

Inequities in Community-Engaged Autism

Research: Community Member Perspectives

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ABSTRACT

Background: A history of exclusion and barriers to research participation exists for autistic individuals. Barriers to full community engagement have left under-engaged members of the autism community feeling isolated, frustrated, distrustful, and less informed about opportunities for research participation.

Objectives: This study aimed to identify gaps in community-engaged research (CEnR) approaches in autism research by examining autism stakeholders' (autistic adults, autism caregivers/parents, and service providers) perspectives about the risks, benefits and gaps in CEnR and suggestions on addressing the gaps related to autism research priorities.

Methods: Via qualitative narrative inquiry (n=53), using a 16-item semi-structured instrument, we collected data from autism stakeholders representing different lived experiences and perspectives among autism communities. We primarily recruited via major autism advocacy and research organizations. Transcripts from a focus group (n=6) and individual interviews (n=47) were thematically coded.

Results: Participants expressed a lack of diverse representation in autism CEnR and in autism research subject populations. They suggested that an approach to community engagement that includes those often excluded from the process, and creates shared ownership in the decision-making process and a trusted platform for the autism community across demographic and diagnostic characteristics is important for understanding how to translate that information into effective and inclusive approaches.

Conclusions: Autism stakeholders value research inclusivity, are interested in research participation, have the ability to make their own participation decisions with and without support from others (dependent on their preferences), and believe that research about adults with autism

is important and beneficial towards addressing complex problems related to access to care.

KEYWORDS: Community health research, Health disparities, Community Health Services, Power sharing, Health promotion

Introduction:

With over 5 million (2.2%) Americans living with autism, it is among the leading diagnosed neurodevelopmental conditions.^{1,2} While research has progressed in understanding autism, there remains much to learn about the needs of the autism community. Most research explores screening, prevention and treatment focusing on applied behavioral, physical, sensorimotor therapies, and underlying biological mechanisms.³⁻⁵ Yet, members of the autism community with more complex medical and psychosocial needs, racial and socioeconomic diversity, women, and older adults remain underrepresented in research.^{1,6} Another important gap exists regarding the use of participatory approaches where autistics contribute to research planning and implementation.⁷⁻⁹

One approach, community engaged research (CEnR), has long been a valuable approach to help identify and address health disparities and inequities by engaging with the communities, particularly BIPOC populations disenfranchised from research processes.¹⁰⁻¹² CEnR focuses on the community-researcher relationship, enhancing meaningful translation of research results through diverse perspectives and experiences.^{9,13-15} It requires a continuum of partnership, cooperation, negotiation, and commitment to the community's voice and a joint community-academic action plan to address a health issue.¹⁶ However, examination of how CEnR is perceived among autism stakeholders has not been widely explored especially in U.S. populations.

Lessons from emerging research can guide efforts in community engagement, redefine the concept of community, and establish effective partnerships between communities and

researchers.¹⁷ These partnerships are crucial for developing interventions, conducting needs assessments, promoting health, and providing resources.¹⁷ CEnR proves to be a suitable and practical approach for engaging with autism stakeholders, including hard-to-reach and complex subgroups. Despite concerns about including autistic individuals with intellectual disabilities or limited verbal communication, studies highlight various barriers such as knowledge gaps, mistrust, accessibility issues, communication challenges, biases, and systematic exclusion.¹⁸

Studies reveal divergent perspectives between autism researchers and autistics on community engagement, with researchers perceiving engagement while autistics feel disengaged.^{9,19} Other studies have identified barriers to full community engagement, leaving under-engaged members of the autism community feeling isolated, frustrated, distrustful, and less informed about research participation opportunities.^{8,20,21} Like other populations, the autism community is not homogenous and does not speak with one voice.¹⁶ Some advocates argued that researchers should prioritize attending to stakeholders' interests, particularly in research aimed at expanding beyond mere cure to community engagement.^{22,23} These findings underscore the importance of studies examining the gaps in community engagement and enhancing understanding of the diverse needs and experiences within the autistic population. Notably, an important gap is the lack of U.S.-based studies that examine perceptions of CEnR in the autism community.

