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Biases, barriers, and possible solutions: Steps towards addressing autism researchers under-engagement with racially, ethnically, and socioeconomically diverse communities

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Abstract

Autistic individuals who are also people of color or from lower socioeconomic strata are historically underrepresented in research. Lack of representation in autism research has contributed to health and healthcare disparities. Reducing these disparities will require culturally competent research that is relevant to under-resourced communities as well as collecting large nationally representative samples, or samples in which traditionally disenfranchised groups are over-represented. To achieve these goals, a diverse group of culturally competent researchers must partner with and gain the trust of communities to identify and eliminate barriers to participating in research. We suggest community-academic partnerships as one promising approach that results in high-quality research built on cultural competency, respect, and shared decision making.

Keywords

autism; ASD; race; ethnicity; socioeconomic status; engagement; diverse; barriers; biases; participation

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Autistic (Botha, Hanlon, & Williams, 2021; Bottema-Beutel, Kapp, Lester, Sasson, & Hand, 2020; Vivanti, 2020)¹ people of color and people from lower socioeconomic strata are historically underrepresented in research (Robertson et al., 2017; West et al., 2016). Most large national autism databases disproportionately include White participants of middle-to-high socioeconomic status (Kuhlthau et al., 2018). The challenge of nationally representative and diverse sampling in research is not unique to autism. Poor diversity in recruitment has generally plagued clinical trials (Downing et al., 2016), leading to barriers in generalizing study findings. Lack of representation in autism research also contributes to health and healthcare disparities (Smith, Gehricke, Iadarola, Wolfe, & Kuhlthau, 2020) among historically marginalized groups.

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Autism researchers must accomplish three major tasks to address disparities stemming from under-representation in research. First, we must support and promote diversity, equity, and cultural humility among autism researchers. Second, we must conduct research that addresses the specific needs and interests of under-represented populations. Third, we must collect large nationally representative samples, or samples in which traditionally disenfranchised groups are over-represented, to both potentially replicate commonly accepted findings in autism and gain insight on the barriers and facilitators to better health outcomes among these groups (Robertson, Sobeck, Wynkoop, & Schwartz, 2017; West et al., 2016).

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To accomplish these tasks, it's helpful to understand how historical exploitation, systemic racism and exclusion, and clinician biases contribute to mistrust in research and limit participation. It is also important to be aware of structural barriers that inhibit participation in research even among interested participants.

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Historical Exploitation, Biases, and Barriers

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Many people of color distrust researchers because research traditionally has been designed to benefit and protect White individuals (George, Duran, & Norris, 2014) without concern for the health and safety of racial and ethnic minority participants (Riva, 2016). Although we now have formal institutional review and legal protections against abuses, people of color *still* contend with researchers' and healthcare providers' implicit and explicit biases (Maina, Belton, Ginzberg, Singh, & Johnson, 2018). These biases contribute to poorer physical and mental health outcomes across all stages of life (Bailey et al., 2017; Neblett Jr, 2019; Trent, Dooley, & Dougé, 2019).

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Evidence of implicit bias also is present in the assessment and diagnosis of autism. For example, several studies that explored the experiences of parents of color find that provider bias and providers' dismissing parental concerns impede access to timely assessment and diagnosis (Dababnah, Shaia, Champion, & Nichols, 2018; Voliovitch et al., 2021). Consistent with caregiver report, several observational studies have found that clinicians are more likely to assign autism diagnoses to White children at earlier ages (Begeer, El Bouk,

¹For this manuscript we have chosen to use both identity- and person- first language throughout to acknowledge the range of preferences of our stakeholders. We respect, and are engaged in, the ongoing conversation.

Boussaid, Terwogt, & Koot, 2009; Mandell, Listerud, Levy, & Pinto-Martin, 2002) and more accurately (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007) than to children of color. These findings are also consistent with larger surveillance studies that find that diagnosed autism prevalence differs across race and ethnicity even after controlling for socioeconomic status (Durkin et al., 2017). These biases likely result from and contribute to continued mistrust of health professionals and to missed opportunities for research participation.

Logistical, practical, and systemic barriers also limit participation in research among people of color and people from lower socioeconomic strata. For example, people of color may be concentrated in poorer communities that are farther away from research institutions (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Participating in research often requires access to reliable transportation and frequently requires taking time off work. It also may require access to a fast and reliable internet connection, a resource many families may not have. Finally, participants who do not speak English often are explicitly excluded from participating in research.

In addition to research participation not being feasible for families of color, often the research questions themselves are not directly relevant to them. Until recently, researchers primarily identified questions of interest in a top-down, culturally uninformed fashion where the researcher controlled all aspects of research design and execution without feedback from their stakeholders (Benevides et al., 2020; Clark & Adams, 2020). Lack of enthusiasm for the research question may lead to low participation rates. Emerging evidence suggests that important facilitators to increasing Black caregivers' engagement in autism research are having a culturally responsive research team and advancing research that includes and is sensitive to Black experiences (Shaia, Nichols, Dababnah, Campion, & Garbarino, 2019).

