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Racial and Ethnic Diversity in Autism Research

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Racial and Ethnic Diversity in Autism Research

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Carly Beth Hyde

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ABSTRACT OF THE THESIS

Racial and Ethnic Diversity in Autism Research

by

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Master of Science in Community Health Sciences
University of California, Los Angeles, 2022
Professor May Sudhinaraset, Chair

Autism research offers many direct benefits to participants, and the conclusions from studies are often integrated into evidence-based policy and practice within healthcare and education systems. For decades, autism research has vastly underrepresented the experiences of minoritized racial and ethnic groups. Without representation in research, diagnostic tools and therapeutic interventions may not address the specific needs and strengths of diverse populations. Ultimately, this gap perpetuates health, economic, and educational disparities for populations who face "double vulnerability" due to the intersection of marginalized race and disability status. Underrepresentation of minoritized populations can be understood using the Social-Ecological Model (SEM), which characterizes influences on health behavior into policy, community, organizational, interpersonal, and individual levels. This project utilized the SEM to evaluate the underrepresentation of Black, Hispanic, Asian, American Indian, and Pacific Islanders in autism research. First, autism research enrollment was examined through the lens of the SEM. Second, participant enrollment at the University of California, Los Angeles's Center for Autism Research and Treatment (UCLA CART) was assessed using annual enrollment reports. Third, solutions to address under-enrollment of minoritized racial and ethnic groups at UCLA CART were identified using the SEM. Promising and evidence-based solutions include: community engagement, patient navigation intervention, improved research design and recruitment methods, culturally-adapted intervention, and standardized data reporting.

The thesis of Carly Beth Hyde is approved.

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2022

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Preface

This paper discusses diversity, which is an expansive topic with a multitude of definitions. A person can be defined by any number of descriptors, including (but not limited to) their gender, age, race, ethnicity, sexuality, country of origin, religion, income, education, location, language, immigration status, or disability status. While this paper will attempt to consider many aspects of diversity, it will primarily focus on race and ethnicity. This is an oversimplification of human complexity, but race and ethnicity status continue to be frequent sources of discrimination in the United States. Race and ethnicity are not independent factors for health; instead, it is the cultural and political reactions to these identified characteristics (i.e. racism and discrimination) that influence health status (Kagawa-Singer, 2000).

Race and ethnicity are also inextricably connected to other social determinants, which coalesce to impact a person's health and well-being. This paper will discuss other aspects of diversity (such as income and education) as they relate to race and ethnicity, though it is understood that associations between race, ethnicity, income, and education are true at the population level but will not apply to every person of a certain race. Overall, more autistic children in low-income households are from marginalized racial and ethnic groups than the overall autistic population, and this association between race and socioeconomic status influences discussions throughout this paper (Anderson et al., 2022). The purpose of this paper is not to perpetuate stereotypes, but to discuss the realities that disproportionately impact minoritized populations.

Just as there are a multitude of ways to describe the characteristics of a person, there are also a variety of words that can be used to describe an individual's racial or ethnic identity. This paper will discuss six demographic groups, described henceforth as Black, Asian, Hispanic, American Indian, Pacific Islander, and White. In later discussion of specific population prevalence rates, individuals who identify with multiple racial or ethnic groups will be counted as "multiracial." One caveat, also indicative of the particular confusion that results from contrived demographic categories, is that individuals who self-report as Hispanic will be counted as Hispanic regardless of their reported race. White will be used to describe non-Hispanic White people.

These terms reflect the demographic data collection forms used by National Institute of Health (NIH), though they have been appropriately criticized as vague and poorly reflective of diverse and dynamic populations. Health disparities are not always consistent within these broad populations and evaluation based on more narrow descriptions of country of origin or immigration status would reveal more nuanced information. However, such nuanced literature about autism is extremely limited. The term BIPOC (Black, Indigenous, or Person of Color) will be used to collectively describe non-White populations. This imperfect term has been criticized for omitting Hispanic populations, and many people considered BIPOC do not personally identify with the term (Deo, 2021). However, it will be used in this paper for its relative clarity in describing minoritized racial and ethnic groups.