Our literature search uncovered a limited set of initiatives such as the Continuity of Care and Support for Autistic Adults project and the Academic-Autistic Spectrum Partnership in Research and Education, which focus on understanding the health, well-being, and service needs of autistic adults through active participant engagement.^{24,25} Results indicate participant benefits such as

satisfaction with influencing research, enhanced understanding and trust in the research process, expanded support systems, co-learning, and companionship with similar individuals. Moreover, their involvement enhances awareness of the specific challenges faced by autistic adults with high support needs and underscores the importance of inclusiveness, transparency, clearly defined roles, effective communication tools, and strategies in community engagement.^{24,26}

The current study aimed to explore the perception of CEnR among autism stakeholders through a qualitative approach. This involved examining the perspectives of autistic adults, autism caregivers/parents, and service providers (hereafter autism stakeholders) regarding the risks, benefits, and gaps in CEnR, and providing suggestions for addressing these gaps in relation to autism research priorities and diversifying representation in CEnR. This endeavor is crucial for pinpointing solutions to overcome barriers and enhance inclusivity among autistic stakeholders. Incorporating a diverse representation of stakeholders provides insights into perspectives that transcend these groups, thereby impacting autistic individuals.

Methods:

Research Design

We conducted qualitative narrative inquiry which allows for the collection of robust descriptions/stories of the lived experiences and perspectives of participants.^{27,28} The semi-structured guide engaged discussions around perspectives, personal involvement, CEnR benefits and risks, and collaboration suggestions in autism research.²⁹ We explored personal characteristics and how participants view themselves in the larger context of CEnR. We

integrated focus group and individual interviews to enhance data richness and identify individual and contextual conditions around CEnR.³⁰

Instrument development

The interviews in this paper were part of a larger sequential, mixed-methods study focusing on stakeholder and researcher beliefs about ethics and community engagement in autism research. The first phase involved semi-structured qualitative interviews with three stakeholder groups: adult autistics, parents and caregivers, and service providers. The interviews aimed to explore beliefs about ethical research and the connection between ethical research and community engagement practices. The interview guide was developed collaboratively and refined through input from a Stakeholder Advisory Board (14 members, including adults with autism, representatives of advocacy organizations, parents and caregivers, academics with varied expertise) and piloting with two volunteers.

Participant Recruitment

Purposively sampling, we recruited via major autism advocacy and research organizations (utilizing an IRB-approved flyer outlining the project briefly) and supplemented with convenience sampling by inviting contacts within the autism community to post recruitment information on social media. Using an IRB-approved consent form, participants gave verbal consent at the beginning of interviews. Our sample (n=53) is composed of autistic adults, autism caregivers/parents, and service providers.

Data collection

To ensure data richness and depth, we conducted one focus group with six autism caregivers (parents or guardians) and individual interviews with the remaining 47 participants, all guided by the same interview guide and audio recorded with consent. The focus group comprised autism caregivers meeting specific inclusion criteria: self-identifying as a caregiver for an autistic individual, >18 years old, and U.S. residence. This ensured some consistency in experiences. The focus group, conducted via Zoom, lasted approximately 75 minutes. Due to participant scheduling constraints, we shifted from additional focus groups to individual interviews across various categories of autism stakeholders. Inclusion criteria for individual interviews encompassed individuals >18 years old, residing in the U.S., and falling into one or more of the following categories: self-identified autistic adults with legal self-guardianship; parents/guardians of autistic individuals; or service providers providing care to autistic patients. Individual interviews, lasting 17-69 minutes (mean= 41 minutes), were conducted via Zoom or email in one case to accommodate accessibility needs.

Analytic Methods

Recordings were transcribed verbatim and coded in NVivo v12 (QSR International, 2019).³¹ Employing inductive practices rooted in grounded theory, the analysis identified themes through annotations and coding. To ensure reliability, the coding process underwent multiple rounds of review and team meetings. Initially, all six research team members independently conducted open coding of three transcripts, which were then merged and compared to establish a preliminary coding scheme.^{32,33} Subsequently, a coding dictionary was developed, defining each theme and code. For example, Theme: CEnR benefits; Definition: how CEnR can benefit autism research; Codes: enhanced community engagement, improved research relevance. Three

