI autism therapies and supports that are intentionally inclusive from early stages, rather than relying on cultural adaptations that are completed after the “standard” therapy has been tested. Such frameworks will help researchers understand and examine the structural, social, cultural, and individual determinants that influence the success of different therapeutic approaches for unique children and families. Integrating such frameworks may also reduce *tokenization* by encouraging a thorough examination of social-cultural determinants and experiences, and not solely relying on the experiences of individual team members to “check” the appropriateness and relevance of various approaches. Below, we briefly describe a few such frameworks that might be helpful in guiding this work.

Additive- and strengths-based cultural research approaches

Autism research (and research from other fields that inform EI autism research and therapies) often approach minoritized cultures through a deficit-oriented lens. In other words, individuals from minoritized families are often inherently viewed as being different than a “standard,” which can have negative effects such as 1) othering children and families from minoritized communities; 2) viewing common preferences and practices as being inherently lower quality or different than “ideal” practices; and 3) creating division within the autism and autistic communities. Therapies based on deficit-oriented research frameworks will aim to change the

behavior of children and caregivers from minoritized cultures to meet the “ideal standard,” which can result in teaching caregivers or children to do things that are not compatible with their preferences or social-cultural context. For example, therapists have asked bilingual families to only speak English to their autistic child, as English was considered the language of instruction and being exposed to multiple languages could “confuse” autistic children. However, this advice was rooted in monolingual, English-speaking bias and not empirical evidence, and did not consider that many bilingual families find it more comfortable and intimate to speak their heritage languages at home.

Alternatively, **strengths-based approaches** to cultural research²³ seek to understand the value of various cultural practices in facilitating child development. Rather than simply seeking to increase the use of “standard” behaviors by caregivers and children, strengths-based approaches will look for ways to build on the existing practices in different communities (“additive approaches”). Strengths-based approaches to research will examine the successful practices and routines used by families from minoritized communities and support development in those contexts. These approaches will also examine and dismantle structural barriers that influence the use of different practices, rather than place the blame on individual families for not implementing “ideal” standard practices. This strengths-based, additive approach plays a key role in many culturally-informed frameworks for child development.

NOTE: *Some researchers have used “strengths-based” approaches to mean using a community’s strengths or unique characteristics to help them attain a “standard” ideal. This is not what we mean by strengths-based. These approaches should re-conceptualize what “ideal care” and “ideal outcomes” mean based on characteristics and social-cultural contexts for unique communities.*

Example of strengths-based approaches: Toy Play and Adult-Child Interactions

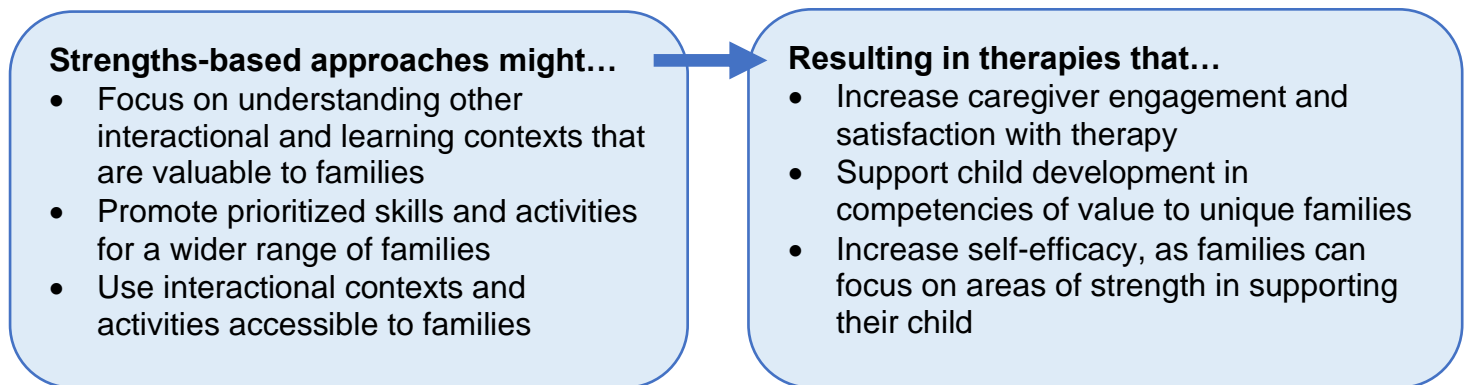
Independent symbolic toy play is seen as a critical marker for communication and cognitive development in autistic children, and therefore many EI autism therapies will focus on teaching autistic children to play with toys in specific ways within an adult-child interaction (and measure developmental skills in this context). But some cultures value other types of play and interactional contexts, and some families do not have access to the types of toys that are valued in therapy contexts the types of toys that are valued in therapy contexts.

Deficit-based approaches might...

- Implement toy-based therapies with all populations
- View a lack of toys as an inherent impediment to a child’s development
- Promote toy play according to “ideal” play trajectories
- Encourage all caregivers to engage in toy play with their child

Resulting in therapies that...

- Enforce activities and skills that are not priorities for some families
- Ignore the value of other types of interactional contexts
- Neglect to support skill-development that families value
- Make some families feel guilty for not having access to “ideal activities” for their child



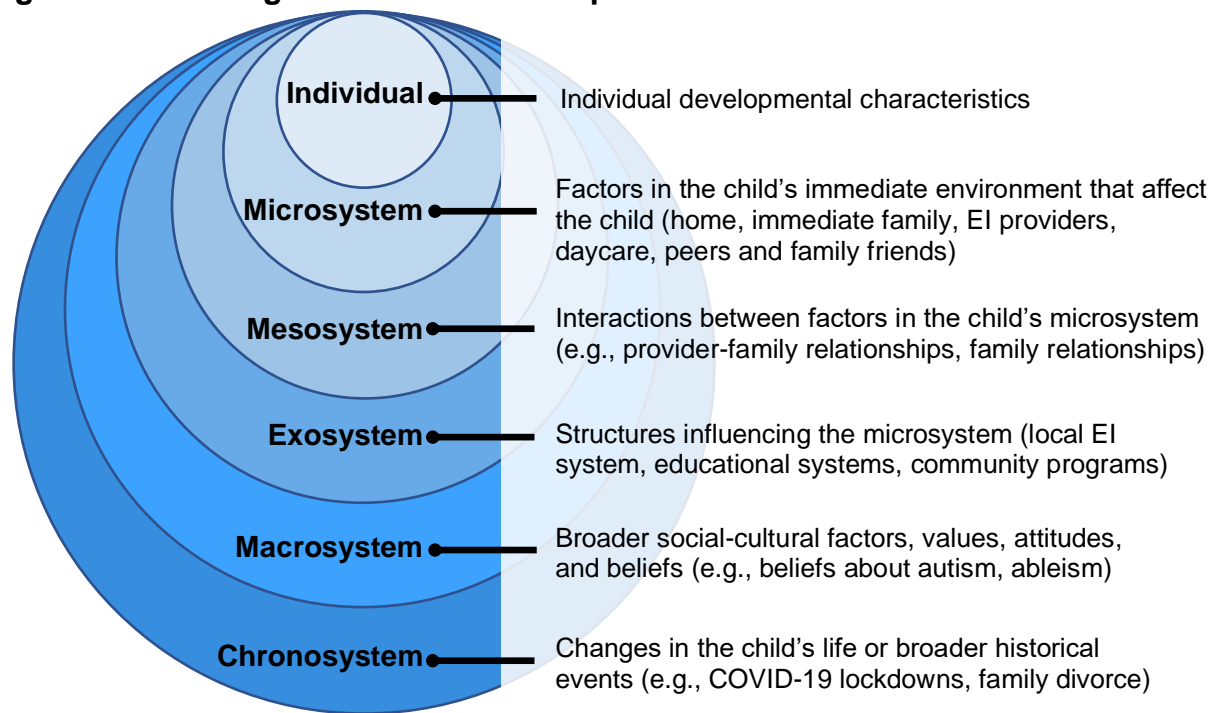
Importantly, additive and strengths-based approaches will benefit all autistic children and families, not only those from historically excluded and minoritized communities. As stated previously, no community is a monolith, and preferences and priorities will vary between members of a community. Expanding “ideal” practices for supporting young autistic children to be inclusive of a wide range of preferences and experiences will increase therapeutic options to the benefit of the entire autism/autistic community.

In addition to this overall approach to research with children and families from excluded and minoritized communities, we recommend that you utilize culturally-informed frameworks of child development. We will describe a couple of such frameworks below.

Bioecological model of development

The bioecological model of development posits that development results from interactions between a child and various contextual factors situated at different “levels” in their environment (see Figure 1).²⁴ Some models used in EI research focus on the important relationship between caregivers and children in shaping a child’s development (e.g., transactional theories of development,²⁵ social-interactionist theories of development²⁶), but the bioecological model incorporates factors outside of this immediate relationship. In summary, it posits that development results from a complex system of relationships in the environment surrounding a child, from the immediate family and local community, to educational/healthcare systems, and to the political environment and even time as factors that influence development. These factors have relationships with each other as well as with the child. This model may help you evaluate the contextual factors that facilitate or hinder the success of different therapy approaches, and may help you situate EI experiences in their lifespan context. Thorough evaluation of these factors may also help you and your community partners understand each other’s perspectives and experiences.

Figure 1. Bioecological Model of Development¹⁹



Extension of the bioecological model: Integrative Model of Child Development

Since the development of Bronfenbrenner's bioecological model, others have extended this work to integrate further dimensions. García-Coll and colleagues²⁷ developed an integrative model of child development for children in minoritized communities. This model explores how factors such as racism, discrimination, oppression, and segregation interact with a family's unique cultural background and traditions to influence developmental competencies, the nature of development-enhancing activities and opportunities, and functioning within the dominant social-cultural context. As with the strengths-based/additive approaches explained earlier, this model does not simply seek to identify areas of "disadvantage" compared to those in the dominant culture. It aims to identify unique factors and processes that stand apart from those in the dominant culture—whether due to the cultural heritage of families, access to resources, or the emergence of different beliefs and practices resulting from an incompatibility of their background with that of the dominant culture. Identifying such factors and processes (e.g., "promoting environments" and "adaptive culture") may be a powerful way to create therapies and supports that address the specific needs, experiences, and practices of families in minoritized communities

Cultural Frameworks of Development and the Context of Disability

It is important to note that many popular culturally-informed developmental frameworks do not specifically address the context of disability or ableism, but the contextual factors included in these frameworks may also shape the way individuals view disability and the characteristics of

autism. For example, there is evidence to suggest that caregivers' experiences with ableism and autism-related discrimination and stigma are related to their mental health²⁸; one study even found that such discrimination influenced parents' depression and parenting behaviors, which had a downstream impact on their autistic child's internalizing and externalizing behaviors.²⁹ Here, we see how experiences of disability-related discrimination may also play a role in shaping the child's development.

It is also possible that cultural conventions and expectations may influence the extent to which autism characteristics and impairments are disabling. That is, social conventions are greatly shaped by culture, making it possible that some characteristics of autism are more or less compatible with current neurotypical conventions in different cultural contexts. In other words, to connect this with social models of disability, there may be some social-cultural environments that are already inclusive of some characteristics of autism while others may not be.

Social-cultural context and factors such as racism and discrimination can also influence caregivers' priorities for their child's EI therapies, as would be posited by models such as the integrative model of child development. For example, children of color may face racism and discrimination in community settings among (or influenced by) people in the dominant culture, which could be exacerbated by ableism. Thus, a caregiver may wish to reduce some self-regulatory behaviors for their child (e.g., self-talk, stimming) to try to "remove" the outward appearance of disability, thus helping their child remain safe in the community. Understanding the contextual factors influencing child development and well-being (and their intersections) can help to develop supports that facilitate autistic children's inclusion and well-being at multiple levels (e.g., individual-level supports, family-level supports, community supports, social-cultural advocacy and change).

Equitable, anti-racist approaches to community engagement

It is vital that you use methods within your community-engaged projects to reduce the impact of racism, classism, and other historical problems in autism research. This will ensure that community partners feel comfortable contributing to the research process, and that the research has a real, positive impact on them and their community. Many researchers have used harmful, insincere, and nonreciprocal methods to study underserved communities in the past. Much of this research has also been conducted through a deficit-oriented lens. This has contributed to distrust of researchers and research institutions, and to severe imbalances of power in community-based research.

While the increased presence of researchers who are themselves autistic or from other underserved communities has greatly benefitted the field, even researchers who are part of the community they are studying have a position of power relative to their community partners and research participants. Additionally, they may be viewed as representing a larger organization or university that has harmed the community in the past. Regardless of your own personal identity, examining your motivations for partnering with these communities and reflecting on whether there is actually alignment between your research goals and the goals of these communities is critical before embarking upon research with communities that have often been mistreated by researchers and research institutions.

Throughout this document, we will describe specific strategies you should use to create an inclusive project. However, you must first understand these problems; reflect on how they're represented in your beliefs, studies, lab structure, workflow, and other logistics; and then take steps to change your systems to ensure you can collaborate comfortably and effectively with all community partners.

Ableism and exclusion: Connections to Comparative Effectiveness Research

Comparative effectiveness research can be used not only to find new ways of support, but to explore harms and benefits of traditional approaches compared to newer or adapted approaches that better account for these historical problems in autism research. Fully embedding anti-ableist, anti-racist, and anti-classist approaches will require a radical shift in therapeutic approaches; the robust development and testing of such approaches is a vital first step towards achieving more equitable and inclusive therapies of autistic children in EI. You should engage with community members to develop new approaches and adapt existing approaches to be more inclusive. Furthermore, this work must occur with autistic people in leadership positions to guide research agendas affecting autistic people. As a researcher (neurotypical or neurodivergent), you bring important knowledge about research methodologies, but credit and authority must be given to the autistic people at the forefront of innovating these new therapeutic approaches.

As this body of work develops, the use of comparative effectiveness research will enhance caregivers' ability to make decisions for their child's care. Such studies comparing traditional and emerging approaches on outcomes that are valuable to the community will provide families with the information they need to make decisions for their child, with their child's long-term outcomes in mind. For example, many caregivers have reported that they will "set aside their culture" to use approaches that they're told will best help their child¹³. Developing culturally-additive and neurodiversity-aligned approaches, or adapting existing approaches to fully embed these principles, will allow caregivers to understand the impact of these approaches on a wider range of outcomes when compared with the therapies and outcomes historically prioritized by research and clinical settings. This may also provide empirical evidence that individuals will be more likely to benefit from approaches that are culturally additive. This in turn will further motivate researchers and clinicians to develop and implement culturally responsive practices. This may alleviate guilt, shame, or pressure to conform that families from minoritized communities may currently experience. This may also facilitate the inclusion of individual autistic people in their local community and cultural context.

Finally, many community members oppose current therapeutic approaches due to the discriminatory or negative impact they have on their lives and their child. In addition, there are many commonly recommended, standard practices that have a dearth of empirical evidence to support their widespread use.⁵ Comparative effectiveness research studies provide a way for researchers to challenge the status quo and fully explore the potential effectiveness and harms of these approaches, especially as they compare to approaches preferred by the community.

Additional Reading

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Racial and ethnic equity and inclusion in autism and early childhood research:

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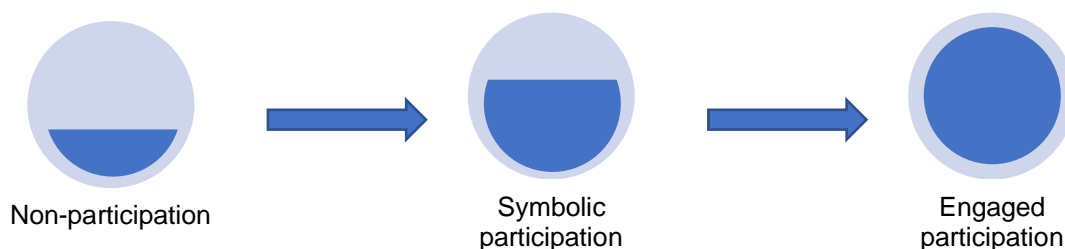
Levels and Principles of Community Engagement

Community-engagement is a critical way to combat the problems that are commonly perpetuated by autism research. Community members have valuable expertise and knowledge about autism, social-cultural contexts, and how the environment can be supportive or disabling for specific characteristics or impairments. In this section, we will describe some fundamental concepts of community engagement to help you determine the engagement approaches you may want to use in your research.

Levels of Engagement

The extent to which you engage with community members may vary based on your goals, resources, timeline, flexibility, and more. You may even choose to engage with different community partners at different levels throughout your project. The “level of engagement” should also guide how you plan activities, integrate feedback, and compensate community partners.

There are many frameworks describing different continuums or levels of engagement (see “References and Additional Resources”). Here, we describe a 3-level continuum of engagement created by Goodman and Thompson (2017):



Non-Participation: Researchers learn how to reach community members and educate them about research topics.

- This level of engagement usually refers to outreach and education opportunities. It is often used for recruitment and dissemination-related efforts. However, there is little to no reciprocity between the community and the research team; the community is not involved in creating research at this stage. If there is a member from the community on the research team (e.g., an autistic researcher who helps to plan an outreach event), it may still be non-participation if there is no reciprocity between the research team and the community members they hope to reach with the event.
- Such non-participatory engagement might be used to establish initial relationships with various community members or organizations. They should be centered around the needs of the community, as established by that community.
- Examples of community-engaged non-participation methods might include:

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- Giving lectures and presentations about topics relevant to the community, such as early autism identification to Early Intervention providers or resources about understanding sensory needs for caregivers and/or autistic adults
- Providing free developmental screenings at a daycare or community health organization
- Providing sensory friendly events or spaces to the community
- Hosting discussion-based events on relevant topics to the community
- Some researchers may attempt to use non-participatory engagement inappropriately to solely benefit the researchers. For example:
 - Holding an outreach event that does not meet the community's needs, just to benefit recruitment for a research study
 - Suggesting a collaboration with a community center or group, but not asking about or following through with collaborations that could benefit the center/group and exclusively using the collaboration to recruit research participants or obtain support.

Symbolic Participation: Researchers ask community members for feedback and help with their research studies.

- At this level, you may consult with community members to understand their perspectives on a topic, but community members are not heavily involved in conceptualization, design, final decision-making, or carrying out the study.
- This level of engagement is typically more appropriate for short-term participation. This might be a helpful form of engagement for research teams with limited resources, community members with limited time, or for projects that are already underway where there is little flexibility in changing your methods. You can use this approach to make your research more relevant to the community's needs and preferences.
- Examples of symbolic participation might include:
 - Inviting caregivers of autistic children to share their concerns or challenges, and using this information to determine your study outcomes (rather than relying on previous research alone)
 - Asking a local community health organization about their methods of outreach to help you design recruitment strategies for groups you are having trouble reaching
 - Seeking community insight about the results of your research study to aid in data interpretation and analysis
- Some researchers might also use symbolic participation inappropriately. For example:
 - Gathering feedback from community members as a gesture without taking it into consideration or implementing their suggestions
 - Declining further follow-up with members of a focus group, even if they express interest in seeing if and how their feedback is incorporated or providing further support for the research process
 - Asking community members to collaborate in the research project at a very late stage, where only very limited or superficial changes can be made
 - Pressuring an autistic co-author to disclose that they are autistic in publications or letters of submission, prioritizing the appearance of community-engaged research over the comfort and privacy of the autistic researcher

Engaged Participation: Researchers and community members work together to co-create research focused on community preferences.

- At this level, community members have input on all aspects of the research process, their ideas take priority, and they often have decision-making authority. As a researcher, your role is often to use your scientific and methodological knowledge to guide, facilitate, and collaborate with community members to implement their ideas rather than simply viewing them as suggestions or input.
- This level of engagement requires a lot of time, resources, and ongoing partnerships. It puts community members in leadership positions and empowers them to guide the future of autism research, supports, services, and knowledge-production.
- Community members will collaborate with the research team throughout the entire stage of the research process, from conceptualization to dissemination of study results.
- Examples of engaged participation include:
 - Community-based participatory research or participatory action research projects in which autistic people are engaged at all components of the research process as co-leads and trusted as experts.
- A comparative effectiveness research study in which an advisory board of community members are involved in conceptualizing the study (e.g., choosing therapies and outcomes of interests), planning the study, conducting the study, interpreting the results, and writing manuscripts for publication. The advisory board has decision-making authority and they are appropriately educated about research methods so they can make informed decisions. They are credited as authors and key contributors to the study

Principles of Engagement

There are many principles that must be integrated throughout every step of your community-engaged project, regardless of the level of engagement. These principles must be continuously centered and revisited to ensure they are being upheld for the entire duration of your community-engaged project and not just at the outset when commitment, motivation, and resolve is strong. Here, we will summarize the principles of engagement created by PCORI. The full version of PCORI's Equity and Inclusion Guiding Engagement Principles can be found in the References and Additional Resources below.

1. **Inclusion:** True inclusion goes beyond having representation from autistic people, their families and communities and the creation and fostering of inclusion is the responsibility of the research team. The project must be structured to seek out the perspectives of all partners, which requires humility from those in positions of authority and power. The goal is to establish a sense of belonging for everyone through a commitment to authentic engagement.
 - a. **Explicit Invitation:** community members should be explicitly invited to participate in your project. This must include outlining expectations, compensation, levels of engagement, etc.
 - b. **Welcoming Environments:** be attentive to what an inclusive environment looks like for your community members. Develop norms and procedures to ensure participation takes into account different identities, preferences, and

communication styles. You may need to individualize your engagement strategies for different community partners to ensure you are welcoming of a diverse range of communication, sensory, and executive functioning preferences.