Outside of the complexity of racial and ethnic labels there is a parallel conversation about identity taking place through the neurodiversity movement. Many autistic self-advocates have voiced preference for identity-first language, including the term "autistic," rather than the person-first language (i.e., "person with autism"). Both terms were coined by self-advocates: person-first language signifies that autism is only one component of a person's identity, whereas identity-first language acknowledges that autism is a fundamental component of a person's life that should not be pathologized or stigmatized (Vivanti, 2020). In reality, autism can be both a challenge and a strength to a person and their family, and there is no universal consensus on terminology. Many researchers use both “autistic person” and “person with autism” to acknowledge the diverse preferences of self-advocates and families, therefore both terms will be used in this paper. However, the neurodiversity movement has also been largely White, which complicates self-selection of descriptors for those who will be the topic of this paper.

The other group highlighted in this paper are the families of autistic people. Many of the concepts discussed can be applied to autistic people or their parents, grandparents, siblings, friends, etc. The intersection between race and autism is complex and made no easier by language, which will not be sufficient to inclusively describe all people. Nonetheless, the central aim of this paper is to characterize concerns related to BIPOC autistic adults and children, along with their families, communities, medical, therapeutic, and educational providers, and the research institutions that generate and investigate their treatment and care.

Section 1 discusses the various influences on BIPOC research participation, both broadly and specifically related to autism. Section 2 offers a case study examining one autism research institute and recommendations for addressing barriers to research enrollment. Throughout the commentary, the author aims to avoid Western-centric and deficit-focused frameworks, which assumes that White experiences are standard and variations from White norms are problematic. This attempt will be enhanced by input from a diverse group of readers, whose perspectives will be integrated alongside the author’s, who is herself White. It is the author’s hope that this framework can be used to improve diversity across institutions and fields of research, though sustainable and scalable change fundamentally requires direct and iterative input from BIPOC and autistic communities.

Section 1: Introduction

1.1 Problem Statement

BIPOC participants are underrepresented in autism research. This problem exists across disciplines and has persisted through decades (Henrich et al., 2010). Globally, the vast majority of research is conducted amongst subjects from Western, Educated, Industrialized, Rich, and Democratic (or "WEIRD") nations (Henrich et al., 2010). According to a 2007 analysis of six major psychology research journals, 96% of research subjects come from countries with 12% of the world's population. The result is scientific literature that characterizes all humans by the behaviors of a particularly narrow subgroup. Within the United States, where 68% of the world's research subjects are located, participant pools are even more monolithic. Most consenting adult participants are educated, urban, affluent, and White (Downing et al., 2007).

BIPOC underrepresentation is visible across subfields of autism research, including pediatric, genetic, and intervention studies, though the extent of this problem is difficult to quantify (Hilton et al., 2010). A review of 1,013 evidence-based practice articles published between 1990 and 2017 found demographic data in only 25% (Steinbrenner et al., 2022). This review found that 64.8% of identified participants were White, followed by 9.4% Hispanic, 7.7% Black, and 6.4% Asian. Race and ethnicity for the remainder of participants were unreported, making it impossible to assess the true extent of BIPOC underrepresentation. Other reviews have found that some intervention modalities report demographics at a higher frequency, such as parent-implemented interventions (39%) and social skills interventions (62.7%) (Davenport et al., 2018; Robertson et al., 2017). A review of neuroimaging publications found race and ethnicity data in fewer than 5% of articles (Goldfarb, 2021). Another review reported that 40.5%

of articles that reported participant race and ethnicity cited insufficient sample diversity as a limitation to the generalizability of the results, suggesting that many authors who reported demographics also recognized the consequences limited diversity (Pierce et al., 2014). This finding demonstrates that many autism researchers have acknowledged the importance of diverse cohorts but are still unable to enroll BIPOC participants in studies. Unfortunately, it is impossible to tell whether other authors considered participant diversity in their research as their publications make no mention of race or ethnicity.