additional transcripts were coded by three research assistants to assess inter-coder reliability. Discrepancies in new codes were resolved through discussion or merging to eliminate redundancy. To address positionality, we integrated reflexivity with peer debriefing, enabling coders and researchers to discuss biases, assumptions, beliefs, and experiences that might introduce biases into our coding and analysis process. Following finalization of the coding dictionary, two research assistants coded 24 transcripts each, with the remaining five double-coded for consistency. Any comments diverging from the coding dictionary were assigned new codes and assessed for individual importance or reclassification. Inter-coder reliability was verified by the lead qualitative consultant using double-coded transcripts, and a subset of randomly selected transcripts underwent additional coding for quality assurance. Relevant excerpts were extracted to support findings derived from themes and codes addressing the research questions. For this analysis we focused on Section IV of the interview guide (see Table 1), supplemented by additional relevant quotes related to CEnR. All identifiers were removed from the transcripts to protect participants' privacy. Institutional Review Board approval was granted by Drexel University.

Results:

The sample (mean age=42 years) included 53 participants, of which 43 were white, five were Black/African-American, one white and Asian, one Black/African-American and Hispanic/Latino, one identified as multicultural/multiracial, and three preferred not to answer. Fourteen participants identified as male, 39 as female, and one as neither gender.

The majority of the sample had a relatively high educational attainment, with over half (n=34; 62.96%) having completed at least some graduate work. All but one (1.85%) of the remaining participants had completed at least GED or high school degree (n=19; 35.19%). There were 24 autistic participants, 28 parents/caregivers of which six comprised the focus group, and 15 service professionals, with 9 participants identifying within multiple groups (e.g., both autistic and service provider).

Table 2 offers a participant breakdown across stakeholder groups.

Participants highlighted three main themes regarding autism community engagement in research: 1) lack of equity and interconnectedness, 2) fostering trust and authenticity and 3) suggestions to diversify engagement in CEnR.

Theme 1: Lack of equity and interconnectedness in autism CEnR

Participants provided perspectives on what CEnR researchers should prioritize in research, study designs, and conclusions regarding autistic people's experiences, emphasizing the lack of diverse representation and inclusion of autistics in CEnR study populations. They highlighted the importance of engaging autistics from varied backgrounds to address existing gaps and recruit more representative study populations. Participants also noted inequities in autism research representation across demographics such as age, gender, race/ethnicity, socioeconomic status, and functional status.

Participants noted research primarily focuses on infants and toddlers, potentially overlooking therapeutic opportunities for those diagnosed at older ages.

“I think we focused a lot on infants and toddlers and what's helpful for them and I think in some ways that's helpful because early intervention is important, but then I think it falls off pretty drastically as kids get older and then turn into adults.”- (40 years old; female; autistic adult, autism caregiver, and service provider)

Gender-related gaps were expressed as a lack of female representation. Young boys are perceived to have a great deal of visibility and engagement in research.

“I have some friends who have girls who are autistic and they're almost invisible.”- (Focus group of autism caregivers; age range 35-64 years)

Participants expressed concerns about the interconnections of gender and race/ethnicity in representation, particularly noting the inequitable representation of communities of color, especially women of color.

“Yeah, I mean just women as a whole, black people as a whole and just non-white people as a whole are completely left out of any sort of testing, diagnostics.”- (24 years old; female; autistic adult)

Communities of color face stigma and discrimination in various settings, and participants highlighted autism as another context where inclusion is challenging. CEnR is seen as an ideal approach to address this issue, as reflected in the following participant quotes regarding stigma.

“It's definitely boys, small boys and sometimes girls. Definitely not black folks and people of color don't even come under the radar of having things like this or any sort of difference because we're not the default. So, we completely fly under the radar. And if we do get tested and diagnosed then, it's probably going to come with a lot of other things that are more negative for us. There's already a heavy stigma but then it becomes layered and quadrupled to the point where it's, you might not even reach out to be a participant and research or want to be involved in the community because you don't feel a part of it already.”- (24 years old; female; autistic adult)

Participants noted a lack of representation among lower socioeconomic statuses, emphasizing that well-educated or wealthy individuals have better access to research opportunities and services. This leaves those from lower socioeconomic backgrounds underrepresented in autism research and without access to costly services. They likened this feeling of underrepresentation in research to the stigma experienced in clinical settings, as exemplified in the following quotes.