2. **Equitable Partnerships:**

- a. **Partnership:** research teams value and respect the contributions of all community members equally, honor their community partners' other time commitments, and commit to honoring the diversity in their partnerships. Researchers should also compensate partners for their efforts whenever possible.
- b. **Reciprocal Relationships:** Researchers and community members decide on roles and decision-making together.
- c. **Co-Learning:** Researchers should teach community members about the research process ("capacity-building"), prioritize community participation during the research process, and commit to incorporating community preferences and priorities. This is a continuous and iterative process.

3. **Trust and Trustworthiness:**

- a. **Transparency, honesty, and trust:** researchers are clear, share information, and are open with their partners. They should spend time building trust with their community partners so that partners are comfortable sharing their opinions and asking questions.
- b. **Explicit Definitions:** Trustworthiness is perceived differently by individuals. Explicit conversations are needed to create understanding among researchers and community partners about what trustworthiness means to each individual, how it is being fostered, or how it is being suppressed.
- c. **Respect for Mistrust and Skepticism:** Some community members may naturally be skeptical and distrustful of science and research. This must be respected and validated, and intentional efforts must be made to acknowledge and respect the existence of such mistrust and skepticism and address how this collaboration will be different.
- d. **Trust is a dynamic process:** The burden to demonstrate trustworthiness is on the people with the most power and authority and needs to be continuously nurtured, reviewed, and potentially repaired.

4. **Accountability and Actionability:** researchers should put processes in place to make sure that the research team stays accountable for upholding the principles of engagement. They should continuously make sure that their actions are in line with the principles of engagement, and that they are staying committed to the community partnership.

- a. **Expect regression but work on challenging it:** behaviors and decisions tend to gravitate toward past norms and power dynamics unless the team continuously fights against them.
- b. **An opportunity to model equity and inclusion:** processes of accountability allow members to model behaviors of equity and inclusion beyond just reviewing progress.

Several research-practice partnerships have developed principles and guidelines for community engagement with autistic community members. We encourage you to review each of these resources listed below to learn more from the wide-ranging experiences in these engagement projects.

References and Additional Resources

Guidelines for Engaging with Autistic People, co-created with autistic people

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Community Engagement: Levels and Principles

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Getting into the mindset for community-engaged work: Reflection Questions

Our attitudes about autism, disability, therapies, research, and systems of support are influenced by these biases as well as our own personal experiences and background, in positive and negative ways. Self-reflection is for examining the attitudes, beliefs, and biases that may influence your community-engaged work. This, alongside proactive information-seeking about the gaps in your beliefs and knowledge, will ensure that you treat all community partners (and their ideas) with respect. Here, we provide questions for reflection to ensure you have the appropriate mindset needed to engage with community members in trustworthy, appropriate ways. These questions will help you identify gaps in your knowledge and areas in which you may require additional support and resources to build trust with your community partners.

A note on reflection: There are many barriers that prevent people from fully reflecting on their biases, or taking actions towards ameliorating these biases. Here is a list of considerations that may help you reflect more effectively:

- Unfamiliarity with biases or negative impacts of past actions
- Uncertainty or passivity about ways to respond to discrimination
- Hesitancy or fear of “rocking the boat” and making suggestions to change commonly-accepted practices
- Unconscious or implicit biases
- Redirection of conversations to topics you know more about, preventing you from learning more and engaging with information you’re unfamiliar with
- Defensiveness
- Focusing on intentions over impact (e.g., difficulty accepting that an action caused harm when the intention was positive)

Establishing an inclusive mindset

1. What do I know about ableism, racism, and other common biases that have informed autism research?
 - a. How often do I think critically about the influences of these biases (on individual and systemic levels) on my work?
 - b. How often do I think critically about the influence of my work in perpetuating or combatting these biases?
 - c. Many of us may have a “spiky” knowledge set when it comes to biases. For example, a researcher may have spent significant time thinking about racism but not classism, or vice versa. Even within a given topic, a researcher might have familiarity with culturally-responsive practices related to one under-represented culture, but may not be familiar with how to extend that to a different culture. What types of biases or combinations of biases are you less familiar with? What topics would you most like to learn about?

Reflection Questions

- d. What people or sources of information can I consult to learn more about these biases and systems that influence my work?
2. What models, theories, frameworks, and experiences inform my personal outlook and beliefs about autism (e.g., causes, development, the role of therapies/supports for autistic people)?
 - a. How did I learn about autism?
 - b. How often have I had the chance to learn from the experiences of autistic individuals?
 - c. How often have I experienced an autistic person being in a position of leadership in my life? (E.g. an autistic supervisor, mentor, employer, professor, teacher?)
 - d. How much breadth or diversity of experience has there been in my experiences with autistic people? Consider identity factors such as: socioeconomic status, family structure, communication modality, language background, cultural background, racial identity, gender identity, age, co-occurring disabilities and psychiatric conditions, intellectual disability, other marginalized experiences
 - e. How might ableism inform my beliefs about autism and/or their underlying theories?
 - f. How might my beliefs be shaped by the centering of white, monolingual boys in autism research?
3. How do my beliefs compare to community members' beliefs? Why?
 - a. What do I know about the wide-ranging beliefs about autism and disability by different groups in the autism/autistic communities?
 - b. What sources of information can I consult to learn more about community members' beliefs, preferences, and needs?
 - c. Do I take community members' beliefs as seriously as those of other researchers?
4. What do I consider an "ideal outcome" for an autistic child? What does "quality of life" for autistic individuals mean?
 - a. What do I know about the ways that desired childhood competencies are influenced by factors such as culture, social systems?
 - b. What do I know about autistic people's goals and preferences, and what sources of information inform my knowledge about this topic?
 - c. How are my beliefs about an "ideal outcome" influenced by ableism?
5. What do I think of as an "ideal caregiver," and an ideal caregiver of an autistic child? What informs these beliefs?
 - a. What do I know about caregiving styles across cultures?
 - b. To what extent do my beliefs account for the wide variety in caregiving styles and family structures?
6. What terminology and framing do I use to describe autism?
 - a. How might this terminology/framing influence someone's beliefs about autism (e.g., perpetuate positive, negative, or neutral beliefs)?
7. What sources of information am I exposed to, and which do I trust? How may those sources be influenced by common biases?

Examining the therapies/supports of interest

1. How might my work (or similar work in my field) contribute to ableism and stigma experienced by autistic people, caregivers, and others in the autism community?
2. What theories, models, and frameworks underlie the therapeutic approaches/supports I plan to study?
 - a. How might ableism influence these underlying theories?

Reflection Questions

- b. How might the approach or underlying theory be influenced by racism, ableism, language bias, and other forms of bias?
3. What is the desired long-term goal of this therapeutic approach/support?
 - a. Am I collecting data to inform our understanding of the long-term impacts?
 - b. Do these goals center non-autistic norms, goals, and styles of learning?
4. What outcomes am I hoping to impact directly?
 - a. Are these outcomes important to autistic people and families?
 - b. To what extent do these outcomes center the norms and priorities of white, affluent monolingual and English-speaking families?
5. How might this therapy/approach impact skills in other developmental domains, in positive and negative ways?
 - a. What steps am I taking to examine and measure these possible effects?
6. How might this approach perpetuate stigma for autistic people, caregivers, and those at different intersections of identity?
7. How might this therapy improve autistic people's lives?
8. What do I know about the systems in which my therapy will be implemented?
 - a. What are the constraints of these systems (e.g., limitations on session length and/or frequency, eligibility criteria), and can my approach be adapted to fit these constraints?
 - b. Are there people for whom my approach may be inaccessible?

Establishing goals for your community partnership

1. Why do I want to conduct this research study (e.g., continue my line of work, contribute to understanding of a topic, to support autistic children and/or families)?
2. What skills and experiences do I have that will contribute to the successful conduct of this study?
3. What skills and experiences am I missing?
 - a. Who on my research team can fill in these gaps?
 - b. What kinds of expertise (e.g., specific skills, personal lived experiences) will make the study stronger?
4. Why do I want to do community-engaged work?
 - a. What do I expect to gain from doing community engaged work, and to what extent is this a driver behind my desire to do community engaged work?
5. How much decision-making authority am I willing to share? And on which project components?
6. How will I handle community members' interpretations/opinions that differ from my own, or that may even be controversial to the research community?
7. What sources of information and support can I consult to learn more about community engagement?
8. What consequences might I face for doing community-engaged work (e.g., delayed deadlines, lack of support from the system) from colleagues and community members, and what can I do to ameliorate these concerns?
9. Are there any community groups whose opinions I trust or value more than others (e.g., caregivers VS autistic adults)? How might that influence my community-engaged work?

Section 3: Strategies for Engaging Community Members

This section will describe strategies for planning and conducting community-engaged research projects. In each section, we include additional resources for further reading on specific topics, but please see the “Recommended Resources for Further Learning” at the end of the tool for links to other toolkits which include robust guidance on multiple topics referenced here. As you will see in this guide, there is no single way to do community-engaged research. Reading multiple resources and tools can help you create a plan that is individualized to your specific resources and needs.

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Community-Building and Establishing Trust

Community-engaged research brings together individuals with different talents, perspectives, and mindsets to collectively achieve a common goal. A successful partnership requires a thoughtful process of building trust to create an inclusive, respectful, and productive working relationship for all partners. Community-building is the process of creating that reciprocal, productive, and trusting relationship. It provides the foundation upon which you can build a successful partnership to work towards your shared goals.

Community-building should start before you even have a specific project in mind. As researchers whose work directly impacts autistic people and their families, it is your responsibility to seek relationships with the autistic and autism communities, even outside the context of a specific project or study. As discussed in the previous section, you can reflect on ways you are connected to these communities, and ways you can deepen your understanding of or relationship with the community at large. Additionally, think about organizations in your local setting with whom you may have shared goals, and how your work currently affects them. For example:

- Do you know EI clinicians in your area? How do you interact with them?
- How do you contribute to your local community's understanding of autism, child development, or other topics about which you may have knowledge (e.g., through continuing education training or outreach events)?
- What opportunities do you have to learn from people in the community (e.g., through informal discussions, meet-ups, online forums)?

Before you even begin engaging with community partners on a specific project, consider deepening your ties with these communities. Then, building upon your knowledge from and relationships with community members, you can begin building formal relationships with community organizations and individual community partners with whom you will work on specific projects. You may find that community-engaged research ideas evolve organically through your ongoing and informal relationships, leading to innovative research you could not have developed on your own.

Once you do initiate a formal project, community-building should be part of every step of the process. It starts in the very beginning, when you first reach out to community partners with whom you may want to partner (e.g., in the materials you use to recruit and onboard community partners). It should be embedded in the structure of your engagement activities. For example, how do flyers used for identifying partners frame autism and the value of therapies for different families? Do you demonstrate your commitment to inclusion through the design of accessible activities and accommodations and are you doing so from the outset of your project (rather than asking about accommodations at a later time)? In this section, we will describe ways to ensure your engagement activities are structured to continuously build and maintain trust with partners throughout the course of your project.

Once your partnership officially begins, it is important to create a strong working relationship between all the collaborators on the team including community partners, organizations, and all the members of your research team. Here, we describe suggestions for creating an inclusive and welcoming environment in which people feel comfortable sharing their experiences and contributing their ideas.

Building Capacity for Collaboration, Inclusivity, and Understanding

You may be collaborating with a diverse group of community members for your project. It's important for you *and* your community partners to understand and be responsive to the varying preferences and priorities in the autistic and autism communities.

- Some community partners may not know a lot about autism, neurodiversity, and autistic self-advocacy. This may be especially true for caregivers of autistic toddlers in the EI system, as they may be learning about autism for the first time. Providing some resources or education about these concepts can help these community partners better understand the autistic community partners they will collaborate with.
- Autistic community partners may not know a lot about the Early Intervention or educational systems, or how to navigate these systems, even if they participated in them as a child. Providing some basic information about the systems of interest can also help these community partners understand the perspective and needs of caregivers navigating the systems.
- EI regulations vary by location. You can ask community partners to share more about their personal EI experiences to understand these differences and how that might impact their perspectives about the research you will create together.
- Priorities and parenting practices may differ for individuals between and within cultural groups. Additionally, many people face systemic barriers and bias when navigating different systems of care (and within the community at large). Providing resources about these cultural differences, barriers, and biases can foster understanding when working with a diverse group of community partners.

When do I implement capacity-building for collaboration?

You may start this foundational capacity-building during the recruitment/onboarding process. For example, you can provide videos or resources about topics related to your project (e.g., the Early Intervention system, neurodiversity). You can also present your community partners with a list of “guiding principles” with a basic description of your mindset towards inclusion and information about these topics (See Appendix A for an example). At this stage, you can also ask community partners if there are any guiding principles or topics related to inclusion about which they require more knowledge, and invite them to provide any feedback they have about initial guidelines. You can also include this capacity-building during the process of creating community guidelines as a group, which is discussed below. After creating community guidelines, it will also be helpful to provide more details or “refreshers” about these concepts with the entire group throughout the project.

Informal Community-Building

Unlike research studies in which you maintain a professional distance from your participants, in community-engaged work, your relationship with community partners will also encompass a more personal relationship. As with any working relationship, people have different preferences in how well they want to get to know their collaborators. Thus, in community-engaged projects, you may also want to spend some time getting to know each other as individuals. We recommend doing some “informal” community-building as well where appropriate. For example:

- Sharing information about hobbies and areas of passion/interest
- Sharing motivations for joining the project and/or experiences with the topic of the research study

To respect everyone’s boundaries and preferences around working relationships, these activities may be optional. If discussing these in a meeting (in some sort of “ice breaker” activity), we highly recommend that you provide questions in advance so community partners can prepare answers. It may also be helpful to be explicit about it being acceptable to skip a question. Consider modeling this behavior yourself.

Creating a Strong Working Relationship: Establish Community Guidelines

You and your community partners should develop and agree on community guidelines to ensure the collaboration is effective, comfortable, and respectful. These guidelines should apply to your communication with your partners *and* communication between community partners. Community guidelines should be discussed and agreed upon before formally working on your project, and revisited throughout the collaboration.

Who creates community guidelines?

You may create guidelines yourself, or you may collaboratively create guidelines with your community partners. You may also start with some researcher-created guidelines and work with your partners to adapt them for your specific project and the unique needs of your partners.

Researcher-created community guidelines

Benefits of creating community guidelines yourself include:

- Demonstrates the collaborative nature of your work from the beginning
- Helps you establish your responsibilities to your community partners in a way that is mindful of your resources, preferences, and expertise (e.g., procedures for gathering feedback, personal accountability, how you will mediate disagreements)
- Efficient for short-term community engagement (e.g., focus groups) or one-on-one engagement (rather than engagement with groups of community partners)
- May better reflect your available resources and expertise. For example, if you do not have a staff member who is available as a “neutral party” to review feedback surveys, you will not offer this up in your researcher-created guidelines
- Creating guidelines takes work, and offering a first draft yourself may decrease some of the labor required of community members

Community-Building and Establishing Trust

Limitations of creating community guidelines yourself include:

- These guidelines may not be reflective of the unique needs and preferences of individual community partners
- Reinforces a dynamic in which the researcher has more power over community partners

Collaborative community guidelines

Benefits of creating community guidelines in collaboration with community partners include:

- Presents an opportunity for individual community partners to work collaboratively towards an initial shared goal
- Creates a more balanced power dynamic as partners have ownership over the procedures and conduct of the community-engaged project

Limitations of creating community guidelines in collaboration with community partners may be:

- You have less control over the outcomes of the guidelines. This is useful for balancing power between researchers and the community members, but will require you to be more flexible in how you plan on conducting the project.
 - Strategy to overcome this limitation: Be transparent about your limitations. This way, your community guidelines will fit your actual capacities, and you will not overpromise to your partners.
- Potential for partners to have disagreements from the outset of the project, before they have established initial trust
 - Strategies to overcome this limitation: Anonymous voting on community guidelines so that people don't know who agreed/disagreed about a guideline; researcher-led facilitation of discussions about guidelines for increased control in beginning stages of the partnership; begin with more informal community-building so that partners can get to know each other more and understand their commitment to a shared goal
- Requires more labor from community partners

You may also use a combination of approaches. For example, start with some guidelines you created about principles related to inclusion and your responsibilities to community partners (e.g., Appendix A) and communicate your openness to adapt and change these together with your community partners. Provide some recommendations for additional guidelines you and your partners may want to adopt.

What should your community guidelines address?

Your community guidelines will outline rules for your working relationship and the structural/logistic components of your collaboration. Agreement on these guidelines from the outset of your project builds a strong foundation of trust, camaraderie, and understanding. Not only does this provide structure for your project, but it also helps to mediate any disagreements or conflicts that may arise during the project. Below, we outline some specific topics to address.

It's important to note that preferences for communication and working relationships will vary across your community partners. When you begin creating these guidelines, you may explain concepts such as “equality versus equity” and “competing access needs” (see Structuring Engagement section below) to illustrate that using different methods of participation may contribute to a more meaningful and inclusive collaboration for all partners. This helps community partners understand that they may have different needs and preferences, but all partners' needs are valid and should be respected as much as possible. Your community guidelines can then be created with the understanding that there may not be one single way to uphold some principles, as we will explain below.

Philosophy statement or project goal

One of the foundations of a strong partnership is agreement on your goals and overall philosophy for your project and/or collaboration. When first building connections with community members, you should articulate your research philosophy to potential partners, such as your overall mindset towards supporting autistic people, your overarching goals or developmental domains you plan to address, and your vision for the nature of your collaboration (see “identifying community partners” below for more information about your initial philosophy statement). Then as you begin your community guidelines, you should work as a group to refine and collectively agree upon this guiding philosophy statement with all project partners. You can revisit this philosophy statement throughout your collaboration to ensure your project remains aligned with this mission, and if necessary, you can collectively amend the statement as needed.

If you are collaborating with community members in a less-engaged level (e.g., consultation at a symbolic participation level of engagement), you can specify the goals of the existing project and ensure that all partners understand the limitations around changing the project philosophy based on the stage of the project.

Creating a respectful environment

Respect looks different for each individual. For example, some people value using a formal register of communication in working relationships, whereas others don't care as much about formality or have difficulty navigating or switching between different levels of formality. Discussing these signs of respect, how they may vary, and building understanding around your partners' preferences is an essential foundation for creating community. Sometimes you will not be able to create a community guideline about a discrete action, but instead you will create guidelines about understanding and accepting differences in the ways that people demonstrate respect (or other skills/preferences; see the example at the end of the section).

Creating an inclusive environment

It is essential that you create an inclusive environment for your community partners, which means an environment in which each individual feels safe, respected, accepted, and comfortable sharing their perspectives and learning from others in the group. This environment is created through the language and actions used by you, your team, and your community partners. It is important that **all collaborators** understand the importance of promoting an inclusive, anti-racist, and anti-ableist environment, and that they embrace the diversity of perspectives that result from such a collaboration. Below we list some topics to cover in

community guidelines and community-building efforts to create an environment inclusive of a wide range of identities, and we also include some recommendations about ways to structure your project to facilitate an inclusive project. Please see the additional resources for more information about these important and complex topics.

Promoting a racially and culturally inclusive environment

- Allow people to share information about their culture and preferences, if they would like.
- Share information about things such as: common stereotypes and biases related to racism and discrimination in autism research, microaggressions to avoid
- Example Resources:
 - https://academicaffairs.ucsc.edu/events/documents/Microaggressions_Examples_Arial_2014_11_12.pdf
 - <https://sph.umn.edu/site/docs/hewg/microaggressions.pdf>

Promoting an environment inclusive of transgender, non-binary, and gender non-confirming people, and people of other diverse gender identities

- Gender identity and autistic identity [may be intertwined](#) for some autistic people, and more generally autistic individuals are significantly more likely to be transgender. Even if your study is not directly related to gender identity, it is important to be inclusive of these experiences. Strategies for promoting a gender inclusive environment may include things such as familiarizing yourself/partners with information about preferred pronouns, meeting structures to accommodate voice- or appearance-related dysphoria, and more.
- Example resources:
 - Pronoun Guide: <https://www.glsen.org/activity/pronouns-guide-glsen>
 - Tips for allies: <https://glaad.org/transgender/allies>

Promoting the inclusion of disabled people

- Educate yourself and community partners about language that may be harmful to people with physical, mental, and developmental disabilities or medical disorders. Allow individual community partners to share terminology preferences to use or avoid as well.
- Educate yourself and community partners about microaggressions and common stereotypes about disabled people, autistic and neurodivergent people, and other relevant populations.
- Discuss topics such as sensory processing, executive functioning, and other characteristics around which you may create modifications or alternate participation options (see “Structuring Engagement” section below for more information)
- Example Resources (also discussed in the next section):
 - Infographic: [How to Make Meetings Accessible for Everyone](#)
 - Autistic Self-Advocacy Network: [Accessibility Resources](#)

Promoting inclusion of diverse family structures and socioeconomic status

- Avoid assumptions about individuals’ access to resources, responsibilities, and caregiving priorities and roles.

Communication styles and preferences

Communication styles and preferences will likely vary between community partners, especially if partnering with autistic and non-autistic community members. You should work with community partners to create community guidelines related to communication preferences that should be upheld by the entire group. It may be difficult to accommodate *all* preferences at all times, but building understanding of different preferences can maintain trust between partners when their preferences are not being followed. Please see the section below for more information about different communication strategies and styles you may need to accommodate in your community partnerships.

Additional Topics for Community Guidelines

There are a number of other topics about which you should create community guidelines and processes. Below is a list of additional important topics, but see the additional resources for more ideas about strategies to integrate these ideas into your guidelines.