Lack of diversity in autism research is a concern for two primary reasons. First, there are many direct benefits for participants. Research is a pathway for autistic people to access free and high-quality interventions, receive expert assessments and feedback, dialogue with specialists, reduce cost for out-of-pocket genetic or behavioral testing, gain understanding about developmental needs and strengths, and connect with resources in the community. The second and more pressing issue is that research findings may be biased by lack of population representation, which would negatively impact all stakeholders.

The conclusions from research studies are often integrated into evidence-based policy and practice, directly influencing the methods utilized by providers in healthcare and education systems (Chezan et al., 2022). Without BIPOC representation in research, diagnostic tools and therapeutic interventions may not address the specific needs of diverse populations (Shanawani et al., 2006). Providers may not be prepared to incorporate a BIPOC family's strengths and preferences into their treatment while still adhering to "best practices," which may have been optimized for mostly White families during research development (Trembath et al., 2019). This knowledge gap can lead to poor treatment outcomes, wasted time and financial resources, and frustration from all involved. Healthcare systems also suffer from lack of diversity in research, as ineffective treatment and intervention across the lifespan can increase the overall cost of care for autistic individuals (Shonkoff et al., 2009).

Slow progress in diversifying research cohorts also impairs investigators. There are low rates of recruitment and high rates of attrition for BIPOC research participants, which impacts the validity, replicability, and generalizability of study conclusions (Moore & Symons, 2009; Nock & Ferriter, 2005). In the last year, millions of dollars in funding have been allocated to research initiatives aimed at promoting diversity both amongst research participants and within academic institutions (AAN, 2021; INSAR, 2021; SFARI, 2020). However, the success of these efforts depends on the ability of investigators to understand why minoritized populations have not participated in research previously.

Most importantly, the problem of underrepresentation in research has broad consequences for both BIPOC autistic people and their communities. Across income groups, BIPOC autistic children have poorer overall health than White autistic children (Anderson et al., 2022). Insufficient knowledge about the particular health profiles of autistic people in minoritized communities leads to undiagnosed or poorly managed co-occurring health problems (D. R. Jones et al., 2020). Caregivers whose autistic children have unmet service and medical needs experience greater emotional and financial burden (Burke & Heller, 2016). Stereotypes and racism throughout medical, educational, and judicial systems contributes to resource gatekeeping as well as dangerous situations that threaten the safety of BIPOC autistic people.

Addressing health disparities requires assessing race and ethnicity through research, and BIPOC families deserve evidence-based research that reflects their strengths and diversity (Shanawani et al., 2006). BIPOC individuals have expressed feeling that participating in research is an opportunity and a right, and others have expressed feeling “left out” of the research process

(Locock & Smith, 2011). Therefore, autism researchers, institutional organizations, and policy makers, who hold the power to reduce barriers to research participation, have the responsibility to identify solutions without overly burdening BIPOC families or demanding their involvement.

1.2 Background

Autism spectrum disorder is a neurodevelopmental condition characterized by social communication difficulties and restricted and repetitive behaviors. Symptoms of autism often begin to emerge in the first and second years of life, and most children can be reliably diagnosed by 3 years old (Lord et al., 2006). Autism is frequently accompanied by a number of co-occurring lifelong health problems, including intellectual disability, psychiatric and behavioral challenges, epilepsy, sleep difficulties, and digestive problems (Neumeyer et al., 2019). Across the lifespan, autistic people face higher healthcare costs, higher rates of hospitalization, lower quality of life, and lower life-expectancy than individuals without autism (Arias et al., 2018; Bishop-Fitzpatrick & Kind, 2017; Shea et al., 2018).