“I think the doctors talked down to us because they don't think we know anything, and then especially if you are a person with color or in lower economic status of any kind definitely stuck.”- (Focus group of autism caregivers; age range 35-64 years)

Some participants highlighted challenges in research participation, including issues with location and timing. They noted that autism research is often conducted at large universities and hospitals, making it inaccessible for families living far from these institutions. This lack of representation hampers the inclusivity of studies for autistic individuals residing in rural or remote areas.

“A lot of the research is done in the biggest city in the state. But many don't have access to any kind of transportation or no idea of how to find it, because it's very hard to find a way to participate in research to begin with.”- (25 years old; female; autistic adult and autism caregiver)

The lack of representation across various demographics such as age, gender, race, and socioeconomic status is exacerbated by limited engagement across the spectrum of functionality within the autism community. Participants observed a lack of representation in CEnR, noting that the focus on high-functioning children excludes those with higher support needs, nonverbal individuals, those with comorbidities, and learning disabilities.

“I feel like there's a lot of, either focus on high-functioning autistic children or really severely autistic children or adults. There's not a lot in the middle.”- (35 years old; female; autism caregiver)

Theme 2: Fostering Trust and Authenticity through Shifting Power Dynamics in CEnR

Participants were asked about the potential benefits of a community-engaged approach to autism research, defined for participants as bringing multiple stakeholders together, including those with direct lived experience, to identify research topics and collaborate with researchers. Most perceived CEnR as beneficial, noting it allows for sharing perspectives and experiences among stakeholders, facilitating direct learning about autism from diagnosed individuals and their caregivers. Additionally, participants believed community-engaged research could bridge divides within the autism community, fostering support systems to alleviate isolation many may encounter.

“So many benefits! I mean, number one; if you're not dealing with strictly parents or children or autistic adults, you're dealing with the general community. You're giving them an opportunity to learn about diversity and inclusion and learn about this population that maybe they had never even interacted before, and just learn some skills in how to work with and be around and deal with people who are on autism spectrum because they are so different. I think it could dispel a lot of assumptions for people. Make it not seem so scary and normalize it a little bit.”- (42 years old; female; autism caregiver)

Participants highlighted that community-engaged research (CEnR) enables researchers to gain insights into issues relevant to the autistic community that may not be uncovered elsewhere. They emphasized the ethical value of this approach, as it allows individuals to express their own experiences, fostering respect between researchers and autistic individuals while shaping

research priorities. Additionally, CEnR enables researchers to witness the direct impacts of their work and facilitates partnerships between autistic individuals and trusted resources within the autism community, fostering connections among diverse stakeholders.

“If it was well done I would hope it would break down the barriers between the parents and the different factions in the autism community, the “lower functioning” versus “higher functioning”, versus the researchers, versus the parents that want a cure and the parents that are like “I can work with this, this is okay.”- (43 years old; female; autistic adult)

While many participants acknowledged the potential benefits of community-engaged research (CEnR), some raised concerns that they wished researchers to address. They highlighted historical patterns of excluding community concerns from research agendas and expressed worry about differing agendas and perspectives between autistics and researchers. Additionally, participants voiced concerns about introducing strangers into autistic individuals' lives, the use of medical jargon causing exclusion, and the risk of favoring researchers in power dynamics. They also cautioned against potential biases that may arise from certain subsets of autistics being more outspoken, potentially skewing research priorities away from the broader population's needs.

“The problem in autism in particular is that any group that is identified as autistic and advocates on behalf of autism is only representing a tiny minority of the group. In fact, they are representing the minority that needs the help of researchers the least. So, I see this as a bigger problem in autism to how they are giving the role, giving the voice to subjects that have the condition is

particularly problematic in autism as far as influentially research goes.”- (54 years old; female; autism caregiver)

A participant suggested a "vetting" process prior to participation in CEnR, citing an example where autistic adults may prefer exclusion of parents of autistic children from conversations. They emphasized the importance of distinct inclusion representing the unique lived experiences of autistic individuals. Additionally, some participants advocated for separate forums for caregivers due to differing experiences.

“One of the risks is if when you want to engage the community - some of my friends would not like this. I feel like you need to have the autism parents' community engaged too. The problem is the minute we know they're showing up we don't show up.”- (32 years old; female; autistic adult)

Similarly, fostering trust among various autism stakeholders would encourage more genuine and uninhibited responses from autistic individuals.