Protecting each other's privacy: Although there may not be the same regulations around privacy amongst community partners as there are with research participants, it is important to respect individual's preferences around their personal information. For example, some may feel comfortable disclosing their neurotype between partners in a project, but do not want this information shared publicly. You may also discuss sensitive topics and personal experiences during engagement activities that partners do not want to be shared outside of a partnership. It can also be helpful to discuss ways that members can indicate when they are sharing something that they would like to be kept confidential, and reinforce the value on personal choices around privacy by modeling these behaviors and asking about privacy during the collaboration. Guidelines related to how information will be shared formally (e.g., publication of quotes tied to names; disclosure of neurotype, medical conditions, or other information in public-facing activities) and informally (e.g., between partners in engagement activities) is crucial for ensuring everyone is comfortable sharing their honest experiences and perspectives.

Gathering and integrating feedback: As we will discuss below, it is vital that you gather and integrate feedback from your partners to ensure your engagement activities are successful. Creating guidelines about this process will help to set expectations and make partners feel comfortable giving critiques.

Mediating disagreements: There will likely be times when partners disagree with each other about a decision or topic related to the project, or express perspectives that violate the principles of inclusion reviewed above. Outlining procedures related to disagreements and mediation will set expectations and help keep you and your team accountable for mediating disagreements in a way that is fair to all partners.

Decision-making and Leadership Structure: You should outline the ways in which decisions will be made, including information about who makes decisions (e.g., researchers and/or community partners) and how decisions are made (e.g., consensus or "majority rules," specific processes for voting and decision-making). Establishing these processes early on will also help with mediating disagreements and conflicts.

Accountability for upholding responsibilities (to the project, to each other): You may outline policies for how you will be accountable to your partners, and how your partners need to be accountable to the project and to each other. In addition to setting expectations around accountability, this will also facilitate an unbiased process when there are lapses in accountability by you or your partners.

Example: Your group wants to create a community guideline about paying attention to others when they contribute to the discussion.

“Active listening” is commonly used to describe a way of demonstrating engagement when another person is communicating. It includes behaviors like positioning the body towards the person communicating, looking at them, nodding, smiling, and using other facial expressions, and not speaking or interrupting when another person is communicating. But “active listening” alone is not inclusive of diverse communication conventions.

For example, autistic and neurodivergent people may have different or more neutral facial expressions when listening, and they may find that monitoring their facial expression and eye contact takes away from their ability to process someone’s message. Additionally, people in many cultures and regions use “cooperative overlapping” in which they speak while another person is communicating to demonstrate their engagement and enthusiasm for the communicator’s message. For these individuals, long pauses or a lack of overlapping may make it seem like people are not attending to them.

Original Guideline: “We will use active listening to demonstrate respect and attention when someone is communicating.”

- Not specific enough for everyone to understand
- May make some feel pressured to follow the “standards” of active listening prioritized by the dominant culture even if they’re uncomfortable or their needs aren’t met by these standards.

Updated Guideline: “We will commit to engaging and attending to others when they are communicating. We all use a variety of signs to show that we’re engaged. Examples include positioning our body towards the communicator, using eye contact, nodding, using other nonverbal cues (smiling, “mhm,”), and others. However, the absence of one of these signs does not mean we are not paying attention.”

- Gives specific examples to facilitate understanding
- Includes wide-ranging behaviors inclusive of the group’s specific preferences

Additional Guideline: “If someone feels they are too tired, overwhelmed, or distracted to actively engage, they can leave the room [/turn off their camera] to take a break. They can contact the project facilitator to fill them in on details missed during this break. They may also contact the project facilitator to schedule a make-up meeting or activity if they feel they cannot actively participate in the meeting.”

- Gives an option for instances in which someone feels they cannot uphold the guideline so they can maintain the trust of their community partners

Revisiting Community Guidelines

In addition to creating community guidelines at the beginning of your partnership, you should continually revisit and reflect on your guidelines—both personally and as a group. The dynamic of your partnership may change over time, and it is important to think about how effective your guidelines are at supporting everyone’s ability to communicate and participate. You may find that you need to adapt guidelines to fit different phases of the project, or to fit changing communication and participation needs of individual partners. This will help to create a stronger ongoing partnership, deepen your relationships with your community partners, and can even contribute to personal growth and development that motivates many people interested in collaborative projects.

Additional Resources

Creating an Inclusive Environment:

- D’Alonzo KT. Getting started in CBPR- Lessons in building community partnerships for new researchers. *Nurs Inq.* 2010;17(4):282-288. doi:[10.1111/j.1440-1800.2010.00510.x](https://doi.org/10.1111/j.1440-1800.2010.00510.x)

Decision-Making and Mediating Disagreements:

- Resnik DB, Kennedy CE. Balancing Scientific and Community Interests in Community-Based Participatory Research. *Account Res.* 2010;17(4):198-210. doi:[10.1080/08989621.2010.493095](https://doi.org/10.1080/08989621.2010.493095)
- Ginzburg SL, Dimitri NC, Brinkerhoff CA, England SA, Haque S, Martinez LS. Exploring intergroup conflict and community-based participatory research partnerships over time. *Research for All.* 2022;6(1). doi:[10.14324/RFA.06.1.16](https://doi.org/10.14324/RFA.06.1.16)
- Webinar: Autistic Adults and Stakeholders Engaging Together for Suicide Prevention (Decision making addressed at 27:00) https://www.youtube.com/watch?v=GugnZAY_nVg
- Seeds for Change Consensus Decision-Making Guide: <https://www.seedsforchange.org.uk/shortconsensus>
- PCORI Guide, Leading and Contributing to Team Decisions: <https://research-teams.pcori.org/team-decisions>

See Appendix A for sample researcher-generated Guiding Principles.

Identifying Community Partners

As stated earlier, it is vital that you already be engaged with the autistic and autism communities in some capacity before you begin a formal community-engaged process. Your commitment to learning from the community, even informally, is crucial to establishing a strong foundation for a formal community partnership. It demonstrates that you may be a trustworthy person that an individual or organization can feel comfortable collaborating with, even if you have never collaborated with them specifically in the past. You may have informal relationships with community members or organizations that organically result in opportunities for formal partnerships. But you may also have to seek out additional community partners with whom you have no relationship.

When identifying new community members or organizations to work with, it is important to center your commitment to building an inclusive and welcoming community from the beginning—in your approach to identifying community partners. The materials and activities used to recruit community partners should include enough information to allow them to make fully-informed decisions about knowing if the project is right for them.

Identifying Individual Community Partners

Who should I work with?

There are several factors to consider when deciding who to partner with, such as:

Personal Factors:

- Your research philosophy
- You and your team's connection to your topic
- Perspectives and experiences missing from your research team
 - It may be difficult to identify gaps in your knowledge and expertise, but this is crucial for community-engaged research. You and your team can reflect on your own beliefs and experiences (e.g., using the questions in section 2 above) to identify areas for additional learning and perspectives you may want to focus on more closely in your community-engaged project.
- Communities who are directly impacted by your research question of interest
- Communities who have been excluded from the research process in the past

Logistic Factors:

- Available resources (time, funding, accommodations)
- Length of the partnership
- Scope of the project
- Desired level of engagement
- Expertise of the research team

We will describe some of these factors below.

Agreement on your Research Philosophy

The foundation of a strong partnership is agreement on a shared mission or philosophy for the project. **You should partner with individuals who will agree with the overall goal of your (e.g., the “philosophy statement,” as described above).** This will make it easier to make decisions about the conceptualization, analysis, and interpretation of your research study; even when there are disagreements about individual decisions, you will have a shared understanding of what you are collectively working to achieve. Clearly articulating the mission and intentions of your project will be vital to finding appropriate community partners. This can include things like:

- Commitment to creating an inclusive environment
- Potential frameworks you historically use, or plan to use
- Developmental domains or general outcomes you plan to target (i.e., based on any clinical experience or your area of research)

You will collaboratively refine the philosophy statement to satisfy all community partners, but you can give your general ideas about these components of your philosophy statement and communicate about flexibility in the statement. For example, if you plan to use social models of disability, you can tell partners about using this lens to develop a support, but also specify that you will work collaboratively with them to decide about how this model will be applied in your study.

You do not need to have a complete philosophy statement before engaging with community members; all researchers are in different places in the development of their research philosophy, and one of the most important benefits of community-engaged research is that the community can have an active role in shaping the philosophies utilized in research. Early career researchers or later-stage researchers without robust community relationships may wish to have a more open-ended philosophy statement, and include information about your commitment to developing a philosophy alongside your partners. Later stage researchers and those with community connections (whether they are themselves a member of the community of interest or because they have other community relationships) may have a more developed philosophy, and may have deeper understandings about the “non-negotiables” to include in their initial philosophy statement.

It’s possible that your institution may have a mission or history that is incongruent with the philosophy statement you agree upon with your partners. Be transparent about the missions and histories of your supporting organizations (e.g., your department or funding agency, if applicable), what the limits of your influence may be on these organizations, and if these your organization’s mission will influence your project in any way. For example, even if you are committed to embedding social models of disability, your funding source may require you to report on outcomes that are based in the medical model (such as decreased overall autism characteristics as an “ideal outcome”); this must be communicated with potential partners upfront so that they can make a decision about their comfort with a collaboration in that environment.

Historical exclusion from the research process

Community-engaged research is a way to empower community partners to take a lead role in producing knowledge and developing services that directly impact their lives. It makes research

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more reflective of the real-life experiences and concerns of community members. You should aim to partner with individuals who are members of the community of interest, and who may have been left out of the knowledge creation process in the past. This facilitates research outputs that will combat disenfranchisement historically perpetuated research.

Avoid Tokenism

Tokenism is when you nominally include someone from a marginalized community in your project as a symbolic act to signal inclusivity, without consideration of why their community has been excluded in the past and the ramifications of this exclusion on the community, or without a commitment to incorporating their views. Signs of tokenization may be:

- You include someone from a specific group to “check a box”
- You include someone on your project but do not deeply engage with their perspectives or integrate their suggestions in the project
- You include someone from a community on your project without considering the social-cultural factors influencing their perspectives in the design and conduct of your project
- You assume that one individual (or a small number of people) from a community can represent the wide range of perspectives within the community

Remember: No community is a monolith.

There is wide variability in perspectives between and within communities. We should never assume that all members of a community will have the same perspectives on a given topic. Discussing and representing this variability in your project is a key strength of community-engaged approaches and must be your highest priority as you are capacity and trust building. It helps to ensure that your study is acceptable and relevant to a wider range of people, not just those who have historically been centered in autism research.

It's impossible to include *every* perspective in your project, but you should think about who is not included in your project, who might disagree with the choices made by your team, and how your choices could impact people who are not on your team.

Common Question: Should I work with autistic people *and* caregivers?

Some people are concerned about working with autistic people *and* caregivers in EI research because they assume these communities will have competing perspectives and interests. However, this is not necessarily the case. There will be disagreements between and within these groups, and you may find that community partners with different opinions on some topics have a lot of commonalities in other ways.

Furthermore, one group of people often left out of the conversation is **autistic caregivers of autistic children**. Autistic caregivers have unique perspectives, and they may also help bridge the gap between autistic adults and caregivers who do disagree on some ideas.

Who should I avoid working with?

The mission of your project must be clear and agreed upon by all members of the partnership. **Therefore, you should avoid working with people who do not agree with the overall mission of the project.** It is possible that the specific goals or design of your intended project may shift throughout your collaboration, but the underlying aim of the project must guide the partnership. It is important to clearly describe your philosophy using language that is accessible to people with wide ranging knowledge about autism. You should also state that even though you will refine this philosophy together, following the philosophy is a core component of joining the collaboration, and if a potential partner does not agree with the mission then they should not join the project.

For example, if you intend for your project to focus on supporting sensory regulation for autistic toddlers through a neurodiversity-aligned framework, it is possible that the *specific* therapy or study design you use changes as you begin your collaboration. However, the overall goals (e.g., supporting sensory regulation, using neurodiversity as a guiding framework) will stay the same. Agreement on these components of the mission will guide your group to choosing the study components that you believe will best accomplish your mission. You may also find that some people are unfamiliar with terms like “neurodiversity.” Providing a definition and giving concrete examples of what the goals of a “neurodiversity-aligned therapy” might be can help to describe this mission to potential partners. This will increase the accessibility of research partnerships to a wider audience (e.g., not only people with extensive knowledge about autism), while still ensuring that people who join the partnership are fully informed about the goals of the developing project.

Additionally, remember that your community partners will not only have to work with you, but with each other. As stated in the previous section, it is vital to foster an environment of inclusion and respect in your partnership. Part of your overall mission should therefore be to build and maintain this community. Processes should be in place (e.g., through explaining foundational “guiding principles” and potential community guidelines during onboarding) to ensure that partners will be comfortable committing to creating such an environment. You can also include some basic education about these principles to ensure that project partners are comfortable upholding principles about which they are not currently informed.

For example, if a potential community partner expresses that they do not believe in a guiding principle related to inclusion of diverse gender identities, they may not be an ideal partner because they disagree with the overall mission of your project to foster an inclusive environment in this regard. But you may find that some potential partners do not know a lot about gender identity, and will be on board to follow related principles and guidelines given education on the topic. You can probe about people’s knowledge, desire for resources, and comfort with various principles throughout the onboarding process.

If a potential partner expresses that they disagree with the guiding mission, or that they feel uncomfortable following principles related to inclusion and respect, they may not be an ideal person to partner with. You should build in ways for potential partners to opt out of participating throughout the onboarding and collaborative process without requiring them to disclose the

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specific guideline they disagree with, or the reason why they are no longer interested in working with you (see “Offboarding” for more information).

Although there are expectations to remain “neutral” when conducting science, it is impossible to approach science from a neutral standpoint. Everyone has a unique worldview that is carried into their work, whether consciously or not. And as explained in Section 2, autism research has historically been influenced by many attitudes, prejudices, and frameworks; thus, *the act of conducting research using the methods and knowledge produced by autism research is always tied to specific ideologies, even if researchers are not explicitly aware of them.*

Therefore, it is critical to reflect on and have an active stance on principles that have the potential to perpetuate oppression, prejudice, and inequities in autism research and clinical practice. Understanding “dissenting” opinions can help you design your study to combat common criticisms. However, engaging with community partners with vastly different opinions can damage the trust between you and your community partners, making the partnership less meaningful and effective.

Working with Autistic Youth

Another population you may want to engage with is autistic youth. Although it may not be possible for toddlers to fully report on their experiences with autism or a specific therapy, older autistic children may provide key insights. In fact, children as young as three years old have been engaged in participatory early childhood research in other fields. This tool focuses on engaging with autistic adults and caregivers, but below we provide some *basic* considerations and resources to begin learning how to engage with autistic youth.

- Identifying youth community partners and obtaining consent/agreements: Your methods for obtaining consent should be adapted for children. You will need to obtain parental consent and child assent (broadly described as “agreement”) for these projects. There may be unique considerations around power dynamics and contexts influencing this process based on your identification approach. For example, if identifying children to partner with through their school, they may view your project as some sort of “school assignment” and feel pressured to agree to participate.
- Structuring engagement activities: Your methods of engaging with youth should be different from your methods of engaging with adults. Children may require more or different capacity-building activities to learn about research, and to learn how to collaborate in a group setting. The ways in which they provide feedback may also need to look different than would be expected in older children or adults.
- Power dynamics and decision-making: Cultural norms in many contexts are such that adults often make decisions for children. Thus, many children may not be used to being final “decision makers” as may be desired in a fully-engaged participatory research project. Additional trust- and community-building activities may be required to truly empower children to be decision makers throughout the research process.

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These are just a few of *many* considerations that must be taken into account when engaging with youth. Please see the additional resources below for more information:

- Montreuil M, Bogossian A, Laberge-Perrault E, Racine E. A Review of Approaches, Strategies and Ethical Considerations in Participatory Research With Children. *International Journal of Qualitative Methods*. 2021;20:1609406920987962. doi:[10.1177/1609406920987962](https://doi.org/10.1177/1609406920987962)
- Youth Voice Youth Choice: <https://youth-voice.org/>
- Youth Participatory Action Research Hub: <https://yparhub.berkeley.edu/>
- Offiong A, Willis K, Smith BD, et al. Maintaining Community-engaged Research with Young People in A Virtual setting. *Prog Community Health Partnersh*. 2023;17(2):329-337. doi:10.1353/cpr.2023.a900213
- MacDonald J-AM, Gagnon AJ, Mitchell C, Di Meglio G, Rennick JE, Cox J. Include Them and They Will Tell You: Learnings From a Participatory Process With Youth. *Qualitative Health Research*. 2011;21(8):1127-1135. doi:[10.1177/1049732311405799](https://doi.org/10.1177/1049732311405799)
- Carroll C, Sixsmith J. Exploring the facilitation of young children with disabilities in research about their early intervention service. *Child Language Teaching and Therapy*. 2016;32(3):313-325. doi:[10.1177/0265659016638394](https://doi.org/10.1177/0265659016638394)

How many community partners should I work with?

The exact number of community partners you work with will depend on the structure of your project, available resources, and the scope of the community-engaged project (e.g., one-time input about a project component versus ongoing partnerships). A “sweet spot” for facilitating group meetings often tends to be about a maximum of about 8 people for a facilitator with experience.

If you are conducting short-term engagement to gather perspectives about a topic (e.g., “symbolic participation”), you may consider holding multiple focus groups to engage with a larger number of people. But it may be difficult to collaborate with a larger group of community partners in an ongoing partnership at a fully engaged level of participation. When identifying partners at this level of engagement, remember that you are building a team of partners with whom you will share power and decision-making authority. Consider your capacity to support your partners in deeply understanding and contributing to the research process across multiple activities and stages of the research process.

You may also consider using multiple engagement activities to understand a wider range of community perspectives within the constraints of your experience and resources. For example, you may have a smaller number of partners with whom you partner at the “engaged participation” level in an ongoing capacity, and then you may solicit additional community perspectives about key components of your research project in shorter-term capacities, or at lower levels of engagement.

Improving Equity in Community Partnerships

There are many people who hold multiple marginalized or historically excluded identities who you may wish to prioritize as project partners (e.g., who experience food insecurity, medical

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disorders, other disabilities). They may require different engagement approaches to ensure their participation is satisfactory, such as additional trust-building measures and alternate meeting/compensation structures. We will provide additional information about participation options to increase the accessibility of community-engaged research in a later section, but it is vital to consider ways that the structure of your project is inclusive or exclusive of different members of the community from the beginning.

How do I collect information about potential partners?

You can create a survey to gather information about potential partners' backgrounds, experiences, and interests in engaging in research. This information will help you ensure that your partnership represents a wide variety of experiences, and that your project represents the perspectives you wish to include. You can also consider a one-on-one interview or call to discuss important information if people are more comfortable with sharing information this way. You should also be transparent about why this information is being collected, ensure that disclosing personal information is optional, and specify how their information will be protected. See Appendix B for a sample survey used to collect this information.

If you find that all your community partners have incredibly similar experiences, opinions, knowledge, and needs, it's likely that there is an important perspective you're excluding from the process.

It's also important to ensure that you can support your partner's needs (e.g., communication, sensory, cognitive) so they can have a satisfying experience in the partnership. Appendix C includes a sample survey you can use to gather information about potential partners' desired supports; not only does this help you structure your engagement activities, but it demonstrates your commitment to inclusion from the outset.

How do I find potential partners?

There are many ways you can find individual community partners. For example:

- Local meet-up groups for autistic people or families with autistic children
- EI providers and clinics
- Social media
- Local health and child welfare organizations
- The International Society for Autism Research (INSAR) also has a resource to connect community partners and researchers: <https://www.autism-insar.org/page/iccr>

Consider who has knowledge about and access to these different "recruitment" sources. You may want to use a mix of different sources to improve your reach.

Designing Materials to Identify Partners

The materials you use to reach potential partners should be clear and accessible. Consider making different versions of your outreach materials (social media posts, handouts/flyers, videos), including translating materials to other languages, to ensure your approach is successful in engaging people from different communities. You should also consider holding meetings with potential community partners where you can describe the project and answer

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their questions in more detail. These meetings may be a good opportunity for you to gather information about accommodations you can integrate into your project that would support community members' participation.

Critical information to include in recruitment/onboarding materials and activities:

- Goals of the research project
- Your motivations for engaging community members
- Basic structure of the community-engaged activities (e.g., modality, independent or group activities)
- Summary of the required commitment (e.g., frequency and duration of meetings, timeline)
- Compensation (e.g., payment, authorship/credit, opportunities to learn new skills)
- Funding source (if applicable)
- Accommodations, supports, and participation options
- Background information about yourself and other research partners

What should potential community partners know about the project?

After identifying potential partners, you should have additional information available to partners. This can be a written document or video, but we also recommend holding group meetings or scheduling one-on-one meetings or calls to describe this information to potential partners. Here are some recommendations about additional information community partners should know about the project before they agree to join.

- **Communicate clear expectations about the time investment and other requirements (skills, expertise) that you are looking for from your community partners.** It is essential that individuals can make an informed decision about whether or not they want to get involved in this work. If you want to develop a study with community members, make clear which parts they will be involved in designing. Don't overpromise. Think of it like a job description that allows interested community members to decide whether they want to "apply" or not.
- **Be transparent about study goals and components about which you cannot be flexible.** Community-engaged research requires a lot of flexibility so that your project can be shaped around your partners' preferences. However, there may be some critical components of your study about which you cannot be flexible. Telling potential community partners about these inflexible components will ensure that community members who disagree or are not interested in these components can decide if it's the right opportunity for them. For example, if you're interested in studying an in-person approach to providing Early Intervention services, a community member with an interest in telehealth will know that this opportunity may not align with their interests.
- **Communicate about critical principles or frameworks you hope to embed in your work, especially those you are using to prioritize equity and inclusion.** This helps establish trust with potential partners and ensures that your community partners have a baseline level of agreement from which to build relationships, even if they disagree with each other on other project components. You can engage in some basic capacity-building (e.g., through an orientation meeting or "FAQ") or include "guiding principles" for your work to ensure that potential partners are on the same page. Many community partners may be unfamiliar with the terminology and historical/systemic biases influencing these inequities but would be on board with adopting a certain perspective given some

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information and education about the topic. For example, you can explain concepts like neurodiversity and racial and ethnic discrimination in autism research.