There is little consensus about variations in clinical profiles by race and ethnicity (Carr & Lord, 2013; Mandell et al., 2009). Some studies suggest more severe clinical presentation of autism in Black children compared to White children (Cuccaro et al., 2007). At the time of publication, this finding was attributed to underdiagnosis of autism across BIPOC groups, resulting in Black children with milder symptoms who were never identified or diagnosed. However, a more recent study found that intellectual disability was twice as prevalent in Black children compared to White children despite similar rate and timing of autism diagnosis by race (Constantino et al., 2020). Since current understanding of autism physiology does not suggest any mechanism for difference in clinical severity by race, this disparity is likely the result of ineffective or inaccessible intervention and medical care. It may also reflect bias in ascertainment, evaluation, or diagnosis of participants. Ultimately, lack of clarity on this topic reflects the deep entanglement of race, socioeconomic status, access to medical care and intervention, and inclusion of Black participants in autism research. Due to changes in screening policy and insurance coverage in the past decade, the overall prevalence of autism (1.7%) is now similar across race and ethnicity; however, BIPOC children are still less likely to be diagnosed in some geographic regions (Maenner, 2021; Nevison & Parker, 2020). The average age of diagnosis for BIPOC children is up to 3 years later than White children, though this gap is also narrowing (Constantino et al., 2020; Liptak et al., 2008; Mandell et al., 2002, 2009; Nevison & Parker, 2020).

Autism researchers frequently use a favored adage "if you've met one person with autism, you've met one person with autism" to describe the wide variation in symptomatology (McCleery, 2022). Some autistic people are socially motivated while others tend towards social retreat. Cognitive abilities, personalities, interests, and strengths are incredibly varied, and many autistic people thrive with appropriate support (Gerdts & Bernier, 2011). In addition to the clinical heterogeneity seen across the autism spectrum, this population is highly diverse in economic status, family orientation, ethnicity, acculturation status, religion, housing status, family primary language, parent mental illness or addiction status, parent educational attainment, access to pediatric care, and cultural beliefs (West et al., 2016). However, minoritized demographic status is often accompanied by health disparities.

1.3 Disparities in Autism

1.3.1 Healthcare system

The process of obtaining an autism diagnosis is often arduous. Attaining the appropriate referrals can require multiple visits with physicians. Once referred, families often face wait times of months or even years for a consultation with a developmental specialist, which may incur significant financial burden (Brown et al., 2000; Carr & Lord, 2013). BIPOC parents wait an average of three years between first expressing concern to the time a child receives a diagnosis, which is one year longer than the delay experienced by White families (Baio, 2018; Broder-Fingert et al., 2020; Constantino et al., 2020). White and BIPOC autistic children have similar rates of health insurance coverage, but a number of other challenges can impede the diagnostic process (Anderson et al., 2022).

Autistic children have similar rates of health service utilization across racial and ethnic groups, though disparities emerge for children in lower-income households (Anderson et al., 2022). Attending multiple diagnostic visits can be particularly challenging for families who face logistical barriers such as lack of reliable transportation or inadequate translation services. The healthcare setting is also important to the quality of diagnostic testing and speed of referrals; well-financed institutions have greater capacity for specialist follow-up than community-based clinics and hospitals, which may serve a larger number of BIPOC patients (Broder-Fingert et al., 2020; Mandell et al., 2002).

Physician bias can also interfere with diagnosing BIPOC children with autism. BIPOC children across racial groups are screened for autism less often than White children on average, though this gap has narrowed in some geographical locations due to recent policy changes

(Wiggins et al., 2020). On average, BIPOC families attend more physician visits than White families before receiving a formal diagnosis (Mandell et al., 2002). In some cases, a physician may be reluctant to make an autism diagnosis due to insufficient training about early symptoms, prognosis, and treatment for autism, or their own stigma about autism and the emotional and financial impact they believe a diagnosis could have on a family (Mandell et al., 2002). Families may also experience discrimination, indifference, or disrespect from their child's provider, which can impact the quality of the screening and a family's willingness to report concerns (Burkett et al., 2015; Dababnah et al., 2018; Donohue et al., 2019). This may result in physicians discounting parental concerns or failing to inquire about developmental milestones.