“Whereas if you build that community engagement and you're including people, you can build trust. So, for the autistic person, we can understand that you're actually going to care about what I have to say, and you're going to use what's important to me. And for the researcher, the benefit then is that you can get more honest and open responses and data that is genuine because you now

have a relationship and a sense of trust together.”- (33 years old; female; autistic adult, autism caregiver, and service provider)

Theme 3: Suggestions to diversify engagement in CEnR

Participants were asked, “If you could collaborate with an autism researcher as an individual whose life is affected by autism, what would they suggest?” Alongside advocating for diverse representation across various demographics, they recommended measures to improve CEnR effectiveness, including building trust and accommodating diverse communication, social, and sensory needs. Suggestions included holding monthly events, involving individuals on the spectrum in advisory boards, and enhancing recruitment and retention efforts.

“Having us on advisory boards and things when there's actual organizations is good. I know some of us are suspicious of like Autism Speaks having some like token autistic people and we're never sure how much they're actually able to effect change and how much it's just kind of "Look, we have autistic people now." But that all helps. I think just being aware that we're by nature very suspicious and giving us time to kind of come around to the idea is good. And partnering with people that are like known safe people in the autism community always helps.”- (30 years old; female; autistic adult)

Other suggestions included researchers conducting preliminary research through blogs, YouTube videos, and social media (#actuallyautistic) for self-education, involving the community early in the research process, engaging caregivers, teachers, and school

administrators, providing safe and bias-free settings, and offering various interaction modalities (face-to-face, online, mail) at different locations and times to enhance accessibility.

“I get questionnaires all the time through emails, and that's kind of annoying, because it's not person-to-person. But I understand how you're going to glean a whole bunch of information from the community if that's really your only means to do it. I prefer face-to-face or somebody who was an actual human being rather than someone on email asking me a bunch of questions.” - (44 years old; female; autism caregiver)

These suggestions imply that to engage autism communities in CEnR, research has to be made accessible to autistics in ways that also consider support needs, sensory sensitivities, and individual communication preferences.

Discussion:

Our study utilized qualitative inquiry with a sample of autism stakeholders representing different lived experiences. By including diverse stakeholders, we gained a holistic understanding of each group's perspectives on CEnR, facilitating stronger, more relevant, and ethically conducted studies that cater to the diverse needs of communities. The absence of stark differences among our varied stakeholders underscores the collaborative nature of CEnR, emphasizing its value in amplifying diverse voices for meaningful research outcomes. This inclusive approach addresses historical exclusion and barriers to participation, ensuring equitable representation and mitigating research inequalities within the autism community. This is

important because when CEnR fails to include diverse perspectives and voices from the autism community, researchers risk perpetuating inequalities in their research findings.

It's important to acknowledge, our sample predominantly identified as female. While males were less represented, this is especially notable in autism research, where there's increasing awareness of underdiagnosis and misdiagnosis among women and girls. Addressing this trend helps to counter historical gender biases in autism research and ensures a more accurate representation of the autistic population.

Research studies that exclude diverse stakeholders risk generating findings that are less applicable to a broader range of autistic individuals, potentially exacerbating healthcare disparities and fostering mistrust towards researchers. Inclusion of stakeholders with firsthand experiences strengthens research by providing valuable insights into CEnR in autism.^{34,35} Guidelines for researchers may enhance involvement and collaboration, fostering trust within the autism community.³⁴

CEnR occurs under real world circumstances. For CEnR to be embraced by the autism research community, systemic changes are essential to ensure that research participants accurately reflect the diversity of autism. This requires flexible recruitment and research conduct, including various CEnR locations and times, accessible venues, co-learning opportunities among researchers, autistics, and caregivers, trusted community partnerships, and the use of health literacy and linguistic competency (i.e., plain language).^{18,34}

Research employing CEnR in neurodevelopmental disorders challenges the assumption that adults with such conditions lack autonomy and are frequently overlooked in research.