Please see the “consent” section below for additional recommendations about information that potential community partners should know before formally agreeing to collaborate. Appendix D includes sample materials used to tell potential community partners about a project.

Identifying Community Organizations

There are additional considerations for engaging with community organizations. Some organizations may be distrustful of academia and research institutions because of past mistreatment, and because they may believe researchers view themselves as better experts on topics that organizations deal with every day. Partnerships with community organizations may be reciprocally beneficial, but they should favor the benefit of the community organization. Academia and research organizations have greater institutional power than many community organizations. Your role in the partnership should be to use this power and your resources to benefit the organization and build a shared vision for ways to support autistic children and families. When considering if you will partner with an organization, ask yourself the following questions:

What kind of organization should I partner with?

Community organizations vary in their structures, formality, and levels/sources of funding. Some organizations may be highly structured with full-time paid staff who receive large amounts of public or private funding to work on formal projects and initiatives. Some organizations may consist of mostly volunteers and work on advocacy and small-scale projects in their local community. There may also be informal networks of individuals who discuss topics relevant to the community and work towards shared goals, either in-person or online. There is value in partnerships at all levels of this continuum, and who you approach may depend on your goals. For example, if you are working on a study that is more focused on implementation or large-scale policy change, you may find that partnerships with formal organizations (e.g., the Early Intervention system) may be most relevant to your goals. Local organizations may have more insight into a local community’s needs and specific determinants influencing therapy and access to services across a wide range of factors. **Informal networks of community members are often created by individuals who have been disenfranchised or excluded from other more formal organizations, and who may have experiences that are not shared by those who work in formal organizations.** So, consider the knowledge you may already have and whose insight might be missing from your current projects.

You should also consider your available resources when choosing the type of organization to partner with. Organizations with less structure and funding may require more support from your team, whether that is in the form of facilitating infrastructure or providing the funding needed to work on your project’s objectives. Formal organizations may already have staff whose role includes managing research partnerships. So, if you do not have a lot of resources dedicated to community engagement, it may be more appropriate to partner with organizations who already have existing resources or experience with research partnerships.

What tools, knowledge, and resources do I have that may benefit this organization?

Many researchers view access to participating in a study as an inherent benefit and “privilege” for a community organization, but community members may not view your study this way. It is critical to understand an organization’s actual preferences and clearly communicate the logistics of your research to ensure that the partnership is a good fit that will benefit the community organization.

Depending on an organization’s mandate they may receive many requests for partnerships. Some of these requests may be one-sided, meaning that a collaboration would benefit the requester more than the community organization. So, some organizations may not receive your request with open arms. They may have questions. They may not respond immediately. Put yourself in their shoes, especially if you sense resistance. Additionally, consider how much time to give an organization to respond; if the organization you’d like to work with is volunteer-run, expectations should be adjusted and not compared to expectations of an organization that has paid staff.

Community organizations have valuable expertise about the issues and experiences of the people they serve. So, it’s possible that the knowledge and expertise you have to offer may not be related to the content of your research at all. Instead, it may be access to programs and software; methods of data collection and program evaluation; access to volunteers (e.g., you and your research team) who can help the organization with their programs; or even skills that can be used to secure funding for a program an organization is interested in starting or sustaining. You should not view community partnerships solely as ways to help fill community needs, but as a way to help organizations expand successful efforts. Start by asking organizations about ways you can support their needs, rather than assuming the resources you can provide will be beneficial.

Do I have the time and resources necessary to build a meaningful partnership?

Many people are motivated to find community partners for the purposes of a specific project or funding opportunity. But many long-lasting partnerships begin more organically. To create reciprocal and meaningful partnerships, activities should primarily benefit the community. This could mean spending time volunteering as you get to know an organization, asking if there are educational activities that you could help them put together, or doing other activities that may not be concrete things to put on a CV or tenure dossier. But these activities may demonstrate your trustworthiness and may result in organic ideas for research that you create collaboratively with your partners.

Am I prepared to be flexible in adjusting my project to meet this organization’s priorities?

You may have an idea for a study, but after discussing it with a community organization, they may think it’s unhelpful, not feasible, or will be ineffective. Be prepared for community partners to disagree with your ideas. If community organizations and partners do not believe your idea

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will be helpful, you may need to change course and start from scratch in developing a new program or idea to study in collaboration with community partners. If your project has already been funded and you cannot change the details of the project per the organization's feedback, it may not be appropriate to proceed with the partnership. It's ideal to engage with partners at the development stage so that you can make adjustments according to their feedback and needs.

Am I prepared to sustain this partnership outside the project activities and timeline?

An important part of building community partnerships is sustaining the relationship beyond the confines of the project. Research takes a long time, and the needs of community organizations usually need to be fulfilled faster than can be accomplished in a large-scale study. Even after beginning to collaborate on a formal research study, you should have resources (whether this is funding, assistance, providing letters of recommendations, or staff time to volunteer) to continue to help organizations with their other needs that aren't being met by the partnership. Creating sustainable partnerships is also important for maintaining your trustworthiness so partners don't feel tokenized, used, or abandoned after a project is over, or during "waiting periods" in projects (e.g., while waiting to hear if a grant got funded).

How do I hope to benefit from a partnership with this organization?

Partnerships should be mutually beneficial, and therefore it is important to reflect on your desires and expectations of the organization from your partnership. This is important to understand and communicate to organizations so they can make a decision about whether or not they have the bandwidth and resources to partner with you. Additionally, it is important to not view organizations as having "needs", but also as having unique strengths. You may have an idea for a way to help autistic children and families in your community, but it's possible (and likely) that local organizations have a better understanding of families' unique needs and day-to-day lives within their local context. Thus, community organizations may have programming or ideas for programs that will be more effective in supporting people in the community. So, you should view these partnerships as opportunities to learn as well.

How do I find potential community organization partners?

Within your institution:

- Use your institution's resources. Many institutions have community outreach or community engagement offices. There may already be relationships in place that you may be able to leverage. However, consider that the opposite might be true: there may have been a relationship with your institution that no longer exists, or that community organizations aren't satisfied with. This is something you may want to address in your first contact with organizations.
- Ask other faculty in either your department or a related department who may have connected with community organizations in their work before. This could be a helpful way to an introduction. However, be cautious in evaluating other people's relationships with community organizations to be certain their approach aligns with yours and the principles of community-engaged research outlined in this tool.
- If available to you, another great resource is existing research participants. Consider adding a short survey for your participants to ask them about community organizations

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they may be connected with and find support from. But be careful about privacy violations if using this as a way to locate organizations.

Within your local community:

- Get to know your local community or Early Intervention program/providers. It's vital to understand the work being done in the community to know where your work fits in, and how you may be able to complement or expand efforts that are already happening. A great place to connect with may be your city's administration. Many towns have a Health & Human Services (or similar) department that will be knowledgeable about community organizations. Similarly, your local public library can be a great resource for finding community organizations that align with your goals and research.
- Search for organizations online. Depending on the level and context of engagement you are looking for, you may want to look for local organizations or extend your search to organizations further away (or online communities) if your project allows.
- Research an organization's funding mechanism to avoid conflicts of interest. There may also be connections and relationships that align between your research funding and the community organization's funding, which can demonstrate that your research fits well with the goals of the organization you are trying to engage in your research.

Once you've identified an organization you may be interested in partnering with:

- Take time to learn about the organization's programming and community they serve.
- Check your intentions. Do you truly want to partner with this organization in a mutually beneficial way, or to benefit your research? Considering the history of harm and distrust between researchers and communities, what makes you a trustworthy person to partner with? Many organizations receive insincere requests for partnerships and may be sensitive to insincerity. Expressing your genuine interest and respect for the organization, your desire to offer assistance, and your interest in learning from them, can be effective in establishing trust.
- If you have a specific project you would like to collaborate on, provide appropriate information so that they understand what may be required of them. [This article](#) includes questions that community organizations may want the answers to when deciding whether to proceed with a partnership.
- Find a "community champion," or a person who is brought into the partnership and trusted by members of the organization. The community champion can help build proxy trust between you and others in the organization as you cultivate additional relationships.
- Identify additional resources or infrastructure that need to be in place to establish the partnership. For example, if partnering with a local clinic, funding for protected time may be necessary for clinicians to attend meetings.

Additional Resource:

- Saleh A, Saelens B, Hayes M, Committee the HECA, Coker TR. Community Partnership Guide for Engaging with Academic Researchers. *Progress in Community Health Partnerships: Research, Education, and Action*. 2022;16(1):129-134. Accessed August 15, 2024. <https://muse.jhu.edu/pub/1/article/849242>
- Appendix D: Sample Materials for Recruiting Community Partners

Consent and Institutional Review Board (IRB) Oversight

Unlike interactions with research participants, there is no IRB oversight of interactions or responsibilities to community partners unless your community partners are also participants in the research study. However, community partners should know what to expect from the project before they agree to join a partnership. Additionally, researchers and research institutions traditionally hold more power than community members in the context of research projects; it is vital that potential community partners understand what to expect from their interactions with you, and how you will be accountable for upholding the goals and guidelines you agree upon in the beginning of the project. Thus, some form of “consent” or agreement process should be in place before the project begins, and, depending on the level of engagement, as the project evolves.

Your community partners may have to complete required IRB trainings, depending on the nature of your study and the type of engagement. In this section, we will describe our recommendations for appropriate consent of community partners and provide resources for understanding how to involve community partners in IRB-related activities and oversight.

Consent and ethical oversight in community-engaged projects are emerging topics in discussions about community engagement across research fields. As with other community engagement practices, we expect this to evolve over time. Below we describe our recommendations for what this process may look like, but we encourage you to be up to date with advances in the field for more guidance on these topics.

What should consent look like in a community-engaged research project?

The consent process may look different depending on the nature of your partnership. For short-term engagement in which there is a discrete activity or topic about which you are looking for community consultation, this may look more like a traditional researcher-driven process. For longer term projects with a deeper level of engagement, this may be a more collaborative agreement process in which you and your partners discuss and come to a consensus about goals and procedures, and both researchers and community partners sign an agreement (e.g., your “community guidelines”). There may also be a more formal contract process if partnering with a community organization, or in a fully-engaged project in which community partners and organizations are considered additional sites or investigators in the grant.

Regardless of the method of creating an agreement, community partners should know about the topics below to make an informed decision about a potential partnership. You can also review and refine these procedures when creating community guidelines:

- Purpose of the research project and partnership

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- If engaging partners in the conceptualization of the research project, the “purpose” may be more general, such as a specific population or developmental domain the researchers want to target in the study
- They should understand why you want to engage with community partners, and what experience you have with community-engaged research
- Procedures/activities involved in the partnership
 - What will community partners be doing (nature of the activities)?
 - What research guidelines do they need to follow?
 - What kind of information do you expect them to contribute?
 - What level of commitment do you expect from them?
 - For a community organization: What time and personnel do you require from them? What resources are available to help them maintain that level of commitment?
 - What participation options are available (e.g., virtual, in-person, asynchronous)?
 - What is the timeline for the project (grant deadlines, how often you’ll meet)?
 - Many community partners do not know about the timeline of a research study (e.g., the time it takes for participant recruitment, data collection and analysis, the peer review process). Be upfront about the time involved in these processes, especially those which involve a lot of waiting between milestones. It is also worth explaining that timelines in research can shift based on multiple factors outside of a researcher’s control (e.g., multiple rounds of peer review process, etc.) and that flexibility may be required.
- Expectations for upholding research procedures
 - Will community partners need to complete any trainings per IRB guidance (e.g., HIPAA, responsible conduct of research)?
 - How will you and community partners uphold each other’s privacy, and that of other community partners (e.g., not sharing information about other partners’ perspectives)
- Supports, Accommodations, Inclusion
 - What supports and accommodations do you plan on incorporating in your project? What resources might you have for other supports that could enable someone’s participation? Are there any restrictions or limitations?
 - What capacity-building will you do to ensure partners are prepared to contribute?
 - What guidelines and systems are in place to make engagement an inclusive and safe experience for partners with identities that have faced discrimination and marginalization in research and the community?
 - What principles and frameworks will you use to ensure the project and resulting research are ethical and beneficial to the autistic and autism communities?
- Level of engagement
 - Division of responsibilities: Who is responsible for what? What processes are in place for all parties to be accountable for following-through with their responsibilities?
 - Who is on the leadership team?
 - Limitations on input: How will their ideas be used?
 - Authorship expectations (if applicable)
- Voluntary Participation: They can leave the project at any time

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- Compensation:
 - Payment amounts and methods
 - Other compensation activities
- Confidentiality:
 - How will personal information be protected? If sharing personal experiences to inform project design/objectives, will this be tied to individuals' identity?
 - Can partners be anonymous for external-facing activities? For reporting to funding agencies or other organizations?
 - Is there necessary disclosure about potentially sensitive information to other community partners?
- Accountability
 - How will you monitor satisfaction? How will you integrate feedback about the community-engagement activities?
 - Procedures for violations of the contract (on both sides)

How to obtain consent/agreements:

There is no established process for obtaining consent or agreements in community-engaged projects, and the content involved in this process may vary from project to project. For example, in a short-term project, you may provide a form or contract outlining research team responsibilities and community partner expectations that everyone signs. For a longer-term engagement process in which you will work more collaboratively, you may present a more logistics-focused agreement form before the first meeting, and then have an additional agreement based on community guidelines created with all project partners. You may also consider conducting the agreement process in multiple modalities: you can have a formal piece of paper or online form that partners sign, or you can have a meeting in which you obtain a verbal agreement. Flexibility with modalities can also allow you to tailor the process based on individual needs and answer follow-up questions when they come up.

IRB oversight for community partners

Your community partners may be held to the ethical principles and regulations of conducting human subjects research depending on the ways they will be involved in the research study. You should talk with your institution's IRB office to understand the rules of your organization, but here are some general guidelines and resources to consult for understanding if your community partners might also be subject to IRB oversight.

- In general, if your community partners consult on the study consent process, interact with participants, help to gather or analyze data, or have access to any personally identifiable information (e.g., participant videos, survey responses, data), they will likely be subject to the same standards of research ethics as the rest of your research team. This is also important when working with community partners in the participant recruitment process of your study. Your IRB will need you to answer some questions to determine if your community partners are "engaged" in research (here, "engaged" is a regulatory term used by IRBs).

Consent and IRB Oversight

- There are different processes for individual community partners who are not part of organizations and for community partners who represent an organization.
 - Individual community partners may be considered “Individual Investigators” and have a special agreement they need to sign with your organization’s IRB.
 - Community organizations may be treated as additional sites (similar to partnering with another research institution) and may need to have Federalwide Assurance (FWA) that they will comply with federal regulations for the protection of research participants.
 - For more information on these definitions and regulations, [see here](#) from the Office of Human Research Protections (OHRP).

If your community partners are required to complete any HIPAA or human subjects research trainings, they may be able to use your institution’s processes or OHRP’s trainings. Some institutions may have trainings that are specifically designed for community partners, too.

[RE4ALL](#) (“Research Ethics for All”) provides research ethics trainings for community partners with developmental disabilities. These trainings were created as a collaboration between researchers, IRB administrators, and community partners with developmental disabilities. On their website, you can find more information about the training and suggestions for gaining approval for this training from your institution’s IRB.

Additional Resources:

- Solomon S, DeBruin D, Eder M, et al. Community-Engaged Research Ethics Review: Exploring Flexibility in Federal Regulations. *IRB*. 2016;38(3):11-19. Accessed August 15, 2024. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4997782/>
- Office for Human Research. Engagement of Institutions in Human Subjects Research (2008). November 29, 2010. Accessed August 15, 2024. <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/guidance-on-engagement-of-institutions/index.html>
- Office for Human Research. Extending an FWA to Cover Collaborating Investigators (2005). November 30, 2010. Accessed August 15, 2024. <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/extension-of-institutional-fwa-via-individual-investigator-agreement/index.html>
- Community PARTners Research Ethics Training | CTSI University of Pittsburgh. Accessed August 15, 2024. <https://ctsi.pitt.edu/education-training/community-partners-research-ethics-training/>
- Ethics training for collaborators with developmental disabilities: <https://re4all.org/>

Structuring Engagement, Supporting Access Needs, and Facilitating Communication

The frequency, modality, and structure of your community-engaged activities will be impacted by a variety of factors such as accessibility, available resources, and individual partners' preferences. Using multiple approaches to engaging with community members may require more resources, but it can make participation accessible to a wider range of people.

Using multiple approaches may also increase the equity of your project by allowing individual partners to participate in a way that best fits their unique needs and preferences. In fact, relying on one single way of participation most likely means that you're excluding people from your partnership, even if you're using "ideal" engagement and accommodation methods.

Example: Why are multiple approaches needed?

Engaged participation may be the most "ideal" level of community engagement, but many people face structural barriers towards long-term partnerships that you may not have the capacity to overcome independently (e.g., those with income limits; those who work multiple jobs and cannot regularly find time to attend meetings or complete activities). Adding activities at lower levels of engagement may increase the equity of your project by creating opportunities for people to participate who are generally excluded from the process.

In this section, we include recommendations and considerations for:

1. Frequency of Meetings/Engagement
2. Structuring Meetings and Accommodations (sensory, technology, physical accessibility)
3. Facilitating Successful Communication and Supporting Participation in Activities

1. Frequency of Meetings/Engagement

Regular, ongoing meetings

Regular, ongoing meetings (e.g., weekly, monthly, quarterly) can be effective in establishing and maintaining an ongoing partnership. Regular engagement is necessary to achieve "engaged participation" wherein community partners collaborate with you throughout the entire research process. Even if there's a meeting during which you don't have a specific task or item to discuss, you can use this time for community-building and co-learning about common topics of interest. This also helps establish that the relationship is not transactional—in other words, you're not only meeting when *you* need something from your community partners. You can work with your community partners to determine a meeting frequency that works for the needs of the project as well as your community members' other commitments and priorities. Below we list

four common barriers to holding regular meetings and engagement activities, and some potential solutions.

Potential Barriers and Solutions to Regular Meetings and Engagement

Commitment of community partners: Some people may not be able to commit to a regular or ongoing partnerships (e.g., single parents and/or families who do not have access to childcare, people with multiple or high-demand jobs, people with medical challenges). Potential solutions include:

- Add additional short-term participation options so people with time/commitment constraints can still provide input
- Allow for participation in an alternate modality/medium such that it can be scheduled when works best for them (e.g., review meeting recordings and answer questions on their own time, virtual meetings instead of in-person meetings)

Time constraints: You may face time constraints due to deadlines for your project. For example, you may collaborate with community partners on tasks with tight deadlines that do not align with your regular meeting schedule. Potential solutions include:

- If you know about these deadlines in advance, you should communicate these to your community partners ahead of time so that they know you may have busier times.
- If there is a chance that a regularly set meeting may need to be canceled due to a deadline, inform your community partners and seek alternative ways to collaborate (e.g. reschedule a meeting, have people give input on a document remotely, etc.)
- You can also hold optional meetings for those who have time to meet more frequently before deadlines

Research team resources: You may have limited time, experience, financial resources, and personnel on your existing team to support robust and regular community engagement. Rushing into a long-term partnership without appropriate time, resources, or personnel can result in an unsatisfying or even harmful experience for your community partners. Potential solutions include:

- If you do not have the time to appropriately plan long-term partnerships, you can consider other shorter-term options to build up to long-term partnerships (see one-time or short-term engagement section below). For example, you can organize focus groups to better understand community needs or participate in outreach events with community organizations you may want to partner with in the future.
- Establishing a long-term partnership without appropriate time, resources, personnel, or planning can result in an unsatisfying or even harmful experience for your community partners
- Communicate directly with your community partners about what your team is currently able to offer (in terms of time, resources, etc.). Based on your understanding of community partners' needs, you can also budget for additional resources in future grant proposals that will help you develop a closer long-term relationship. You may also find ways to partner with community organizations to fund their organization in ways that will support future partnership (e.g., local grants to fund personnel who may also help to sustain a partnership)

Payment and compensation: Some people may have constraints around payment options that are used for long-term partnerships (e.g., those with income limits due to SSDI restrictions; see Payment section for more details. Potential solutions include:

- Explore different payment options (e.g., short-term participation as an independent contractor vs long-term participation as a temporary employee)
- Provide some participation options on a ‘volunteer’ basis
- Consider additional ways to compensate community partners (e.g., training on a topic/skill of interest)

One-time or short-term engagement

Less frequent or intensive engagement can be effective if your goal is to solicit feedback on specific questions or materials. This is usually more typical of “symbolic participation” or engagement efforts where you aim to consult with or involve community members in only some aspects of the research design and conduct process. This may also be appropriate for projects on which you want community input, but due to time constraints, funding limitations, or restrictions to the changes that can be made, community partners cannot be the final decision-makers. This can also be an effective way to initiate relationships with community organizations (e.g., co-host a lecture or educational event on a topic of interest to the community organization) and to expand participation to people who face barriers to ongoing engagement. Even when doing short-term or one-time engagement, you should still follow-up with these community partners so they understand how their ideas were used and are aware of the status of the project.