In blinded studies, there was a greater degree of disagreement amongst providers about the correct diagnosis for Black children, suggesting that physician bias impacts their accurate assessment of symptoms (Begeer et al., 2009; Neuhaus et al., 2018). Black children are more likely to be misdiagnosed with conduct and adjustment disorders, due in part to racial stereotyping by providers (Mandell & Novak, 2005; Reijneveld et al., 2005). Children from non-English speaking backgrounds are more likely to have language delays attributed to their home environment, and communication challenges between providers and families can further contribute to delayed autism diagnoses (Barton et al., 2012; Mandell & Novak, 2005; Reijneveld et al., 2005). Diagnostic labels for primary learning differences (e.g., autism, intellectual disability) are not assigned equally by race; non-White children disproportionally receive labels of intellectual disability while autism is more frequently applied to White children (Blanchett, 2010). Regardless of whether this disparity reflects population differences in clinical characteristics, bias during diagnosis, or other factors, diagnostic labels impact access to services in both medical and educational systems.

1.3.2 Intervention Services

Early and intensive intervention is the first line of treatment for autism and can be important to the health and wellbeing of a child, as well as the members of their family (G. Dawson et al., 2010; Rogers et al., 2014). BIPOC children are underrepresented in intervention services for a variety of reasons, including the limited availability of experienced or bilingual providers in their geographic area, out-of-pocket treatment costs, negative experiences in treatment, or preferences for alternative or complementary treatment options (Magaña et al., 2012; Thurston et al., 2008). Underdiagnosis of autism or misdiagnosis of other learning differences can impact service access and quality: on average, children with an autism diagnosis receive more special education services than children diagnosed with other types of learning differences (Sturm et al., 2021). Services for autistic children are also more congruent with a child's specific areas of need (Sturm et al., 2021). Providers may also select inappropriate interventions or fail to adequately address variable environmental conditions, resulting in poor intervention efficacy.

BIPOC parents are also more likely to have negative expectations of treatment due to lack of culturally-sensitive protocols, which can impact adherence to intervention (Snell-Rood et al., 2020). Families who view intervention options as ineffective or see the outcome targets as misaligned with their own values are less likely to integrate the routines in their daily lives and are more likely to discontinue treatment altogether (Hwa-Froelich & Vigil, 2004). This can significantly reduce the efficacy of intervention and further perpetuate a family's lack of confidence in evidence-based treatments (Mandell & Novak, 2005). Overall, there is insufficient research on how and why certain interventions work well for some groups but not others, perpetuated in part by lack of BIPOC representation in studies (Lord et al., 2005).

1.3.3 Impact of delayed diagnosis and intervention

Together, these factors contribute to disparities in health outcomes for BIPOC autistic children and adults, which are evident irrespective of education or income (Broder-Fingert et al., 2020; Magaña et al., 2012). The intersection between minoritized race and autism creates situations of "double vulnerability," which impart numerous consequences such as elevated risk for incarceration, lack of educational attainment and employment, poverty, increased psychosocial problems, and shorter life expectancy (Bishop-Fitzpatrick & Kind, 2017; Chang, 2019; Kelly et al., 2005; Reijneveld et al., 2005). Health disparities in the general population persist among autistic adults; BIPOC adults are more likely than White autistic adults to experience major health conditions like diabetes, cardiovascular disease, or hypertension (Schott et al., 2022). Family members of autistic individuals also experience higher rates of mental health disorders, as well as increased treatment costs and reduced employment throughout an autistic child's lifetime (Abbeduto et al., 2004; Carr & Lord, 2013; Montes & Halterman, 2007). These health disparities may also have consequences for institutions; substantial spending on ineffective and inefficient services contributes to the substantial economic cost of autism across the lifetime (Rogge & Janssen, 2019).

1.4 Theoretical Framework: Social-Ecological Model

The lack of diverse representation in autism research is a complex problem that can be better understood using the Social-Ecological Model (SEM). The SEM is a useful conceptual framework that categorizes influences on behavior to aid identification of possible intervention entry points (McLeroy et al, 1988; Stokols, 1994). The SEM includes five levels, which together create a dynamic network of influence: policy, community, organizational, interpersonal, and individual (Salihu et al., 2015). Local, state, and federal laws contribute to the policy level of the

SEM. The community level is influenced by overall convenience and acceptability of research, cultural attitudes about autism and disability, and the physical characteristics of a neighborhood (e.g., public safety and transportation). The rules, regulations, and general attitudes of an institution shape the organizational level of the SEM. Family, friends, and healthcare providers contribute to the interpersonal environment. Finally, the individual level is constructed by a person's knowledge, attitudes, awareness, beliefs, and perceptions as influenced by their social and physical environments. The SEM framework suggests that individuals interact with all layers of their environment. Many of the influences on participation in autism research can be understood using this model. For the purpose of this exploration, the "individual" level describes any person who decides to enroll in a research study, including both autistic adults and the caregivers of autistic children and adults.