Autism researchers will likely experience more success in recruiting if they choose research questions that are relevant and timely and are able to present the research question in an accessible way that connects to the question's relevance to autistic individuals and their caregivers. We propose community-academic partnerships (CAPs) as a shared power approach to developing, designing, and conducting relevant and timely research (Brookman-Frazee, Stahmer, Lewis, Feder, & Reed, 2012; Nicolaidis et al., 2011). We also provide practical suggestions for researchers as they initiate, develop, and maintain these relationships. We acknowledge that we are writing from our own limited perspectives, and the limited perspectives of the available research. As such, we may have unintentionally left out important factors to consider.

Community-Academic Partnerships

Community-partnered research has many iterations. Perhaps the three most relevant to this discussion are: 1) community-based participatory research (CBPR); 2) participatory action research (PAR); and 3) community-academic partnerships (CAP). CBPR engages community members in all aspects of the research and emphasizes building on the community's resources and strengths. PAR has as its goal improving the lives of the participants involved via active participation/choice in the research process. In both CBPR and PAR, community stakeholders generate research ideas. CAPs also include community

members throughout all aspects of the research process and may be used in conjunction with CBPR or PAR approaches. CAPs, however, explicitly permit the bi-directional flow of research ideas between researchers and community stakeholders and have been successfully used in autism research (Drahota et al., 2016; Eisenhower et al., 2020; Feinberg et al., 2021; Pellecchia et al., 2018). Given the bidirectional flow of research ideas explicitly permitted in CAPs they may serve as an ideal stepping stone for researchers who are newer to CBPR approaches but are interested in conducting this type of research. However, we recognize that PAR and CBPR have also been successfully employed in autism research and have been recommended by autistic people as appropriate methods that promote respect, access, and relevance – and therefore should also be explored as methodological approaches by research teams considering community partnered work (Lam et al., 2020; Moody et al., 2019; Nicolaidis et al., 2011; Ostemeyer & Scarpa, 2012).

Before Initiating a Community Partnership

Prior to initiating a community partnership, it is critical for researchers to engage in self-reflection and seek out relevant trainings and readings that advance their cultural humility. Principal investigators should prepare themselves by reflecting on their individual identities (e.g., race, gender, income) (DiAngelo, 2018; Hays, 2001, McIntosh, 2007, Muhammad, 2015) and the primary identities of the organization/community with which they wish to partner. It is also critical to gain an understanding of the implicit and explicit biases that you hold, particularly given the known impact of implicit and explicit bias on healthcare. All individuals, including healthcare professionals, hold explicit and implicit biases (FitzGerald & Hurst, 2017; Phelan et al., 2014). These impact our daily interactions with others and our work. Being consciously aware of these biases allows us to reflect on, challenge, and address them – hopefully limiting their influence in our research and clinical care. Next, it is important to reflect on one’s interest/motivation to conduct partnered research with the identified community as well as how the researchers’ identities, and the intersection of those identities (Crenshaw, 2017), support or inhibit the researcher’s ability to establish trust with partners. Misalignment between the interests and motivations of the researcher and community members would likely perpetuate the cycle of uninformed researcher guided inquiry, greatly diluting or even extinguishing the CAP. For example, if a researcher wrote a grant on a topic without consulting the community advisory board and/or community leaders, the relationship and trust between the researcher and the community organization would be damaged and likely result in the reduced engagement of the community overall – even if the research was in some way relevant to the interests and needs of community members. If these concepts are unfamiliar, workshops or formal coursework beyond the citations referenced in this manuscript may be useful to support learning and self-reflection.

Principal investigators also should cultivate a culturally mindful and diverse research team. Principal investigators should develop a shared understanding of lab members’ individual identities and incorporate formal or informal trainings into lab meetings as necessary. As part of standard practice, facilitate discussions on how our implicit and explicit biases, individual identities, and associated privilege or lack thereof impact our thoughts, behaviors, and relationships with colleagues and research participants. Privilege is defined here as any type of unearned asset one may have based on an identity that holds power in our society

(e.g., the privilege to hold your partner's hand and not risk ridicule or violence if you are in a male-female relationship) (McIntosh, 2007). Note that diverse teams will have an unequal distribution of privilege and that it will be important to facilitate conversations about inequality and the unique experiences of each team member.

Cultivating a diverse team enhances all research; however, as you recruit lab members, be careful to avoid tokenism, which is selecting a team member based on one or more of their identities versus their experiences and abilities (Wright, 2001). It is equally important to avoid asking lab members representing a specific identity to speak on behalf of all members sharing that identity (e.g., asking someone who is Black to speak about "the Black experience"). In an effort to prevent tokenism it can be helpful to think about ways to alter your lab structure and policies to appeal to, and be inclusive of, a diverse working group and to clearly communicate these policies to potential lab members (e.g., website, email signature, hiring ads, during interviews). Fostering an inclusive climate and culture within your lab should result in the recruitment of a more diverse candidate pool across many identities (e.g., race, ethnicity, sexual orientation, age, socioeconomic background), thus maximizing your chances of building a diverse team without resorting to tokenism. Then, once you have recruited a diverse team, it is imperative that you then recognize the strengths, expertise, and perspectives of your team members. It is important to remember this as your team develops new ideas, or executes existing projects. Team members may bring up novel ideas and/or ways to execute study procedures that are inconsistent with the way that you approach developing new ideas or organizing workflow – be open to the ideas, consider them as a team, make pros and cons lists, and then, if at all possible, democratically decide a path forward.