Potential Barriers and Solutions to Short-term Engagement

Trust-building: You may have fewer opportunities to build trust between community partners and your team. This may limit how comfortable partners are with sharing their ideas

- Use the materials you use to recruit and onboard community partners to build trust from the beginning

2. Structuring Meetings: Accommodations and Considerations

It is essential to make your meetings and communications with community partners as accessible as possible. In this section, we will describe considerations for sensory needs, technology proficiency, and physical accessibility, including considerations for in-person and virtual meeting modalities when applicable. We’ll provide more detailed information about considerations for including a wide variety of communication needs in the next section.

In general, it is important to be *proactively inclusive* of a wide variety of needs. From the beginning, you should structure your meetings to accommodate a wide variety of sensory needs, physical access needs, and technology proficiencies/access needs. You can describe these meeting structures before your project begins during your recruitment and onboarding activities. Then, you may gather information about additional accommodations or modifications that individual community partners may need. This can occur during onboarding, when creating

community guidelines, and should be ongoing throughout your project to ensure you are inclusive of changing needs and preferences. Additionally, creating opportunities for people to share their needs and preferences (rather than relying solely on partner-initiated advocacy) takes the onus off of community members to share their needs, and may help to build trust.

Navigating Competing Access Needs

You may have community partners with competing access needs, where supporting one person's needs might inhibit another person's needs. For example, some people may find it useful to hum or use other vocal stims, while another person might find noise to be distracting. There isn't a one-size-fits-all solution for balancing competing needs. Your methods for doing so should be tailored to the specific needs of your community partners. It will also likely be an ongoing process. We will provide some examples of how to navigate competing access needs at the end of this section. Here are some recommendations for ways to gather information and navigating the process:

Before the project begins: Plan a variety of support options from the outset of your project to ensure a wide range of people feel comfortable collaborating with you.

Onboarding: Gather information about individual partners' needs and preferences during the onboarding process. This will give you a sense of potential incompatibilities to plan for. You can also begin introducing the idea of different sensory/communication needs, especially for community partners who are not familiar with these concepts. This will lay the foundation for enhanced cooperation and mutual respect.

Community-Building: When setting community guidelines with your partners, discuss the concept of competing access needs with the group. During this discussion, be sure to make it clear that everyone's needs will be accommodated as much as possible, but it may not be possible to support everyone's needs to the fullest extent at all times. You should also reinforce the idea that different preferences are valid and important. Then, jointly decide on guidelines for navigating specific incompatibilities that may come up. You can identify some potential solutions and open the discussion for community partners to offer their own ideas. You should also explain that this should be an open and ongoing discussion, and that you can make adjustments as a group as individuals' needs change or become clearer over time.

Ongoing: Gather feedback about people's satisfaction with the accommodations and interpersonal communication. This way, you can make adjustments to better adjust for people's changing needs or preferences.

Sensory Considerations:

Community members' sensory needs must be met so that they can be fully regulated, comfortable, and focused during meetings. Importantly, you should create an environment in which people feel comfortable doing what they need to do to meet their sensory needs. Individuals' self-regulation strategies (e.g., stimming) should be *accepted*, not just tolerated. Emphasizing this as a value and priority will create an environment where people are invited to be themselves and may help autistic community members feel less pressure to mask.

You may also have community partners who don't know what stimming is, or its value to autistic people. Providing some basic information about the importance and value of stimming in your onboarding procedures may facilitate trust and understanding between group members.

Sensory Accommodations for in-person meetings could include:

- If you have a specific space already chosen or are limited to a particular location for your meeting, provide information about the space ahead of time (e.g., lighting, chairs, windows) so your community members can prepare for the meeting or tell you about any modifications that would better fit their needs.
- If you do not have a space chosen, ask people about any in-person sensory accommodations they may find beneficial, or environments that are not comfortable for them (certain types of chairs, lights, etc.), so you can pick a space that is as accommodating as possible.
- If you plan on offering food or drinks, ask community partners about their preferences and restrictions for dietary or sensory purposes. Consider restricting the location of where people eat to prevent any sensory discomfort around foods in the main meeting area.
- Reassure community partners that they should feel free to stim or use other self-regulation actions during the meeting (e.g., rocking in their chair). Encourage them to bring and use needed sensory materials, stim tools, and other supports.
- Locate additional spaces that individuals can use if they need a break (e.g., quiet spaces, private sensory spaces)

Sensory Accommodations for Virtual Meetings could include:

- Encourage people to keep themselves muted when they're not taking a turn to reduce noise that may be distracting.
- Allow individuals to turn their cameras off
- Encourage people to wear whatever clothing they find to be comfortable
- Reassure community partners that they should feel free to stim or use other self-regulation actions during the meeting (e.g., rocking while their camera is on during the meeting).
- Ask people to turn their camera off during potentially distracting activities such as eating or cooking during a meeting, moving their camera, or if they have potentially distracting lights (e.g., multicolored lights)

Technology Proficiency and Access:

Some people may not be familiar with, or have access to, technology used during meetings or activities. Providing access to required technology (hardware, programs, etc.) and helping community partners use this technology is necessary for helping them complete activities. For example, you should provide access to technology needed to attend virtual meetings for those who need it (e.g., loaning a tablet with cellular data enabled). You may consider using free or widely-available versions of software (e.g., Google Slides instead of PowerPoint). You may also consider creating and sending tutorials or instructions about how to use essential software in advance, and then giving a short demonstration of a particular tool for everyone who is

attending a meeting. You may also consider having a member of the team available to answer questions by email or phone to help troubleshoot technology. If certain programs or tools are not accessible to a community partner, you must find other ways to collaborate and include these partners in the process.

Physical Accessibility:

Autistic people and caregivers with medical conditions and disabilities have historically been excluded from the research process. Intentional consideration of the physical accessibility of your project engagement will improve equity and representation for this under-considered community. Additionally, some psychiatric and cognitive conditions may impact people's accessibility needs and interactional styles. You should not mandate a disclosure of a diagnosis in order to provide an accommodation or support. A diagnosis does not say with certainty the type of accommodation someone will need. You should ask about preferred supports and accommodations instead of asking if someone has a specific diagnosis. We provide some additional resources below for more guidance about making your project accessible to those with various physical disabilities and medical conditions.

Physical Accessibility Considerations for In-Person meetings could include:

- Ensure buildings are physically accessible for people who use wheelchairs and other mobility aids.
- ASL or other sign language interpretation; live captioning; microphone and/or t-coil
- If looking at presentations/visual aids, make sure you provide detailed descriptions of visuals and that you mention all the information mentioned on the slides aloud
- Choose visuals in colors that are accessible to people with color vision deficiency.

Physical Accessibility Considerations for virtual meetings could include:

- Enable closed captioning
- Offer sign language interpretation
- Offer interpreter services for non-majority-language speakers
- For those not comfortable speaking in front of a group of people, offer that community partners can contribute by using the chat or virtual note taking platforms with a member of the research team reading the content aloud.
- Alt text and screen reader-accessible written documents

Specific Considerations for In-Person Meetings

- Offer childcare for caregivers/parents
- Offer travel vouchers or reimbursement for travel costs to allow people to travel to meetings safely and comfortably. You should also familiarize yourself with parking availability and costs, and validate parking whenever possible.
- Provide a picture of the location and basic information about it (if meeting in person) ahead of time, so people can become familiar with what to expect.
- Offer the option of a hybrid meeting (if possible) so that participants who aren't able to join in-person can still participate

3. Facilitating Communication and Supporting Participation During Meetings and Activities

You can use a variety of strategies and activities to ensure your community partners understand questions and activities, and to ensure successful communication between community partners. You should work with a skilled facilitator when possible, but not all facilitators are knowledgeable about the wide-ranging communication preferences and needs for autistic people or people with other communication disabilities. Below are some guidelines and strategies for ensuring all your community partners have access to communicate their ideas with you and with other community partners.

Strategies for successful communication with partners between meetings:

- **Giving instructions:** Use multiple modalities to provide instructions. Provide screen-reader accessible written instructions, closed captioned videos with step-by-step instructions for more complex or multi-step activities, and audio instructions. Also consider creating video tutorials and picture supports.
- **Complexity:** Keep instructions brief, with additional instructions for those who need more support or prefer more details. Break up long activities into smaller parts to support completion of all activities.
- **Scaffolding/Previewing:** When possible, preview activities in advance so partners understand expectations. For example, if you assign an activity to your community partners after your group meeting, spend a few minutes of your meeting showing the activity to your partners so they know what to expect (e.g., what sections of a document they should review, how to leave comments or feedback in the document).
- **Reminders:** Set up reminders (calendar invitations, google phone number for texting reminders) for independently-completed activities and meetings
 - If working with an existing organization, embed your processes in their system or provide infrastructure that can also help them (e.g., funding for project management system)
 - Consider setting up a private website as a place to post information about the community-engaged project (similar to a page you may use to post information for a class you're teaching). This can be a place where you post meeting recordings and summaries, a description of activities and tasks to complete, and more. You can use programs available by your institution (e.g., Canvas) or freely available websites (e.g., Google Sites).

Strategies to support understanding and participation in meetings:

- **Previewing/Scaffolding:** provide an agenda with estimated time spent for each activity. Provide general descriptions of the activities or discussion questions in advance so people have an opportunity to think about their ideas beforehand. You can also send meeting slides and other relevant material beforehand so people have a chance to review independently. This can help reduce processing demands during the meeting. If questions came up in a “pre-meeting” or in communication prior to the group meeting,

prepare responses to share with the whole group in case another partner had a similar question or concern.

- **Breaks:** If you plan to complete multiple activities within one meeting, plan to use breaks to help people switch to new tasks. You may also plan breaks to break up longer activities.
- **Provide opportunities** for individuals to contribute after a meeting in case they have new ideas or feel more comfortable sharing outside of group meetings. This can include individual meetings, providing forms or surveys for feedback and reflection after meetings, and other strategies
- **Meeting highlights/summaries:** Prepare concise but comprehensive summaries of what happened in the meeting to help people remember and process what was discussed. You can highlight key decisions and actions for a quick summary, and provide more detailed notes about specific discussion points.
- **Small group discussion:** It may be easier for some to follow the discussion with a smaller number of people. Some may feel more comfortable providing input in a smaller group. Additionally, if you are discussing a topic that you believe may be divisive, it might be helpful to first separate into smaller groups before holding a larger group discussion. This way, dissenting opinions can be expressed by meeting facilitators instead of individuals, if there is individual discomfort around sharing dissenting opinions.
- **Confidentiality:** provide a way for people to contribute anonymously (e.g., anonymously sign into a google doc, message privately in chat and meeting facilitator reads it aloud)
- **Use a turn-taking order:** You can use a meeting facilitation technique like “stacking” to establish an order for taking turns in the discussion (for example, asking those who’d like to take a turn to raise their hand and writing down the order), which may help those with difficulty with impulse control to understand when they should or should not take a turn.
 - Provide a space (written paper, chat, etc.) for people to write down their idea or some key words to help them remember when it gets to their turn
 - Provide an opportunity for people to respond to the main point being made before you go to the next person in the list to encourage dialogue and keep the discussion focused
- **Write down notes** summarizing the conversation/takeaways so people can reference it during discussion (e.g., live meeting minutes accessible for those who want it). This may also allow for people to participate if they can’t join a meeting (e.g., community organization and not all the teachers can join the meeting but they can provide input on specific questions beforehand)

Strategies for successful communication during meetings:

- **Jargon:** Provide glossaries for personal reference and explain high-frequency jargon terms. Avoid jargon where possible.
- **Use layperson-friendly language**, for example: “How does X therapy help children learn language?” instead of “to what extent is X therapy associated with children’s expressive language skills?”
- **Processing time:** Pause for ~15-30 seconds after asking a question to allow people to process before the next person speaks. If asking a bigger, overarching discussion question, you may want to allow even longer time (e.g., 3-5 minutes) to allow people to

formulate some ideas. You may even consider breaking large questions into smaller sections or topics based on your community partners' preferences.

Supporting a wide range of communication preferences and needs

- **Recapping:** Summarize what someone said before moving on to the next person to ensure that you and other community partners understand the idea.
- **Communication Partners:** If you have community partners who communicate with the support of a communication partner, make sure this person is informed about the project and also compensated for their time. Although many people may have a trusted family member or friend as their communication partner, you can ask about possible supports that you or members of your research team can provide if their regular communication partners are unavailable to participate.
- **Interpreters:** Consider using an interpreter for community members that do not speak the language used in the meeting (including American Sign Language and other sign languages). If necessary, this could be a trusted family member or friend, but children and family members often take on the role of language broker, which is a burden that could be surpassed by hiring a professional interpreter. Regardless of whether they are a hired professional or someone your community partner already knows, ensure they are informed about the project and compensated for their time.
- **Multimodal communication:** Plan for communication in multiple modalities, such as text-based communication (writing, typing) and symbol-based communication (AAC Device). If allowing multiple forms of communication, make sure you follow-through with these options. For example, if you allow people to participate by typing in a Zoom Chat, make sure you or a co-facilitator monitor the chat and read the message aloud in a timely manner to facilitate their participation in the discussion. Additionally, when asking a question with spoken language, also provide a written form of the question.
- **Questions:** Some people find open-ended questions to be too vague and benefit from more structure to engage in discussions. You can ask community partners about their preferences and consider using different kinds of questions to gather information from your community partners.

Potentially misaligned communication styles

Communication styles and preferences are influenced by culture, neurotype, and other factors. These varied communication styles and preferences can be misaligned at times. It may not be possible to completely accommodate all communication styles all the time, especially during group discussions. We provide some recommendations for accommodating both communication styles when applicable, but this will be individualized to your unique project.

Examples include:

- **Direct vs Indirect communication:** Some people prefer more “blunt” communication styles, whereas others are uncomfortable with direct language or feedback.
 - Rephrase what was said in a different way to make the message more clear for other community partners. For example, if one community partner uses indirect language to make a request, you can rephrase it more directly.

- **Figurative language:** Some people may use or prefer metaphors or figurative language to understand difficult or abstract concepts, whereas others have trouble understanding figurative language.
 - Suggestion: If someone uses figurative language, recast or rephrase their statement to ensure everyone understands. Offer explanations using figurative language or metaphors as supplemental or additional material.
- **Text to augment spoken communication:** Some people find that augmentative text (e.g., closed captions) helps them understand a spoken message. Some people find the text to be distracting, especially if there is not a perfect 1:1 correspondence in the timing and content of the spoken and written messages.
 - Suggestion: Make access to augmentative text optional (e.g., someone can turn closed captions on or off depending on their preference in a virtual meeting)
- **Infodumping:** Many neurodivergent people enjoy communicating by “infodumping,” in which they share a lot of detailed information about an idea or topic of interest. But some people require more time to process language and may be confused about the main idea when a lot of details are shared.
 - Hold optional meetings before or after your primary meeting to give people space to provide more information about their idea. Or, have one-on-one meetings (e.g., a separate physical space or a “breakout room” for a virtual meeting) where either 1) the person who likes to infodump can provide more information, or 2) the person who requires more processing time can review material from the meeting in a more controlled setting
 - Agree on a signal (e.g., raising a hand or using the “raise hand” feature) that someone may use to express when they need time to process, or when they’re overwhelmed by the information
 - Review agendas for each meeting with allotted time for each activity so individuals have a sense of the time they may reasonably have to contribute to the conversation
 - Offer a co-facilitator to have a “breakout meeting” (e.g., a Zoom breakout room for virtual meetings, or a separate space for in-person meetings) where either 1) the person who likes to infodump can provide more information, or 2) the person who requires more processing time can review material with a co-facilitator
 - Use graphic organizers or other visual organization methods to break down large amounts of information

Examples: Competing Access Needs

Example 1: One community partner requires dim lights to concentrate. Another community partner cannot see or read well in dim lighting. Potential solutions may be:

- Discuss that the community partner with sensitivity to light can wear sunglasses during the meeting. If the community partner does not have their own sunglasses, the research team can also talk with them about purchasing sunglasses for them.
- Consider virtual meetings so that individuals can control the amount of lighting in their space.
- Consider using small table lamps to provide additional lighting for those who need it.

Structuring Engagement, Supporting Access Needs, and Facilitating Communication

Example 2: One community partner often uses vocal stims to concentrate, and one is distracted by noise.

- If there are supports that reduce the need for a community partner to use vocal stims, ensure those are in place. For example, if they use vocal stims to regulate their sensory needs when overstimulated, reduce the sensory processing load in other ways. If they use vocal stims to regulate their sensory needs when under-stimulated, see if there are other stims they can use to get their needs met (e.g., a motor stim) or if they can use headphones for additional auditory input.
- If someone is distracted by outside noise, see if they have access to noise reduction headphones or get access to headphones for them.
- If the meeting is held virtually, ensure that people mute their microphones when not speaking.

Example 3: One community partner prefers direct communication, and another community partner gets anxious or uncomfortable with direct or blunt feedback.

- It may be difficult to intervene with incompatible communication preferences between partners with a single strategy. Building understanding and trust between community partners is a foundational step to navigating communication breakdowns. You can teach your community partners about different communication styles to build understanding. You may even leave space for individual partners to share their preferences with the group (if they desire).
- When facilitating meetings, you can recast what was said in a different way to make the message clearer for other community partners. For example, if one community partner uses indirect language to make a request, you can rephrase it more directly.
- Use breakout sessions to give instructions or provide feedback in smaller groups based on individual preferences

Additional Resources:

den Houting J. Participatory and Inclusive Autism Research Practice Guides. Published online 2021. https://www.autismcrc.com.au/best-practice/sites/default/files/resources/Participatory_and_Inclusive_Autism_Research_Practice_Guides.pdf

Shore S, Benevides T. Autistic Adults and other Stakeholders Engage Together Engagement & Compensation Guide. Published online December 2018. <https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf>

Participatory Research – Academic Autism Spectrum Partnership in Research and Education. <https://aaspire.org/inclusion-toolkit/participatory-research/>

Autistic Self-Advocacy Network: Accessibility Resources:

- Inclusive Meetings: The Autistic Self Advocacy Network’s Community Living Summit: <https://autisticadvocacy.org/policy/briefs/community/#inclusive-meetings-the-autistic-self-advocacy-networks-community-living-summit>

Structuring Engagement, Supporting Access Needs, and Facilitating Communication

- Autistic Access Needs: Notes on Accessibility:
<https://autisticadvocacy.org/resources/accessibility/#autistic-access-needs-notes-on-accessibility>

Appendix C: Communication and Participation Preferences Survey

Building Capacity for Engaging in Research

Most community partners will not know about the intricacies of the research process when entering a partnership. A critical part of community engagement is teaching your partners about core concepts so they can fully participate in the process. This can include information related to the research process, autism, the therapy approaches of interest, and more. Teaching community partners about research and the details of your specific project can:

- Help community partners understand your expectations and what you're asking them to do
- Allow community partners to provide fully-informed input
- Build understanding between community partners and researchers with different backgrounds, experiences, and areas of knowledge/expertise
- Correct power imbalances between researchers and community partners
- Be a meaningful experience for community partners who wish to learn more about research and the theory and practices underlying your research study

EXAMPLE: Why is capacity-building needed?

An advisory board member was asked to contribute ideas for the dissemination of research findings, but they did not know what “dissemination” meant. They did not ask what it meant because *they felt like they should have known* given that other people in the group seemed to know what the term meant. Later, they said they wished they had known what the word meant sooner so they could have contributed more ideas. They also wished they knew what the researchers were already planning via “traditional” methods of dissemination, so they could help think of *new* ideas the team didn't already know about.

Setting the Scene:

Identify the concepts, processes, and terminology that are important for community partners to understand. This can be research concepts, clinical concepts, theories of development, and more. This could also include providing definitions and/or a glossary for high-level academic language and terms that may come up in discussions or resources.

Consider: How much information is critical to understanding and contributing to the discussion? What information might be helpful or interesting, but not essential?

- Capacity-building is an important foundation for participation, but you must consider your project partners' other commitments and time restrictions. Focusing on the most critical information, and explaining why this information is important, is more respectful of their time.
- Some community partners join research projects to learn more about research, so they may be interested in learning about things in more detail. Providing opportunities for

“supplemental” capacity-building can foster deep partnerships with these community members and help them meet their own goals.

- *EXAMPLE:* [The AASPIRE Network](#) has described holding separate “science geek” meetings that allow them to participate in discussions requiring a deep level of scientific knowledge, without requiring it of all community partners.

Identifying Sources for Capacity-Building:

Next, you need to identify sources of information to teach people about these concepts. There may be pre-existing resources, or you may need to create resources of your own. Some resources may be designed for community-engaged projects, but sometimes resources (YouTube videos, blog posts, etc.) intended for students may also be valuable. Consider:

- How accessible are these resources for my community partners (modality, reading level, physical accessibility)?
- Create opportunities for community partners to ask questions about capacity-building materials (e.g., holding an “office hour” when partners can ask questions about videos/reading material they reviewed independently)

We also recommend that you develop a glossary by starting with a list of terms you think may need explaining, and as the process goes on, more terms can be identified by your community partners and added to the glossary. This may also take away some of the fear around asking clarification questions. You can distribute this glossary and reference it during meetings so it's easy to access both beforehand and in the moment.

As stated in the *Identifying community partners and consent* sections, you will do some basic capacity-building about research and your project through this onboarding process. You can integrate this content in your onboarding materials, and also make reference to this throughout the project as necessary.

What resources exist for capacity-building around research topics?