1.5 Research Aims

Three aims comprise this evaluation of barriers to BIPOC research enrollment. Aim 1 assessed autism research broadly, while Aims 2 and 3 applied the Social-Ecological Model (SEM) to the University of California, Los Angeles (UCLA) Center for Autism Research and Treatment (CART).

Aim 1: Use the SEM to understand policy, community, organizational, interpersonal, and individual-level barriers to enrollment for BIPOC autistic people and their families.

Aim 2: Assess BIPOC enrollment in research at CART.

Aim 3: Engage the SEM to identify opportunities to improve BIPOC enrollment in research at CART.

Section 2: Aim 1

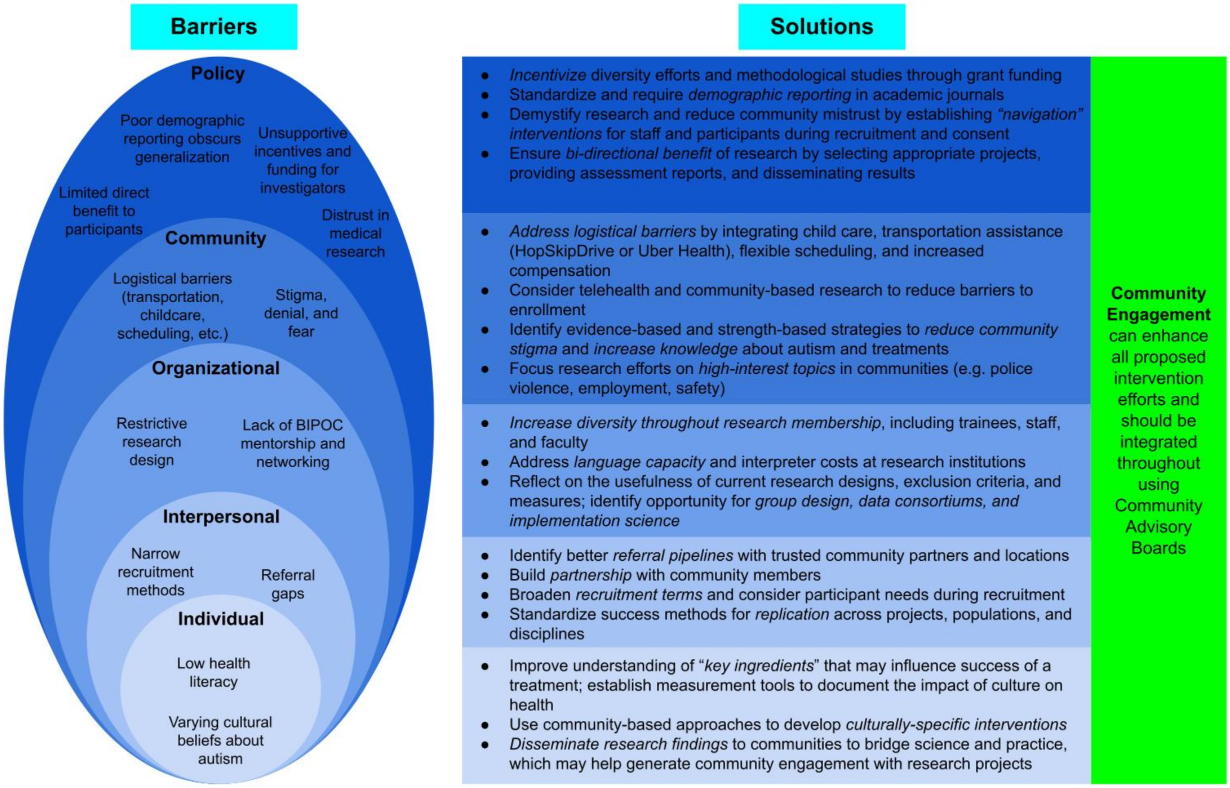
Aim 1: Use the SEM to understand policy, community, organizational, interpersonal, and individual-level barriers to enrollment for BIPOC autistic people and their families.