We recognize that we have provided a lot of direction on fostering culturally competent and diverse teams without much context and few examples. As such, we have intentionally chosen references that provide definitions and rich and descriptive examples of power, privilege, intersectionality, tokenism, and avoiding asking members of a specific identity to speak on behalf of all members (e.g., Holloway, Cohen, & Domínguez-Pareto, 2018).

Developing and Maintaining Community Partnerships

Both research groups and community organizations can initiate partnerships. If you want to work with a community group, reach out and share your interest. Schedule a meeting where you can learn more about the organization's current needs and interest in research prior to pitching your ideas. When you meet, be prepared to have reflective (vs. reactive) and respectful conversations about your research, including your motivations and interests. This is important for all researchers, but it is even more important for researchers who do not share any identities with their research population. It may be helpful to acknowledge differences and indicate that you want to hear all feedback and concerns. For example, you can say, "I acknowledge that I am a White woman, and I hope to be a strong ally for this organization. I am excited to have this meeting with you and learn about the ways I can support your organization's mission through research." Finally, indicate your interest in establishing a partnership with shared decision-making power early and empanel an advisory board of community members to formalize the shared decision-making process.

As you build relationships, identify problems and challenges that are important to your stakeholders. What are their burning questions? What keeps them up at night? This might not be your original research question – that is okay. It is important to be flexible. Next, it can be helpful to audition a short-list of identified problems to the advisory board (or similar decision-making body) to vet them, develop possible solutions/hypotheses and identify possible funding mechanisms. Be clear with partners about the success rates of grant applications and include submission-time-to-start-time in proposals. This is critically important as some community partners will not be able to wait to conduct the proposed work. Consider alternative funding mechanisms that may accelerate the timeline (e.g., foundation grants, private donors). Once the partnership is established and projects have been initiated, it is important to maintain relationships with community partners. Invite your community partners to lab meetings and social events and include them in all plan-change decisions. Incorporate them into the budget as paid research staff whenever possible.

We encourage principal investigators who are invested in reducing disparities in autism research, but feel under-prepared to do so, to 1) complete formal coursework and self-reflection to gain knowledge and skills, and 2) collaborate with principal investigators leading CAPs to gain initial experience by leveraging your skills (e.g., methodological and/or analytical strengths) in exchange for their CAP experiences.

Engaging and Recruiting Research Participants

Although critical to the process, establishing a strong CAP and identifying and pursuing research ideas vetted to be important and relevant to the community will not be enough to address and eliminate logistical, practical, and systemic barriers that limit or prevent community members from participating in research. You must work with your partners to identify community trusted leaders who can guide you on respectful and supportive ways to engage, recruit, and support individuals participating in your research study. Barriers to participating in research will be unique to the context and research population. Additionally, it is important to have culturally responsive, reflective, and respectful conversations with community leaders and prospective research participants to address questions and concerns related to the research process and negative past research experiences (George et al., 2014). Although we have seen some recent progress in including autistic people and parents of children with autism as important stakeholders guiding research directions (Benevides et al., 2020; Clark & Adams, 2020), we rarely see autistic individuals of color sharing their experiences (Jones & Mandell, 2020).

Conclusion

To reduce disparities stemming from underrepresentation in autism research, we need to conduct culturally competent research that is compelling and relevant to people of color and people from lower socioeconomic strata. We also need large, nationally representative samples, or samples in which traditionally disenfranchised groups are over-represented, to set the stage for replication studies and to gain insight into the impact of race and class on outcomes. To accomplish this third goal, a diverse group of culturally competent researchers must partner with and gain the trust of communities to identify and address or

eliminate barriers to participating in research. We suggest CAPs as one promising approach that results in high-quality research built on cultural humility, respect, and shared decision making. Although community partnered research is more expensive and time consuming than investigator-led research, it is an important method that can be used to build trust between researchers and the community, reduce or eliminate barriers to participating in research, and ultimately answer important research questions for diverse communities that will impact health and well-being. These activities involve increased involvement of researchers and include more targeted and inclusive efforts for recruitment; ultimately requiring the support of various funding organizations and institutions that support autism research. There are various ways these efforts should be supported, including targeted or limited funding opportunities for researchers or research topics, incentives for broader inclusion, recruitment of faculty and clinical staff, and other mechanisms to support community partnered research. This may ultimately require organizations to participate in efforts to reduce implicit bias. Such efforts have already begun, and should continue to be fostered and expanded.

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