You will want to find resources that specifically address the concepts in your project. Here are some basic resources to start:

- Building Research Integrity and Capacity (BRIC) training: US Department of Health and Human Services Office of Research Integrity <https://ori.hhs.gov/basic-research-concepts-brc>
 - Nebeker, C., Simon, G., Kalichman, M., Talavera, A., Booen, E., & Lopez-Arenas, A. (2015). [Building Research Integrity and Capacity \(BRIC\): An Interactive Guide for Promotores/Community Health Workers](#). San Diego, CA: BRIC Academy.
- PCORI Research Fundamentals Training: <https://www.pcori.org/engagement/research-fundamentals>
 - [Research Fundamentals Supplement](#): The PCORI Engagement Award that funded this project also produced a supplement to PCORI's training specific to EI autism research in collaboration with our advisory board of autistic people and caregivers.
- PCORI Guide for Engaging with Research Partners about Data and Analysis: <https://www.pcori.org/sites/default/files/2021-09/PCORI-Guide-for-Engaging-with-Research-Partners-about-Data-and-Analysis.pdf>

Capacity-building for community organizations

When working with community organizations, you must also support their capacity to engage in research (and related activities). This will be much more individualized to an organization's specific mission, structure, and more. This capacity-building process may not only include teaching organizations about the structure, politics, and rules of conducting research, but also helping to secure funding and resources necessary for them to contribute to the project. For example, if working with clinicians, you may need to secure funding to protect time for them to contribute to the project (i.e., so they can have a reduced caseload). You may be able to secure access to project management software or resources they can use to better communicate with you. You may also secure funding to have a dedicated member of their team spend time on the project and communicate between your team and the rest of their organization. Your project should not put a strain on an organization's resources, but instead your partnership should enhance the organization's mission.

Additional resources:

- Wangen M, Escoffery C, Fernandez ME, et al. Twenty years of capacity building across the cancer prevention and control research network. *Cancer Causes Control*. 2023;34(Suppl 1):45-56. doi:[10.1007/s10552-023-01690-2](https://doi.org/10.1007/s10552-023-01690-2)
- Deeb-Sossa N, Manzo RD, Kelty J, Aranda A. Community-responsive scholar-activist research: conceptualizing capacity building and sustainability in a Northern California community-university partnership. *J Community Pract*. 2022;30(1):71-83. doi:[10.1080/10705422.2022.2033375](https://doi.org/10.1080/10705422.2022.2033375)
- Medina NG, Ávila LSB, Mendez LB. Collaborative Transdisciplinary Research In A Small Institution: Challenges And Opportunities. *Informing Science: The International Journal of an Emerging Transdiscipline*. 2018;21:235-253. Accessed August 15, 2024. <https://www.informingscience.org/Publications/4028>
- Rubin CL, Martinez LS, Tse L, et al. Creating a Culture of Empowerment in Research: Findings from a Capacity-Building Training Program. *Prog Community Health Partnersh*. 2016;10(3):479-488. doi:[10.1353/cpr.2016.0054](https://doi.org/10.1353/cpr.2016.0054)

Compensation and Payment

Participation in a research project takes time and effort, whether you are a trained researcher or a community partner. As such, you should compensate community partners whenever possible. This may be in the form of payment or other opportunities beneficial to your community partners. Below, we describe potential payment and compensation considerations for community partners at the individual and organization level.

Payment for Individual Community Partners

It is vital to understand how you will be able to pay community partners before you begin identifying partners, because many payment options are inaccessible to various people. You may have institutional restrictions on how you can pay people with discretionary funds or grant-funded projects. Two common ways that universities will use to pay individual community partners include hiring them as **temporary employees** or **independent contractors** (per current IRS worker classification rules).

Hiring project partners as **temporary employees**: This is often the route deemed appropriate for ongoing partnerships with individuals.

- **Benefits:** Payment may occur more immediately and predictably (i.e., through direct deposit)
- **Limitations:** Lengthy hiring and onboarding process involving potentially sensitive procedures such as background check, proof of citizenship, and more.

Hiring project partners as **independent contractors**: This route may be determined to be more appropriate for some short-term tasks, or at the “symbolic participation” level.

- **Benefits:** Easier hiring and onboarding process
- **Limitations:** This payment process may require more approvals than the temporary employee process, depending on the structure of your organization. This may mean a longer lag between when you initially submit invoices and when your partners receive their payment.

Considerations for commonly excluded groups:

Some groups that may experience restrictions on payment include undocumented individuals (i.e., due to proof of citizenship) and individuals receiving Social Security Disability Insurance (SSDI) benefits (i.e., due to limits on employment and monthly income).

- The temporary employment process might be more beneficial for people with monthly income limits due to the predictability of pay dates. Monthly income is usually calculated based on when payment is received, not when the work was performed.
- You can also consider partnering with organizations serving people in these groups. This way, you may be able to get feedback or partner with individuals within the structure of their regular commitments and without burdening their limited work schedule or payment constraints.

Tips for planning payment:

- Consider different types of participation activities to allow people to get paid in a way that meets their constraints based on payment. Individuals in your human resources and finance departments may have more information about allowable payment mechanisms and worker classification expectations based on the activities in your project.
- Be honest about available payment options and benefits/limitations of these options. If you have flexible opportunities that would allow payment in multiple routes (i.e., ongoing as a temporary employee, short-term as an independent contractor), this can also allow people to choose the method of participation that works best for the wide variety of things they have to consider.

How much should you pay community partners?

- The specific amount you pay community partners depends on your resources and the nature and extent of work they will contribute. You may pay partners more for deeper levels of engagement to reflect their increased authority and role in the project. You may decide to use an hourly rate or flat rate for completing activities, depending on the nature of the activities and if it's a short-term or ongoing partnership. In the experience of the authors of this toolkit, \$50/hour tends to be a minimum amount to pay community partners, but this will vary based on your unique situation.
- Advisory board members for the project that funded the creation of this toolkit were compensated at \$100 to approximate (as closely as possible, given the budget limitations) the amount that would be paid to researcher consultants.

Other Compensation Ideas for Individual Community Partners

- Training community partners or organizations in specific skills
- Offering relevant resources (e.g., information sessions or educational materials, screeners)

Compensation/Reciprocity for Community Organization Partners

As described above, you should focus resources on enhancing community organizations' capacity to engage in research. Beyond this, there are other ways you can compensate or demonstrate reciprocity to community organizations. These should be tailored to an organization's unique strengths and needs. For example:

- Offer to hold educational events or outreach efforts that will benefit their community (e.g., presenting about an autism-related topic the community wants to learn about)
- Facilitate organizations' ability to secure funding (e.g., through supporting grant writing, alerting them to various funding sources, or other efforts identified as areas of challenge for an organization)
- Paying for things like food, refreshments, supplies, etc. for a community organization partner event (i.e., they bring the people, you pay for the infrastructure)
- Helping community partners or organizations connect with other organizations or departments within your institution if it is of benefit to them.

Compensation and Payment

- Offering to volunteer at a community organization
- Offering to use your social media platforms to disseminate community organization's events and resources.

Additional Resources

- Compensation Framework | PCORI. May 3, 2017.
<https://www.pcori.org/resources/compensation-framework>
- Shore S, Benevides T. Autistic Adults and other Stakeholders Engage Together Engagement & Compensation Guide. Published online December 2018.
<https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf>

Gathering Feedback and Measuring Engagement Success

You should gather feedback from your community partners to ensure they are having a satisfying experience. You may also use this to ensure you are upholding any community guidelines you set with your community partners. Gathering feedback at regular intervals can help you update your procedures.

Considerations for Gathering Feedback

Invite critique or “negative feedback” about the project. Many community partners may feel intimidated or uncomfortable providing honest feedback that they think could cause offense to the research team. They may also worry that providing critiques could impact their relationship with the team (e.g., being asked to leave the project or not being invited to join future projects) or their role in the project (e.g., being ignored or given limited opportunities to contribute). So, without explicit invitation to provide critique, community partners may feel uncomfortable sharing this honest feedback.

- From the beginning of your project (e.g., foundational community guidelines), tell your community partners about the value you place on honest feedback and your dedication to making the collaboration a valuable experience for them. This can help to build trust from the beginning of your partnership.
 - Everyone goes through periods of time when they may feel defensive about critiques, especially if they are feeling burned out or overworked. If you feel that you may be defensive about critiques, ask someone else on your team to review feedback.
- You can also provide ways for partners to provide critiques anonymously if they feel more comfortable (e.g., anonymous survey, communication with a member of the research team who is uninvolved in other components of the project)

Invite your partners to provide feedback even if they think it seems unimportant or inconsequential. You should reassure your partners that you want to create an optimal experience. If they find that something could be improved or needs to change to fit their needs, it's possible that the change could also have a positive impact on others in the group. And even if they are the only person a change would impact, their satisfaction is important to you. This may be especially important for autistic and neurodivergent people who may be used to “masking” or suppressing their own preferences and needs to fit the “norm” of neurotypical people. Promoting an inclusive environment and inviting them to provide all feedback may help these community partners feel comfortable advocating for their needs and expressing themselves authentically. This also applies to asking questions, particularly clarification questions. Assure your partners that any and all questions are welcome. If someone has a question it is likely that someone else in the group had the same question; if not now, maybe in the past. Model this behavior by always explaining jargon terms and avoiding abbreviations that are common in research (e.g., PI, NIH, etc.) and, if truthful, say that you didn't know what this meant at first either.

Be transparent about ways you will integrate and communicate feedback from your community partners. You can even communicate about positive feedback you received (e.g., “many of you reported that you appreciated our addition of calendar invitation reminders. We’ll continue to use those going forward.”). This helps affirm that you are taking your partners’ feedback seriously. If you receive negative feedback about any of the processes involved (e.g., meetings are not accessible enough, lead times for meetings are not long enough, etc.) be sure to acknowledge this and take responsibility if appropriate.

- If you cannot integrate someone’s feedback (e.g., restricted resources, demands of project timelines, managing conflicting feedback), you should also communicate about why you are unable to use that feedback. However, you should do your best to integrate their feedback in another way if possible.
- You should also be clear about accountability and potential consequences related to feedback. Some community partners may have concerns that critiques could get someone in trouble (for example, a research assistant being fired or another community partner being removed from the project). Outlining procedures around accountability and procedures when guidelines are violated can reassure your partners that, unless one of these guidelines is crossed in a substantial way as agreed upon by the group, their feedback will not get anyone in trouble.

How to Gather Feedback

- **Pre-existing surveys:** You may use a pre-existing survey meant to measure the strength of community partnerships across disciplines (e.g., [Goodman et al., 2017](#)). This allows for comparison across studies, but not all constructs on the survey may be relevant to your project. You should also consider the accessibility of these surveys for autistic community partners and whether or not you should adapt them to support all community partners’ ability to complete the survey.
- **Create your own survey:** You may choose to create a survey about partners’ satisfaction with the project. This can be based on your community guidelines and specific activities. This limits comparison with other projects, but may provide you with more specific feedback you can quickly incorporate into your project.
- **Feedback meetings:** You can hold meetings with board members to solicit feedback about the project and partnership.

Measuring Engagement Success

The science of community engagement is quickly evolving. As such, there are calls for researchers across disciplines to formally measure and report the effectiveness of their engagement strategies. Some teams have developed satisfaction surveys intended to be used for highly-engaged projects across disciplines, but measurement in this area is still emerging. Regardless of your project’s specific goals and structure (e.g. level of engagement; partnerships with organizations and/or individuals), you should aim to measure and report about the success of your partnerships. Not only does this add transparency to the research process, but it can help you and other researchers update engagement procedures in the future. In the additional

Gathering Feedback

resources below, we list some examples of surveys or frameworks you may consider using to measure your partners' satisfaction with engagement.

Additional Resources:

Goodman MS, Ackermann N, Pierce KA, Bowen DJ, Thompson VS. Development and Validation of a Brief Version of the Research Engagement Survey Tool. *International Journal of Environmental Research and Public Health*. 2021;18(19):10020. doi:[10.3390/ijerph181910020](https://doi.org/10.3390/ijerph181910020)

Gordon B, Van De Griend KM, Scharp VL, Ellis H, Nies MA. Community Engagement in Research: An Updated Systematic Review of Quantitative Engagement Measurement Scales for Health Studies. *Eval Health Prof*. 2023;46(4):291-308. doi:[10.1177/01632787231203346](https://doi.org/10.1177/01632787231203346)

Chung J, Sarathy A, Hsieh YG, et al. Assessment of Stakeholder Engagement in a Down Syndrome Research Study. *J Patient Cent Res Rev*. 2021;8(1):64-67. doi:[10.17294/2330-0698.1777](https://doi.org/10.17294/2330-0698.1777)

Henrick EC, Cobb P, Penuel WR, Jackson K, Clark T. *Assessing Research-Practice Partnerships: Five Dimensions of Effectiveness*. William T; 2017. Accessed August 16, 2024. <https://eric.ed.gov/?id=ED610463>

Patient Centered Outcomes Research Institute. Measuring What Matters for Advancing the Science and Practice of Engagement. Published online 2023. <https://www.pcori.org/sites/default/files/PCORI-Measuring-What-Matters-for-Advancing-the-Science-and-Practice-of-Engagement.pdf>

Appendix E: Example Satisfaction Survey

Funding and Support for Community-Engaged Research

Unfortunately, the time/resource-intensity and the innovative nature of community-engaged projects can present challenges to securing resources and funding. This may be especially challenging for early career researchers and researchers from groups that have been historically minoritized in academia (e.g., researchers with disabilities, researchers of color, those at the intersection) because they face additional demands to their career advancement and may not be able to take the same kinds of risks as researchers with tenure or who face fewer barriers to funding/career advancement.

Autism researchers at more advanced stages of their career should prioritize supporting community engagement as a vital component of autism research to facilitate funding (e.g., through peer-reviewed processes and funding agencies). These cultural/systemic changes in academia will not happen overnight, but even small changes by individual researchers can add up to a large shift. Structural changes in funding and publication practices around community-engagement will also be necessary for long-lasting change. There are some promising avenues like internal university grants and recent calls for proposals by the NIH that include community-engaged components.

Despite potential challenges to conducting fully-engaged participatory research (e.g., participatory action research, community based participatory research), it is important to keep in mind that community engagement can be developed at different levels of engagement and participation. There are many ways to involve community members that may be more feasible for people at early stages of their careers, or at institutions that are less well-funded, so they can include this type of work in their research and build experience while on the tenure track.

Examples of Alternative Approaches:

- Conduct delphi studies, qualitative studies, or use other “formal” research approaches to gather community opinions about a topic that can be disseminated in peer-reviewed journals or conferences.
- Use lower frequency or less intensely engaged approaches (e.g., consultation via one-time focus groups), including those that may be fairly implemented on a volunteer basis
- Consider hiring research assistants or staff from the communities you hope to center in your research, and involve them in the design and decision-making processes in your research.
- Consider dissemination efforts at community organizations (e.g., non-engaged participation in an educational lecture to community members) to establish initial relationships

Although the above suggestions may not take the recommended community-engaged approach we outline in this tool, they may contribute to making early childhood autism research more aligned with community perspectives. They may not be sufficient for what is considered “true” community engagement, but it is better than having no representation at all from the community that is being studied. These partial efforts can also help to promote the inclusion of researchers from marginalized communities; showing that you value their personal experiences and the

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unique contributions they may make will support their development and encourage and enable their participation in science.

How to secure funding for community partnerships

Lack of support for participatory research within the system of academia has been noted as a barrier to this type of work by researchers ([Pickard et al., 2022](#)). As this tool has pointed out, community engagement requires a vast amount of resources, both time and financial.

There may be more funding mechanisms for applied research (e.g., effectiveness and implementation trials), but community engagement is essential in all parts of the research-to-practice pipeline. Here are some possible ways to secure funding for community-engaged research:

- Look for seed grants for establishing partnerships through your institution's community health, implementation, public health, or other community-engaged institutes and offices.
- Consider how community engaged work can be embedded in current or upcoming grants
- Identify funding sources that align with your project's goals, e.g., private organizations, foundations, local government grants, etc.
- Look for online resources on funding for community engaged research. Some institutions have organized resources about funding (though not specific to autism).
- Patient-Centered Outcomes Research Institute (PCORI) provides funding for community-engaged research across disciplines, with a specific focus on comparative effectiveness research.

Additional Resources and References

Jordan CM, Joosten YA, Leugers RC, Shields SL. The Community-Engaged Scholarship Review, Promotion, and Tenure Package: A Guide for Faculty and Committee Members. *Metropolitan Universities*. 2009;20(2):66-86. Accessed August 15, 2024. <https://journals.indianapolis.iu.edu/index.php/muj/article/view/20391>

Pickard H, Pellicano E, den Houting J, Crane L. Participatory autism research: Early career and established researchers' views and experiences. *Autism*. 2022;26(1):75-87. doi:[10.1177/13623613211019594](https://doi.org/10.1177/13623613211019594)

Examples of institutional programs supporting community engagement:

- <https://ictr.wisc.edu/just-research-program/>
- <https://healthinstitute.illinois.edu/community-impact/community-academic-partnerships/community-engaged-funding-scholarship>
- <https://www.feinberg.northwestern.edu/sites/cch/get-support/arcc/index.html>

Offboarding

The last stage in a community-engaged project is “offboarding,” or ending the partnership. This is a part that often gets forgotten or addressed in a less-than-ideal way. Researchers are often pulled in different directions and may simply forget to address this stage of the process. Give offboarding some thought even in your very initial project planning by making it an “official” project phase, rather than an afterthought.

The end of a specific project does not mean the end of a working relationship, but this is not always the case. You want to end your collaboration in a way that leaves the possibility of future collaborations. **You should always make sure to thank people for their contributions and celebrate the work that you have accomplished together.** Even if there is no immediate funding for another project to work on together, you can jointly think about ways to keep your relationship going even in the absence of funding. For example, are there professional development opportunities you could offer your partners? Are there ways for them to contribute to other projects going on in your lab? Are there lab events such as an end-of-year celebration community partners can be invited to? What can your lab do to facilitate their own ideas or projects going on in their own organization?

This may be especially important when engaging with community partners in a short-term way (e.g., through “symbolic engagement”). As the engagement activities end, inform your partners about the timeline from their involvement to the dissemination of results. Update them about the progress of the study and how their contributions were used. For example, if they gave feedback about a survey used to collect data, it could take *years* before the results of the study are published. Updating them on a quarterly, semi-annual, or annual basis (depending on the project) can help to keep them engaged. This can be as simple as putting a reminder on your calendar as these updates are easily and unintentionally forgotten. Tell them when data collection is over, when data analysis and interpretation is happening, and send them the results at the end of the study. This may also help if you want to engage them in other parts of the research process as well.

What if someone leaves before the end of a project?

You may have individual community partners leave before the official end of the project. This could be for a variety of reasons that may or may not have anything to do with your project. For example, if someone realizes that they do not agree with the mission or principles of the project after the group discussion about community guidelines, they may realize that it is not a good opportunity for them and wish to leave the project. You may also have community partners who have substantial life events or responsibilities that make it difficult for them to commit to the project partway through. Community-engaged projects are dynamic, and some partners may become uninterested in the project as it changes over time; for example, if you switch the therapy you will deliver in your study, a partner who was specifically interested in the original therapy choice may not want to be involved anymore. You should create opportunities for people to leave the project at various stages of the collaboration.

Considerations for departing partners include:

- Provide opportunities for partners to leave the project without guilt, and without disclosing the reason for leaving the project.
- Invite people to provide feedback about the project, as it may provide an opportunity for you to update procedures to be more acceptable or inclusive in the future.
- Clarify preferences around authorship and privacy if they leave the project early. Depending on when the partner leaves, they may or may not have contributed a sufficient amount to be considered an authored contributor on published manuscripts or materials. Ask about their preferences for authorship (e.g., named or unnamed contributor in the Acknowledgements section of a paper) going forward.
- Ask if they would like to be contacted with project updates or future partnership opportunities. You may find that someone does not have time to commit to a project due to a life change, but may wish to rejoin the project in the future as things resolve.

Additionally, a partner's departure from the project should be handled such that other community partners are not left questioning the situation, but respecting the privacy of the departing partner as well. You can keep this vague to protect privacy (e.g., "they needed to prioritize other things"), but leaving a departure unacknowledged can have others wondering what happened.

Recommended Resources for Further Learning

Tools and Guides

den Houting J. Participatory and Inclusive Autism Research Practice Guides. Published online 2021. https://www.autismcrc.com.au/best-practice/sites/default/files/resources/Participatory_and_Inclusive_Autism_Research_Practice_Guides.pdf

Shore S, Benevides T. Autistic Adults and other Stakeholders Engage Together Engagement & Compensation Guide. Published online December 2018. <https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf>

Participatory Research – Academic Autism Spectrum Partnership in Research and Education. <https://aaspire.org/inclusion-toolkit/participatory-research/>

Wainer AL, Walton KM. A Workbook to Support Community- Engaged Autism Research: Published online 2022. https://nisonger.osu.edu/wp-content/uploads/2023/04/A-Workbook-to-Support-Community-Engaged-Autism-Research_Fillable.pdf

*McCloskey DJ, Akintobi TH, Bonham A, Cook J, Coyne-Beasley T. Principles of Community Engagement (Second Edition). https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

*Patient-Centered Outcomes Research Institute – Building Effective Multi-Stakeholder Research Teams: <https://research-teams.pcori.org/>

*Duea SR, Zimmerman EB, Vaughn LM, Dias S, Harris J. A Guide to Selecting Participatory Research Methods Based on Project and Partnership Goals. *JPRM*. 2022;3(1). doi:[10.35844/001c.32605](https://doi.org/10.35844/001c.32605)

*Stakeholder Engagement Navigator. <https://dicemethods.org/>

*These resources are not specific to autism, but provide helpful guidance, examples, and resources for choosing engagement strategies and structuring community-engaged projects.