Participatory methods like CEnR hold potential for addressing unequal power dynamics by engaging autistic individuals in all research decision-making stages.^{34–37} This aligns with the experiences of marginalized communities, as highlighted in our study, where participants expressed feelings of exclusion, stigma, discrimination, and limited access to research opportunities.^{37–39}

While CEnR remains underutilized in autism research, particularly in the U.S., our findings underscore the necessity of creating inclusive spaces for marginalized community members. A recent UK study highlighted the numerous benefits of participatory methods in autism research, including early conflict identification, reduced mistrust, increased community empowerment, improved research conduct, and translation into interventions and policy.³⁴ This growing recognition of CEnR's potential, especially evident in non-U.S. contexts, aligns with our study's findings, indicating stakeholders' appreciation for research inclusivity, willingness to participate, and recognition of the importance of research on autistic adults in addressing access-to-care challenges.^{34–36,40} Autistic individuals and caregivers who are not researchers have limited opportunities for meaningful input in shaping research agendas, implementation, and dissemination.

Our study enriches CEnR autism literature, stressing inclusive collaboration to address diverse community needs. While diversity is inconsistently identified in existing yet scant literature, an Australian study found that participants underscore the importance of accessible

research involvement, shifting responsibility onto academics to foster inclusive environments and trust.¹⁹ Challenges persist in disseminating CEnR findings, necessitating effective communication and policy translation. We offer practical suggestions to enhance engagement in CEnR, emphasizing the importance of building trust, accommodating diverse needs, improving recruitment strategies, and leveraging platforms such as social media for dissemination and community engagement. Systemic changes are needed for flexible and inclusive autism CEnR, involving autistic individuals in decision-making to mitigate power imbalances. Additionally, longitudinal research is essential for understanding long-term impacts of interventions and services on individuals, providing insights into evolving needs.

A limitation in our study is potential selection bias resulting in representation of those who were able to consent, more readily participate, and with fewer communication challenges. However, participants' individual lived experience in the autism community provides valuable insights. Using qualitative methods lends itself to richer exploration and knowledge gained through narrative than quantitative measures would have enabled in this context. The strength of this study is that it contributes to the literature by providing insight into the perspectives and readiness for CEnR approaches to autism research directly from members of autism communities.

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Table 1: Selected Interview Guide Questions for Analysis

The purpose of this interview is to better understand how researchers conduct their research from the perspectives of autism stakeholder groups. In this interview, you will have the opportunity to talk about various aspects of autism research.

The answers you provide here will be kept private so feel free to share as much information as you are comfortable with. If at any time you are uncomfortable with the questions I am asking, feel free to choose not to comment. This discussion should take approximately one hour.

I will be securely storing your responses so that I do not miss anything important that you say. The information will be kept confidential and any names or other identifying information you may use will be removed from the transcripts. Do I have your permission to store your responses?

Do you have any questions before we begin? By agreeing to go forward with the interview you are giving consent to participate.

Section IV. Community Engaged Research

1. How much do you think researchers consider the perspectives of people on the autism spectrum and their families when designing their studies and drawing conclusions?
 - a. Why do you think that?

There are many different ways that researchers can engage people who aren't researchers, but whose life experience is related to their research, in their studies. This is called community-engaged research. One definition of community engaged research is that "community-engaged research centers around fostering collaborations with and among groups of people affiliated by geographic proximity, special interest, or similar situations with the goal of addressing issues that affect the wellbeing of the people within the group. (Harvard Catalyst Institute)"

2. Have you ever participated in this type of research?
 - a. If so, can you describe specific examples of community engagement in research that you have used or seen?
 - b. If not, have you been a participant in any type of autism research?
3. What do you think could be potential benefits of a community-engaged approach to autism research?
 - a. Are there ways of involving the community that are, to you, preferable to others?
 - b. Are there risks to this approach?
4. If you could collaborate with an autism researcher as a person with a connection to autism, what kind of research would you suggest they do?
5. Is there anything else you would like to add?

	Focus Group (n=6)		Individual Interviews (n=47)	
Age range (years)	35-64		24-60	
Gender # (%)	Female	5 (83.3%)	Female	34 (72.3%)
	Male	1 (16.7%)	Male	13 (27.7%)
Stakeholder category # (%)	Parent/Guardian only	5 (83.3%)	Autistic adult only	15 (31.9%)
	Parent/Guardian & provider	1 (16.7%)	Parent/Guardian only	17 (36.2%)
			Provider only	6 (12.8%)
			Autistic adult & provider	9 (19.1%)