2.1 Methods

Aim 1 was addressed using literature across disciplines. First, a thorough review of policies and publications guided identification of focus areas at each level of the SEM. After these topics were developed, possible intervention options were reviewed. Evidence to support possible solutions to identified barriers was presented when available and limitations were discussed. This process was iterative and fluid; solutions also informed understanding of barriers. The narrative summary was reviewed by faculty at the UCLA and additional information was provided when requested.

2.2 Results

Multiple barriers and promising solutions were identified at each level of the SEM. Figure 1 summarizes the results for Aim 1.



- *Incentivize* diversity efforts and methodological studies through grant funding
- Standardize and require *demographic reporting* in academic journals
- Demystify research and reduce community mistrust by establishing *"navigation" interventions* for staff and participants during recruitment and consent
- Ensure *bi-directional benefit* of research by selecting appropriate projects, providing assessment reports, and disseminating results

- *Address logistical barriers* by integrating child care, transportation assistance (HopSkipDrive or Uber Health), flexible scheduling, and increased compensation
- Consider telehealth and community-based research to reduce barriers to enrollment
- Identify evidence-based and strength-based strategies to *reduce community stigma* and *increase knowledge* about autism and treatments
- Focus research efforts on *high-interest topics* in communities (e.g. police violence, employment, safety)

- *Increase diversity throughout research membership*, including trainees, staff, and faculty
- Address *language capacity* and interpreter costs at research institutions
- Reflect on the usefulness of current research designs, exclusion criteria, and measures; identify opportunity for *group design, data consortiums, and implementation science*

- Identify better *referral pipelines* with trusted community partners and locations
- Build *partnership* with community members
- Broaden *recruitment terms* and consider participant needs during recruitment
- Standardize success methods for *replication* across projects, populations, and disciplines

- Improve understanding of "*key ingredients*" that may influence success of a treatment; establish measurement tools to document the impact of culture on health
- Use community-based approaches to develop *culturally-specific interventions*
- *Disseminate research findings* to communities to bridge science and practice, which may help generate community engagement with research projects

Community Engagement can enhance all proposed intervention efforts and should be integrated throughout using Community Advisory Boards

Figure 1: Barriers and solutions to autism research enrollment framed using the social-ecological model (SEM).

2.2.1 Policy Level

Research incentives and funding

Since 1993, the NIH Revitalization Act has legally required NIH to establish guidelines to include participants across racial and ethnic groups in studies (Geller et al., 2018). However, an analysis of published randomized control trials over the subsequent two decades demonstrated that this policy change did not significantly impact inclusion of participants from minoritized race and ethnicity groups (Geller et al., 2018). The lack of measurable change can be attributed in part to the existing incentive structures in academia. Investigators face pressure from funding institutions to recruit quickly for their projects, often leading them to select convenience samples. Purposeful sampling is expensive, time-consuming, and often neglected in study budgets (Maye et al., 2021). Well-intentioned researchers may partake in some diversity efforts during recruitment, but without comprehensive understanding about the causes of historical non-participation by BIPOC families or knowledge about best practices for diverse recruitment, these efforts are unlikely to succeed. When initial attempts to diversify participant pools fail, researchers also often increase enrollment numbers by recruiting more easily accessible White participants. Ultimately, the consequences of a monolithic sample seem minimal compared to the fear of an underpowered project.