Related Resources and Examples

Below are additional resources about ways to engage with community members in different types of autism research, and examples of community-engaged autism research). This includes research in which community members are part of the research team (as opposed to research that gathers community perspectives on a topic, such as qualitative studies of community

Recommended Resources for Further Learning

perspectives about a specific therapy or implementation context). Because we were not involved in these projects, we cannot comment on the success of community engagement strategies or experiences of individual community partners involved in these studies.

Brookman-Frazee L, Stahmer AC, Lewis K, Feder JD, Reed S. Building a Research-Community Collaborative to Improve Community Care for Infants and Toddlers at-Risk for Autism Spectrum Disorders. *Journal of Community Psychology*. 2012;40(6):715-734. doi:[10.1002/jcop.21501](https://doi.org/10.1002/jcop.21501)

Carroll C, Sixsmith J. Exploring the facilitation of young children with disabilities in research about their early intervention service. *Child Language Teaching and Therapy*. 2016;32(3):313-325. doi:[10.1177/0265659016638394](https://doi.org/10.1177/0265659016638394)

Fletcher-Watson S, Adams J, Brook K, et al. Making the future together: Shaping autism research through meaningful participation. *Autism*. 2019;23(4):943-953. doi:[10.1177/1362361318786721](https://doi.org/10.1177/1362361318786721)

Hobson H, Linden A, Crane L, Kalandadze T. Towards reproducible and respectful autism research: Combining open and participatory autism research practices. *Research in Autism Spectrum Disorders*. 2023;106:102196. doi:[10.1016/j.rasd.2023.102196](https://doi.org/10.1016/j.rasd.2023.102196)

Jose C, George-Zwicker P, Tardif L, et al. “We are the stakeholders with the most at stake”: scientific and autism community co-researchers reflect on their collaborative experience in the CONNECT project. *Res Involv Engagem*. 2020;6(1):58. doi:[10.1186/s40900-020-00233-2](https://doi.org/10.1186/s40900-020-00233-2)

Kaiser K, Villalobos ME, Locke J, Iruka IU, Proctor C, Boyd B. A culturally grounded autism parent training program with Black parents. *Autism*. 2022;26(3):716-726. doi:[10.1177/13623613211073373](https://doi.org/10.1177/13623613211073373)

Kaplan-Kahn EA, Caplan R. Combating stigma in autism research through centering autistic voices: a co-interview guide for qualitative research. *Front Psychiatry*. 2023;14:1248247. doi:[10.3389/fpsy.2023.1248247](https://doi.org/10.3389/fpsy.2023.1248247)

Tschida JE, Lee JD, Pomales-Ramos A, Koo V. Reported quality indicators and implementation outcomes of community partnership in autism intervention research: A systematic review. *Autism Research*. 2024;17(2):215-233. doi:[10.1002/aur.3103](https://doi.org/10.1002/aur.3103)

https://issuu.com/crae.ioe/docs/crane-starterpack_pages_v5

<https://participatoryautismresearch.wordpress.com/>

Appendices

Appendix A: Sample Guiding Principles

Appendix B: Sample “Recruitment” Survey

Appendix C: Survey about Participation Preferences and Individualized Supports

Appendix D: Sample Recruitment Materials

Appendix E: Sample Satisfaction Survey

Appendix A. Sample Guiding Principles

Guiding Principles

- 1) Our opinions are influenced by our culture, socioeconomic status, religion, education, neurotype, and more. We all have different opinions based on these factors, but that doesn't mean that anyone's opinion is "more correct." It's just based on different experiences. So, when we disagree with each other, we should **work together to find a solution** that makes room for our different experiences and opinions.
- 2) We should consider autistic people's strengths and consider the role of the environment in creating challenges to best support the well-being of autistic people.
 - a) We believe that we must consider the unique strengths of **neurodiversity, neurodiversity-affirming practices**, and autistic people to support their well-being and promote healthy relationships between autistic and non-autistic people of all ages.
- 3) Some autism characteristics, or conditions that commonly co-occur with autism, may be challenging even in an accommodating environment. We need to understand these nuances to best support autistic people while still affirming their autistic identity.
- 4) We understand that each caregiver has unique goals and priorities for their child's development, and we must respect their role as decision-makers and recipients of care in Early Intervention services.
- 5) Because most research and clinical practice has not considered neurodiversity, the information caregivers receive about autism may also not consider neurodiversity or autistic identity. Caregivers may experience real challenges and uncertainties about supporting their child's development and helping them participate in daily activities. We can help caregivers support their child's development while still educating them about autism from an autistic lens.
- 6) Autistic people, autistic caregivers, and non-autistic ("allistic") caregivers all have valuable contributions for research and clinical practice for autistic children. Partnering with individuals from all these groups will ensure that autism supports and services in early childhood consider the long-term well-being and success of autistic people.
- 7) We will use an individual's preferred terminology and identity markers. If someone uses the incorrect terminology, we'll extend them grace and allow them reasonable opportunities to correct their mistakes.
- 8) We will respect each other's privacy by not sharing information about group discussions with people outside of our project.

Our Commitment to the Advisory Board

- 1) We'll provide opportunities for everyone on the advisory board to contribute to project objectives and decision-making. This includes offering accommodations that allow all members of the advisory board to participate successfully.
- 2) We will mediate disagreements in an unbiased way. This means that we won't show preference for opinions or ideas made by certain individuals.
- 3) We will communicate about tasks and activities in a timely manner.
- 4) We will provide ongoing opportunities for advisory board members to provide feedback about the project both directly (to project team members they regularly interact with) and indirectly (to project administrators who can share anonymous feedback to team leaders). We'll use

Appendix A. Sample Guiding Principles

the feedback to continuously update procedures and make sure everyone is happy with the project and their participation.

Terminology

Overarching Concepts

Autism is a neurodevelopmental disability. Autistic people have differences in the development and use of communication, sensory processing, executive functioning, and motor skills compared to non-autistic people. They also often have preferences for routines and objects/topics of passion. Many autism characteristics lead to unique strengths, and some characteristics inherently present challenges for the autistic person. However, many autism characteristics only become challenging for an autistic person when in an unaccommodating environment and/or faced with social norms that do not account for their preferences or needs.

Neurodiversity: An idea that combines the words “neurological” and “biodiversity” to express that there is wide variety in the way that people think, feel, and function. Neurodevelopmental disabilities (like autism or ADHD) are part of that natural variability. Neurodiversity frameworks state there is no single “normal” way of functioning in and experiencing the world.

Neurodiversity-Affirming Practices: This refers to supporting individuals with neurodevelopmental disabilities in a way that values their unique strengths, and considers the ways our environment and social norms present challenges. So, instead of treating autism characteristics as something to be “fixed” to make a person more “normal,” we think about how the environment presents challenges for the autistic person and how we can offer supports and accommodations, rather than force them to change who they are.

Below are some examples of how to use neurodiversity-affirming practices:

- Some autistic people find it easier to use straightforward, literal communication instead of figurative language. For example, if an autistic person wants someone to close the window, they may say “Please close the window,” instead of asking “Is it chilly in here?” to imply that the person should close the window. Allistic (non-autistic) people may consider autistic people to be “too direct,” and autistic people may find allistic people to be too unclear.
 - Traditionally, we would only seek to teach autistic people to understand and use figurative language. But using **neurodiversity-affirming practices** we can teach allistic (non-autistic) and autistic people to understand each other’s communication preferences.
- Some autistic children prefer lining up dolls in specific patterns instead of playing with them in a playhouse.
 - Traditionally, autistic children would be taught how to use the dolls in “pretend play” because this is thought to be the “typical” way to play and is thought to be important for future narrative and cognitive skills. Autistic children may have even been taught to *not* line up their dolls.
 - Using **neurodiversity-affirming practices**: we see that this play preference might be an expression of unique strengths in finding and creating patterns. Not only is this fun for the child, but it could also be important for building other skills in the future. We encourage the child to build on this way of playing, and even if we *show*

Appendix A. Sample Guiding Principles

them other ways to play with the dolls, we do not force them to play in a specific way.

Identity Terminology

Autistic adult/child: an adult or child who meets the criteria for a diagnosis of autism. Some people prefer this term because it shows that autism is an important, essential part of their identity. Surveys have shown that most adults prefer the term “autistic” instead of other identity terms, and this term is growing in popularity with the neurodiversity movement.

Person/child with autism: Some people prefer this term because it shows that autism is just one part of their identity. Surveys have shown that many non-autistic parents of autistic children prefer the phrase “child with autism.”

Neurodivergent: A person who has a neurodevelopmental disability, such as autism and ADHD. Some neurodivergent people are autistic, and some are not.

Neurotypical: A person who does not have a neurodevelopmental disability.

Allistic: A person who is not autistic. Someone may be allistic (not autistic), but still have a different neurodevelopmental disability.

Service Delivery

Early Intervention (EI)*: a program that funds a variety of support services for young children with disabilities (typically from birth to 3 years old) and their families. It is federally-mandated under Part C of the Individuals with Disabilities Education Act (2004). This program provides free evaluations and services, such as speech and occupational therapy, to children with disabilities.

- Early Intervention is the term used to describe this program and research that investigates ways to support children and families served by this program. *We do not use the term “intervention” to imply that autism is a disease or disorder requiring “intervention” to prevent or cure autism characteristics from developing.

Family-Centered Practices: This refers to a core principle of EI, in which clinicians work with caregivers to support their child’s needs and focus on goals that will help the child participate in activities that are important to their family. According to this important framework, providers should 1) teach caregivers about their child’s specific needs, 2) share specific strategies they can use with their child, and 3) help them to choose goals and activities that are important to their family.

Clinicians and caregivers also work together to discover the child’s needs and optimal strategies for supporting their development. For this reason, caregivers are both a decision-maker for their child and a ‘recipient’ of care in EI systems.

Appendix B: Sample Recruitment Survey

Header at the beginning of the survey:

Thank you for your interest in joining the advisory board for our project! The overall goal of this project is to create tools that will help researchers and members of the autistic and autism communities collaborate to create early childhood autism research that prioritizes the needs of autistic people. More information about the project can be found [here](#). Funding for this project is provided by a Eugene Washington Patient-Centered Outcomes Research Institute (PCORI) Engagement Award.

This survey is intended for autistic adults and/or caregivers (e.g., biological or adoptive parent, legal guardian) of autistic children who are interested in joining the advisory board for our project. The survey consists of X questions and will take approximately 10-20 minutes to complete. If you'd prefer to complete this survey by phone or video call with a member of the project team, you can reach out to project team member NAME at email@address.edu to schedule a time to complete the survey. You can also reach out to NAME with questions you may have about completing the survey.

This survey will be used to identify partners from the autistic/autism communities to join the advisory board for this project. Depending on demand, we may not have room for everyone who's interested to join the board, but we will do our best to create opportunities for individuals to participate even if not chosen to join the advisory board.

Section 1: Availability

- This project will take place from April 2023-December 2024.
- You'll be expected to commit 1.5-3.5 hours to the project each month, and be compensated \$100/hour for this effort.
- This commitment will typically include one 1-1.5-hour virtual group meeting and additional time reviewing materials in preparation for the meeting each month.

We are committed to providing accommodations to meet the communication needs and preferences of all participants, so if a virtual group meeting does not meet your needs, we will work with you to find a better mode of participation (such as participation via written feedback; see information in the FAQ document for more information about alternative participation methods).

Additionally, if you do not have the technology required to participate in virtual meetings (such as high-speed internet), we have limited availability of data-enabled iPads and hotspots to loan to our advisory board.

We understand that it can be difficult to predict commitments so far into the future, and that some times of the year may be extra busy for some individuals (for example, the beginning of a school year, holiday travel). Therefore, we hope that interested individuals can participate for at least 75% of the project period.

1. Do you think you can commit 1.5-3.5 hours each month to this project between April 2023-December 2024, missing no more than 6 months total of participation (barring any unexpected circumstances or life events)? We understand it can be difficult to predict commitments so far into the future, so please use the open-text box below to provide more information about your availability to participate in this project if you'd like. (Yes, Maybe, No, open-text)
2. [If YES]: Are there any months during the project period (April 2023-December 2024) when you think it will be difficult to participate in the project? If so, please describe here. For example, if you may be too busy to commit to 1.5-3.5 hours of participation at the beginning of the school year or when traveling over holidays. (open text)
3. [IF NO or MAYBE]: We may recruit additional people to join the advisory board depending on the availability of initial members and project activities. Would you like us to contact you if a position on the advisory board is open for temporary participation (i.e., 1-4 months)? (yes/no)
4. [IF NO or MAYBE]: Would you like us to contact you with other opportunities related to this project as they arise in the future? This includes tasks such as reviewing or piloting materials, helping us disseminate materials to the community, contributing to written publications, and more. (yes/no)
5. [IF NO or MAYBE]: Would you like us to send you information about project tools (e.g., publications, virtual discussions and presentations) at the end of the project period? (yes/no)
6. [if yes to 1, 2, 3, or 4] How would you prefer we contact you in the future (check all that apply)?
 - a. Email (fill in if checked off)
 - b. Text message (fill in phone number if checked off)
 - c. Phone call (fill in phone number if checked off)

(if no to 1, 2, 3, and 4): Thank you for your initial interest in this project. If you're unable to participate in this project, you can stay up to date by following us on Instagram at [ei.northwestern](#). If something changes and you're curious about joining us in this project in the future, please reach out to email@address.edu

(if yes to 1, 2, or 3, proceed with the rest of survey)

Section 2: Demographic Information and Experience with Autism

We are collecting information about individuals' diagnostic status, experiences with intervention, and cultural background to ensure we include diverse perspectives on our advisory board. This information is stored on a password-protected database and will only be used by the project team for the purposes of creating the advisory board. Your responses are optional; if you're uncomfortable answering a question, feel free to skip it. Throughout the survey, you may use

the open-text boxes to share any additional information about survey questions or clarify your answers.

7. What name should we refer to you by (first and last name)?
8. What pronouns do you use (check all that apply)?
 - a. She/her
 - b. He/him
 - c. They/them
 - d. Other (specify)
9. What is your email address? (fill in)
10. What is your phone number? (fill in)
11. What is your age (or approximate age range if you do not wish to share a specific number)? (fill in)
12. How would you describe your cultural background (i.e., race, ethnicity, religion, or any other relevant cultural identifier you'd like to include)? (fill in)
13. How do you prefer to communicate?
 - a. Primarily spoken language
 - b. Primarily written language
 - c. Primarily Alternative and Augmentative Communication (i.e., speech-generating devices, signed languages)
 - d. A mixture of spoken language, writing, and/or AAC
14. Please describe other information you'd like us to know about your preferred communication methods. (open text box)
15. Do you speak a language other than English? (yes/no)
 - a. If so, what language? (open text)
16. Are you autistic?
 - a. Yes
 - b. No
 - c. Unsure

[if YES to "Are you autistic"]:

17. How did you discover you were autistic?
 - a. Formally diagnosed in childhood (by a psychologist, physician, or other professional)
 - b. Formally diagnosed in adulthood (by a psychologist, physician, or other professional)
 - c. Self-diagnosed
 - d. Other (fill in)
18. [If formally diagnosed]: At what age did you receive an autism diagnosis? If you do not know the approximate age, please provide your best guess. (fill in)
19. [If self-diagnosed]: At what age did you self-diagnose as autistic? If you do not know the approximate age, please provide your best guess.
20. Did you receive any of the following interventions/therapies as a child (check all that apply)? If you don't remember the specifics, you can give your best guess and describe additional information in the open text-box.
 - a. Speech therapy

Appendix B: Sample Recruitment Survey

- b. Occupational therapy
- c. Physical therapy
- d. Applied behavior analysis (ABA)
- e. Play therapy
- f. Special education services (e.g., tutoring, support from a special educator)
- g. Medical treatments
- h. Holistic treatments
- i. Other (please specify)

21. Please use this space to include any other information you'd like to share with us about your experience with interventions in childhood. (open)

[For EVERYONE]:

22. Have you been diagnosed with any learning disabilities, mental health conditions, or other conditions/disabilities you would like to disclose? Although this project is focused on autism, we are collecting this information to ensure a diversity of experiences is represented on the advisory board and ensure we can provide appropriate accommodations for individuals who participate. (yes/no)

- a. If yes, which disabilities/conditions? Use this space to provide any information you'd like about these conditions or disabilities. (fill in)

23. Which of the following research-related activities have you been involved in (check all that apply)? If you don't remember the specifics, you can give your best guess and describe additional information in the open text-box.

- a. Project lead/principal investigator of a grant-funded research study
- b. Help to design and conduct a research study as an employee of a research team
- c. Serve on an advisory board for a research study
- d. Participated as a subject in a research study
- e. Participated in a pilot study or focus group
- f. Help disseminate research findings to non-academic audiences
- g. Read academic manuscripts printed in peer-reviewed journals
- h. Attend research conferences
- i. Discuss new research findings with others
- j. Other (please describe)

24. Are you a primary caregiver (i.e., biological or adoptive parent; legal guardian), of an autistic child? (yes/no)

[If NO to "are you autistic" AND "are you a primary caregiver of an autistic child"]: At this time, we are only recruiting autistic adults and caregivers of autistic children to participate in this survey. If you are still interested in this project, please use this space to tell us more about your interest, your relationship to the autism community (e.g., sibling or other family member of an autistic child; clinician who works with autistic children) so we can keep you in mind if opportunities arise for other individuals to join our board. (include open-text box)

[if YES to "are you a caregiver of an autistic child"]:

25. How many autistic children do you have?

- a. 1
- b. 2 or more

Appendix B: Sample Recruitment Survey

26. [If 1]: How old is your autistic child? (fill in)
27. [If 1]: At what age did your child receive a diagnosis of autism? If you don't remember the specific age, please give your best guess. (fill in)
28. [If 1]: Does your child have any co-occurring medical conditions or developmental/learning disabilities you'd like to disclose? Although this project is focused on autism, we are collecting this information to ensure a diversity of experiences is represented on the advisory board. (yes/no)
 - a. If yes, which disabilities/conditions? Use this space to provide any information you'd like about these conditions or disabilities. (open text)
29. [If 2 or more] How old is your oldest autistic child? (fill in)
30. [If 2 or more] At what age did your oldest autistic child receive a diagnosis of autism? If you don't remember the specific age, please give your best guess. (fill in)
31. [If 2 or more] How old is your youngest autistic child? (fill in)
32. [If 2 or more] At what age did your youngest autistic child receive a diagnosis of autism? If you don't remember the specific age, please give your best guess. (fill in)
33. [If 2 or more] Do any of your autistic children have any co-occurring medical conditions or developmental/learning disabilities you'd like to disclose? Although this project is focused on autism, we are collecting this information to ensure a diversity of experiences is represented on the advisory board. (yes/no)
 - a. If yes, which disabilities/conditions? Use this space to provide any information you'd like about these conditions or disabilities. (open text)
34. Has your autistic child (or children) received any intervention, therapies, treatments, or other supports before the age of 5 (Early Intervention, public preschool services, private therapies, etc.)? This does not include treatments or medications for medical disorders unrelated to autism. (yes/no)
35. If yes, which ones (check all that apply)? If you don't remember the specifics, you can give your best guess and describe additional information in the open text-box.
 - a. Speech therapy
 - b. Occupational therapy
 - c. Physical therapy
 - d. Special education instruction (I.e., special instructor, developmental therapist, provider with training in child development in special education)
 - e. Applied behavior analysis (ABA)
 - f. Play therapy
 - g. Medical treatments
 - h. Holistic treatments
 - i. Other (please specify)
36. Please use this space to include any other information you'd like to share with us about your child's diagnostic status and experience with interventions in early childhood. (open)

Appendix C: Communication and Participation Preferences Survey

You can give your partners a survey before onboarding to help you organize your project activities and accommodations. This survey can also be used to explain the structure and accommodations you plan to build into your project activities.

They can complete it independently or you can ask them the questions in a 1:1 meeting. You should adjust the survey based on your individual resources and project activities. You should tailor these questions to fit your project's specific structure/activities and your available resources.

If you are working with a community organization, questions can be tailored to ask about the *organization's* existing infrastructure or preferences (e.g., what programs they already use for communication and project management).

Potential Sections of the Survey:

1. Technology (familiarity and access)
2. Communication from the team (e.g., reminders, logistics)
3. Completing activities: method and supports for completing independent activities
4. Meetings: settings and accommodations
5. Interpersonal communication
6. Physical and Sensory environment (more applicable for in-person meetings)

Below is an example of a survey you could use to ask individual partners about their preferences.

-----SAMPLE SURVEY-----

Participation Preferences Survey

Thank you for your interest in working with us! We want to make this project as accessible as possible, so we plan to use many accommodations and supports. You can tell us more about your preferences for the project on this survey. This will help us plan our activities to make sure you're happy with your experience.

There are five sections of the survey. It will take about 10 minutes to finish. You can do it by yourself, or you can complete it on a phone or video call with someone on our team. Email us at hello@yourorganization.edu with any questions.

Section 1: Technology

We plan to use video calls/conferences for our group meetings. For those who do not have access to a device with high-speed internet, we have a limited number of data-enabled iPads and hotspots available to loan for the project.

1. Do you have access to a device (laptop, computer, iPad) with high-speed internet? (Yes/No)
2. Which of the following programs have you used before? Check all that apply:

Appendix C: Participation Preferences Survey

- Zoom
- Microsoft Teams
- Skype
- Google Meet

We will also have written documents for people to review during the project. And, we will have optional activities to help us design presentations. If you don't have access to the program we use, we'll be able to give you access.

3. Which of the following programs have you used before? Check all that apply:

- Writing/Word Processing
 - Microsoft Word
 - Google Docs
 - Microsoft OneDrive/Sharepoint
- Presentations
 - Google Slides
 - Microsoft PowerPoint
 - Canva

Section 2: Communication from the project team

You will usually complete one activity on your own and attend one group meeting to discuss the activity every month. We can use a variety of methods to communicate with you about the project logistics.

4. How do you prefer to be reminded about activities and meetings? Check all that apply:

- Email reminders
- Calendar invitation
- Text message reminder
- Google Tasks

5. When would you like to receive reminders? Check all that apply:

- Two weeks before the meeting/activity due date
- One week before the meeting/activity due date
- One day before the meeting/activity due date
- Other (please specify)

6. How do you want us to communicate with you between meetings?

- Email
- Text messages
- Phone call
- Google Spaces/Tasks
- Other (please specify)

7. Do you have a support person (e.g., assistant, family member, friend) who you would like for us to include on communication from our team (reminders, emails, meetings, etc.)?

- Yes/No [if yes, provide name and contact information]

Appendix C: Participation Preferences Survey

Section 3: Completing activities

You will usually have an activity to complete on your own every month. For some activities, you will read a written document and answer questions to give your opinion about it. In other activities, you'll answer questions about your experiences to discuss as a group in the monthly group meeting.

Some people like completing activities by themselves, and others prefer some support to complete activities. We want to make sure we have support in place to help you with activities.

8. Which of the following supports would help you complete activities? Check all that apply.
- Have a one-on-one meeting with someone on the team so I can ask questions and share my answers in speech instead of writing
 - Have a one-on-one meeting with someone on the team to help me stay focused (“body doubling”)
 - Complete activities in a working meeting with a small group of people
 - Screen-reader accessible documents
 - Other (please specify)
9. How do you prefer to receive instructions?
- Written step-by-step instructions
 - Video explanations with spoken explanations
 - Examples of responses/answers
10. How do you prefer to complete *long activities* (e.g., over 30 minutes)?
- I like to finish everything at once
 - I like to break it up into shorter pieces
 - No preference
11. What other supports can we use to help you complete activities? (open-ended)

Section 4: Meetings

Each month, we will have a group meeting. Our group meetings will take place on Zoom and will usually be 1 hour long. We will have up to 12 people in each meeting. During the meeting, we will usually discuss the monthly activity you completed on your own. The way you participate in each meeting can be flexible. If you need to miss a meeting, we will offer different ways for you to “make up” the meeting so you can still contribute to the discussion.

Before each meeting, we plan to:

- Send a meeting reminder (depending on answers to questions 4-5 above)
- Send a meeting agenda and meeting slides one week in advance
- Hold an optional “pre-meeting” 30 minutes before the meeting start time so you can ask us questions
- Be available for a “pre-meeting” at another time before the meeting so you can ask us questions about the meeting topics at a time that fits your schedule

Appendix C: Participation Preferences Survey

During each meeting, we plan to:

- Have optional closed captions
- Allow communication in writing through the Chat (instead of, or in addition to, using speech)
- Allow people to join the meeting with their camera off
- Use “breakout rooms” for small-group discussion of sensitive or complex topics
- Have a meeting facilitator available to explain complex topics or talk with you one-on-one, if preferred
- Hold 5-10 minute breaks for activities that last longer than 45 minutes.

After each meeting, we plan to:

- Send a meeting summary and transcript
- Hold an optional “post-meeting” after the meeting ends so you can ask us questions
- Be available for optional one-on-one meetings to process or share additional ideas after the main group meeting

12. How would you prefer to participate in meetings? (You can change your mind later)

- Attend the group meeting
- Meet one-on-one with someone on the project team
- Correspond with someone from the project team over email, phone, or another messaging application (e.g., Google Chat) to discuss the monthly meeting agenda

13. Use this space to tell us about any other supports that would help you participate in the meetings. (open-ended)

Section 5: Interpersonal Communication

People communicate in many different ways. The “rules” of communication are affected by a lot of factors like our neurotype, culture, and more. We will create some guidelines for communication as a group, but we’d like to know more about your communication preferences to help us prepare for our meetings.

14. How do you prefer to communicate in group conversations? (check all that apply)

- Spoken language
- Written language
- Signed language (e.g., ASL)
- Symbol-based communication (e.g., using an AAC device)
- Other (please specify)

15. Which of these communication supports would help you participate in group meetings (check all that apply)?

- Language interpreter (branching logic: specify language)
- Inclusion of a communication partner
- Participating via written language only

16. What else do you want us to know about your communication style or preferences? (open-ended)

Join our Advisory Board!

We are looking for **12 autistic adults and caregivers of autistic children** to join the advisory board for our new project. Together, we will create tools that researchers and the autistic community can use to **co-create early childhood autism research that prioritizes the needs of autistic people and their families.**

Project goals:



- Create a tool that members of the autism community (autistic people, caregivers) can use to learn about core research concepts



- Create a tool that researchers can use to collaborate with the autism community in an equitable, accessible way



- Create a list of priorities and guiding principles for early autism intervention research

What will you do?

Joining the advisory board includes a commitment of **1.5 to 3.5 hours per month**. You will:



- Participate in **monthly group meetings between April 2023 and December 2024**. These meetings may take place in the modality that works best for you: Zoom, messaging applications, phone calls, or another format you prefer.



- Review materials related to project tools between meetings, with additional opportunities to help write and design these project tools (if desired)

Participation is flexible: although this is a nearly 2-year commitment, you may take a break from participating if needed, and short-term opportunities to participate may also be available.

What will you get from participating?

- Compensation of **\$100/hour**, paid monthly
- Training about designing and conducting research studies
- Opportunities to develop skills in writing and designing papers, presentations, and more
- Ongoing partnership with the Early Intervention Research Group ([EIRG](#))
- We will loan you the technology required to participate (i.e., iPad with hotspot) as needed

Project Timeline

The project will be completed in four phases. During each phase, you will attend monthly meetings and review project tools in preparation for meetings, for a total of 1.5 to 3.5 hours each month. If desired, you may also help to write content and design the tools (for additional time and compensation).

See below for a summary of the goals and specific tasks of each phase.

Phase 1: Onboarding (February 2023- March 2023)

Goal: Assemble our advisory board

- Fill out surveys about your preferences for participation
- Meet with the project team and review information to prepare for our first meeting

Phase 2: Learning about Research (April 2023- June 2023)

Goal: Create a supplemental tool to PCORI's Research Fundamentals Training specific to early autism research

- Watch PCORI's Research Fundamentals Training
- Monthly meetings:
 - Share understanding of research concepts
 - Share suggestions for information to include in a tool connecting concepts from PCORI's training to early autism research
 - Make suggestions for the design and refinement of project tools

Phase 3: Creating Research Priorities (July 2023- January 2024)

Goal: Create guiding principles and priorities for future early autism intervention research

- Monthly meeting agenda:
 - Share experiences with early intervention
 - Review information about current autism research and share perspectives about the value of this research
 - Determine priorities, guidelines, and research questions for future autism research
 - Make suggestions for the design and refinement of project tools

Phase 4: Disseminate Project Tools (February 2024- December 2024)

Goal: Disseminate project tools to researchers and autism community members

- Co-write or review manuscripts for academic audiences
- Create alternate versions of project tools for community members (plain text, audiovisual presentations, etc.)
- Help design a website housing project tools
- Disseminate project tools to the community through virtual discussions, presentations, and other methods

Frequently Asked Questions

Who is leading this project?

The project is a collaboration between [Dr. Megan Roberts](#) and [Dr. Morénike Giwa Onaiwu](#). Meg is a speech-language pathologist and researcher who is interested in ways to support caregivers and children with developmental disabilities. Her clinical experiences, relationships with families who participate in the EIRG's studies, and personal experiences have motivated her to pursue research that is focused on the needs of autistic people and their families. Morénike is a global advocate, educator, disabled person of color, non-binary woman, and parent in a neurodiverse, multicultural, twice-exceptional serodifferent biological and adoptive family. Her advocacy, writing, and academic works focus on intersectional justice, meaningful community involvement, human rights, and inclusion. A few additional members of the Early Intervention Research Group will also help to coordinate this project. These project team members have varying personal experiences with autism (are autistic or family members of autistic individuals) and have worked with autistic individuals and their caregivers in both research and clinical settings.

Why are you doing this project?

Many autistic adults report harmful impacts of their early intervention experiences on their long-term autonomy and well-being, and caregivers of autistic children report that many of their concerns are unmet by current interventions. Therefore, we need more research that focuses on goals important to the autistic community, that is created in collaboration with the community. **Researchers investigating early autism interventions have been slow to collaborate with the autism community.** We want to fix this problem by creating tools that researchers and autism community members (autistic adults, caregivers of autistic people) can use to collaborate in the future. And, by partnering with the autistic community through our advisory board, we can make sure that the project tools are helpful and accessible.

Will I be paid for participating?

Yes! See below for additional information about payment:

- How much will I be paid: You will be paid **\$100/hour**, for approximately 1.5-3.5 hours each month.
- How often will I be paid: You will be paid **monthly**.
- How will I be paid? You will be paid by direct deposit by filling out a timecard each month. We are also working on additional payment options (e.g., virtual gift cards, Zelle) to use when needed.

How was this project funded?

Funding for this project is provided by a Eugene Washington Patient-Centered Outcomes Research Institute (PCORI) Engagement Award. The full project title is "*Engaging autistic adults and caregivers to improve PCOR/CER research in early childhood autism interventions.*"

This project is **not a research study**, but funding for a collaborative project between the project team and the advisory board. If you participate in this project, you will not be participating as a traditional "subject" of a research study, but as a partner with the project team. The content, design, and dissemination of all project tools will be determined based on the wishes of the advisory board.

Frequently Asked Questions

I'm interested in participating, but I'm worried the payments will disqualify me from my disability benefits. Can I still be involved?

Absolutely! Some potential activities include reviewing or piloting tools created by the advisory board, attending meetings every few months (instead of monthly), or helping to design or create project tools on a short-term basis. We can work with you to find activities that are best suited to your needs and wishes for working on this project.

What will I do each month?

Each month, we will hold a group meeting over Zoom (or via alternative modality) with the advisory board. Before each meeting, you will review various materials to prepare for these meetings. For example, during phase 3 of the project (creating research priorities and guiding principles):

- **Month 1:**
 - Before the meeting: You will review materials prepared by the project team about recent early autism intervention research studies
 - At the meeting: You will discuss your perspectives about these studies and priorities for future research to include in a project tool
 - After the meeting: EIRG's project team will summarize the meeting and create an initial draft of the project tool/document
- **Month 2:**
 - Before the meeting: You will review the initial draft of the tool created by the EIRG's team
 - At the meeting: You will make suggestions for revisions
 - After the meeting: EIRG's project team will update the project tool with the advisory board's suggestions
- **Month 3:**
 - Before the meeting: You will review the revised project tool
 - At the meeting: You will make suggestions for revisions to the new draft
 - After the meeting: EIRG's project team will update the project tool with the advisory board's suggestions
- **Month 4:**
 - Before the meeting: You will review the revised project tool
 - At the meeting: You will come to consensus about the final version with the advisory board
- **Ongoing:** You will also fill out short surveys every other month to ensure you are satisfied with your participation. Please see the **project timeline** for more details about the goals of these meetings throughout the two-year period.

What do you mean by "project tools"?

The final tools we create during this project may take various forms, such as audiovisual presentations, documents, and/or formal academic manuscripts. For example, for the project tool describing priorities for future early autism research, we may have a document summarizing the advisory board's perspectives on a future research agenda. Then, we may co-write manuscripts for publication in academic journals, create simple-text versions of these documents to be understood by the autism community, etc.

Frequently Asked Questions

What alternatives will you offer for group Zoom meetings?

We understand that large group meetings, and video calls (such as Zoom) are not a preferred context for communication for many individuals. Below is a list of the options we are currently planning to offer, but we will work with you to individualize a method of participation that works best for you.

- Use only audio in group Zoom meetings (camera off)
- Use only the Chat feature in group Zoom meetings (instead of spoken language)
- One-on-one meeting with a member of the project team via Zoom (using video, audio, and/or the chat feature).
- Group discussion via writing in a messaging applications
- One-on-one discussion via writing with a member of the project team via messaging application
- Review meeting summaries or transcripts after the virtual group meeting and provide feedback on the content of these meetings via email, writing, or virtual conversation with a member of the project team
- Respond to questions provided by the project team by email, phone call, or discussion
- Independently review project materials and provide feedback by writing (email) or over the phone/video call

Will you offer any other accommodations or supports?

Yes! We are committed to providing whatever accommodations we can to make this a satisfactory experience. We will individualize accommodations to your needs, but some of the accommodations we plan to use include:

- Live captioning of Zoom meetings
- Meeting agenda provided prior to each meeting
- Meeting summaries or transcripts provided after each meeting
- Email reminders about meetings
- Email reminders to complete tasks between meetings
- Text message reminders about meetings
- Text message reminders to complete tasks between meetings
- Oral/plain language breakdown
- Follow-up meeting with the project team after the group meeting to share additional ideas or check in about the project
- Inclusion of a support person (such as an assistant or caregiver) on emails or in meetings

Who do I contact about the project between meetings, and before the project begins?

You can contact Jordan Lee at email@address.edu. We will provide contact information for additional team members as appropriate throughout the project period.

Appendix E: Sample Feedback/Satisfaction Survey

Satisfaction with Engagement Survey

This survey was used to monitor advisory board members' satisfaction with their participation in the PCORI Engagement Award that funded this project. The purpose was to gather feedback for internal use, rather than serving as a survey to collect data for publication on pre-established constructs related to community engagement. [Goodman et al., \(2021\)](#)'s survey was used to gather ideas for initial constructs and questions, and was heavily adapted to fit the nature of the specific project (e.g., an Engagement Award rather than a formal research study). Specific modifications to item presentation included using more concrete definitions of Likert-scale anchors and including open text boxes with each question to add additional information (see AASPIRE Guidelines (Nicolaidis et al [2019]) for information about creating surveys for autistic adults).

Our advisory board was asked to provide feedback on this survey itself, and modifications were made accordingly. The additional description of each response option was preferred by the vast majority of our advisory board, but this may not be a universal preference; you can consider different presentation options so that this additional description is "optional" depending on individual preferences.

The survey was administered via REDCap, and respondents had the choice of reporting their name or completing the survey anonymously.

It is important to ensure your survey meets your project's specific structure and needs. This survey includes some core processes that will likely occur in an community-engaged project with autistic people and caregivers, but you may add additional items that address specific activities or populations you will work with on your project. Additionally, while this survey focused more on satisfaction with the *project team* (e.g., researchers), survey items such as those in Goodman et al., (2021) may better reflect a project with more shared leadership

1. I am working on tasks that meet my comfort, capacity, and needs.
 - a. **Strongly disagree:** I am very dissatisfied with my tasks, and if the project team does not change their entire approach, I may no longer be able to participate.
 - b. **Disagree:** I am dissatisfied with my tasks, but I think the project team can fix this by making some major improvements to their approach.
 - c. **Neither agree nor disagree:** I'm somewhat satisfied with many of my tasks, but there are some small improvements the project team needs to make for me to be fully satisfied.
 - d. **Agree:** I am satisfied with my tasks, but there are some small improvements the project team could make. However, these improvements are not necessary for my satisfaction.

Appendix D: Sample Feedback/Satisfaction Survey

- e. **Strongly agree:** I am very satisfied with my tasks, and I don't see any way the project team can or should improve.
2. I was given enough resources, supports, and training to participate in this project.
 - a. **Strongly disagree:** The project-related resources they gave were not at all helpful and I feel very unprepared to participate in this project.
 - b. **Disagree:** The project-related resources they gave were only a little bit helpful, and I feel somewhat unprepared to participate in this project
 - c. **Neither agree nor disagree:** The project-related resources they gave were helpful, but I still require more resources and training to fully participate.
 - d. **Agree:** The project-related resources they gave were very helpful, but there are a couple topics I could use a little more training about.
 - e. **Strongly agree:** All the project-related resources they gave were very helpful and I felt fully prepared to participate
3. I was given opportunities to share new ideas regularly.
 - a. **Strongly disagree:** I was never given opportunities to share new ideas when I wanted.
 - b. **Disagree:** I was only given a few opportunities to share my ideas when I wanted to.
 - c. **Neither agree nor disagree:** I was given opportunities to share my ideas about half the time I wanted to
 - d. **Agree:** I was given opportunities to share my ideas most of the time, but there were a few times when I did not have the opportunity to share my ideas when I wanted to.
 - e. **Strongly agree:** I was always given opportunities to share my ideas when I wanted to.
4. My ideas were treated with openness and respect (i.e., not ignored, dismissed, or ridiculed) by the project team and other members of the advisory board
 - a. **Strongly disagree:** My ideas were never treated with openness and respect (i.e., they were always ignored, dismissed, or ridiculed)
 - b. **Disagree:** My ideas were rarely treated with openness and respect (i.e., they were almost always ignored, dismissed, or ridiculed)
 - c. **Neither agree nor disagree:** My ideas were treated with openness and respect about half the time (i.e., my ideas were ignored, dismissed or ridicules about half the time)
 - d. **Agree:** My ideas were usually treated with openness and respect, but occasionally ignored, dismissed, or ridiculed
 - e. **Strongly agree:** My ideas were always treated with openness and respect, and never ignored, dismissed, or ridiculed.
5. There was a good process in place to resolve disagreements.
 - a. **Strongly disagree:** The process does not work and an entirely new process is needed.
 - b. **Disagree:** The process does not currently work, but could be improved with some major changes.
 - c. **Neither agree nor disagree:** The process needs some minor changes to work well for everyone.
 - d. **Agree:** The process could use some minor improvements, but if nothing changed I think it still works well enough.
 - e. **Strongly agree:** The process works great and no changes are needed.
6. The project team helped build trust between members of the advisory board.

Appendix D: Sample Feedback/Satisfaction Survey

- a. **Strongly disagree:** The project team has not done anything to help members of the advisory board build trust with each other.
 - b. **Disagree:** The project team has done very little to help members of the advisory board build trust with each other.
 - c. **Neither agree nor disagree:** The project team helped us build some initial trust, but a lot more work could be done to increase trust between members of the advisory board
 - d. **Agree:** The project team has helped to foster trust between members of the advisory board, but could make small improvements to help increase trust.
 - e. **Strongly agree:** The project team has created an environment in which members of the advisory board trust each other, and they continue to support this trust in ongoing activities.
7. All members of the advisory board demonstrated respect towards the autistic community (for example: using an individual's preferred terminology choices, and neutral and/or identity-affirming lens; acknowledging the variability and nuance in individuals' lived experiences and perspectives)
- a. **Strongly disagree:** Some people on the advisory board treated the autistic community with disrespect, and the project team did not try to address this.
 - b. **Disagree:** Some people on the advisory board rarely treated the autistic community with respect, and the project team's efforts to address this require substantial improvement.
 - c. **Neither agree nor disagree:** People on the advisory board sometimes demonstrated respect towards autistic people, and more effort is needed to support ongoing respect of the autistic community by all project partners.
 - d. **Agree:** People on the advisory board usually demonstrate respect towards autistic people, but could benefit from a little bit more education and support.
 - e. **Strongly agree:** Members of the advisory board always demonstrated respect towards the autistic community
8. If I could go back in time, I would choose to participate in this project again.
- a. **Strongly disagree:** I would not participate.
 - b. **Disagree:** I would only participate if substantial changes were made.
 - c. **Agree:** I would participate in the project as is.
 - d. **Strongly agree:** I would enthusiastically participate in the project as is.
9. The project team has supported successful communication between autistic and allistic (not autistic) partners
- a. **Strongly disagree:** There are many communication breakdowns between autistic and allistic project partners, and the project team has not taken any appropriate measures to prevent these difficulties or address them as they occur.
 - b. **Disagree:** There are sometimes communication breakdowns, and the project team could do a better job fixing and preventing these communication difficulties
 - c. **Agree:** There are occasional communication difficulties, but the project team does a good job fixing these breakdowns when they occur.
 - d. **Strongly agree:** The project team has done a good job facilitating communication, and provides appropriate support to fix communication difficulties.
 - e. Not applicable: I have not perceived any communication breakdowns or barriers of significance

Section 2: Additional Open-ended questions

- 1) Please list or describe any accommodations or supports used in the project that helped you participate in the project successfully.
- 2) Please list or describe any accommodations or supports used in the project that were not helpful or necessary for your participation.
- 3) Please list or describe any additional accommodations or supports we're not currently using that would better support your participation.
- 4) Please list or describe anything the project team can do to improve communication and understanding between autistic and allistic (non-autistic) project partners.
- 5) Please list or describe anything the project team can do to improve communication and understanding between project partners with different perspectives or experiences.
- 6) Please list or describe any information you'd like us to know about your experience with the project and ways the project team could make the project more successful.

Goodman MS, Ackermann N, Pierce KA, Bowen DJ, Thompson VS. Development and Validation of a Brief Version of the Research Engagement Survey Tool. *International Journal of Environmental Research and Public Health*. 2021;18(19):10020. doi:[10.3390/ijerph181910020](https://doi.org/10.3390/ijerph181910020)

Nicolaidis C, Raymaker DM, McDonald KE, et al. Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations. *Autism Adulthood*. 2020;2(1):61-76. doi:[10.1089/aut.2019.0074](https://doi.org/10.1089/aut.2019.0074)