Institutions have the authority to uphold their legally mandated diversity requirements by funding meaningful work in this area. Grant institutions should focus on establishing and validating methods for recruitment and retention of diverse populations for research across health topics (West et al., 2016). As one author describes, research focused narrowly on health disparities can lead to fragmentation between methodologies and disciplines; instead, empirical investigation (i.e., “research on research”) is necessary (Collyer & Smith, 2020). Grant institutions should also prioritize funding projects that allocate substantial efforts toward representative recruitment and be cautious of research projects without a clear and evidence-based plan to address participant diversity. Success in this area should be well-documented and published so that the methods can be integrated into future studies.

Race and ethnicity reporting

A lack of standardized demographic reporting about both research participants and researchers makes tracking progress towards BIPOC representation especially difficult. This problem exists within autism journals, professional organizations, patient advocacy groups, and institutions, and perpetuates a lack of accountability for diversity efforts (Pierce et al., 2014). A review of three large autism publications in 2016 found that 72% of publications did not report race and ethnicity despite previous calls to improve this practice (Pierce et al., 2014). This lack of reporting complicates the ability of investigators to identify strategies that may be promising for further investigation in BIPOC populations. It can also prevent providers from anticipating how a BIPOC family might respond to a particular treatment.

Publishers and investigators also have a responsibility to consider the generalizability of their results based on the demographics of their cohort. It is insufficient for publications to merely acknowledge the limitations of a mostly White participant pool in the footnotes of a manuscript. Journals should require authors to fully describe participant demographics and encourage expanded discussion of generalizability. Academic journals must strengthen their reporting policy to comply with NIH inclusion regulations, especially given that the policy alone has not impacted enrollment in research studies (Geller et al., 2018).

While it is impossible to re-do decades of autism research to include more diverse participant samples, it is possible to consider how research may have biased policies that impact families today. The consequences of obscure demographic reporting are far-reaching because education, healthcare, public safety, and housing policy is often informed by evidence-based research (Trembath et al., 2019). When BIPOC people are not sufficiently represented in research studies, legislators risk overgeneralizing findings from monolithic samples. This can result in standards of care in that are not adequately adapted for the heterogeneous population of autistic people and may even cause harm to BIPOC families. These public metrics are an important step towards accountability in the field of autism research.

Distrust of medical research

Distrust, fear, and suspicion about medical research greatly inhibit the willingness of BIPOC people to enroll in research studies (Tanner et al., 2015; Tromp et al., 2016). Throughout history, authoritative figures have abused BIPOC people in the name of "research". Enslaved Black people were exploited for medical gains, minoritized prisoners were coerced for high-risk experimentation, and throughout the 20th century BIPOC men, women, and children were mistreated by medical institutions and targeted for use in experimental procedures. Dangerous and sometimes deadly experimentation occurred at segregated psychiatric institutions and public hospital wards. The Tuskegee Syphilis study is one well-known example in which indigent Black men with syphilis were followed for nearly 40 years but never informed about their diagnosis nor provided effective treatment once available (Gamble, 1997). To understand the distrust that many BIPOC people hold for medical systems and researchers, it is critical to recognize that the memory of historical misconduct remains alive. First-person experiences of exploitation and abuse in the medical system will continue to be passed through BIPOC communities for generations, particularly if misconduct continues. Lack of confidence about the intentions of researchers is prevalent through BIPOC communalities, but it is particularly acute for medical and genetic research, as well as studies that specifically target minoritized groups (Nicolaidis et al., 2011). Failure on behalf of the medical system to address past misconduct further perpetuates distrust (Ford et al., 2013).

Multiple policies have been adopted in the last century to protect patients, with frequent protest and criticism by physicians and investigators. Researchers have claimed that protections such as "informed consent" would interfere with scientific progress. It was not until 1966 that NIH began mandating informed consent from all participants and standard review of studies by institutional review boards (Breault, 2006). However, the research community has not provided the public with comprehensive and accessible descriptions about the policies and safeguards in place to protect research subjects, which can lead families to fear exploitation. Some BIPOC families believe that informed consent protocols protect investigators from legal repercussions rather than protecting participants, an understanding informed by decades of such occurrences (Shaia et al., 2020). While institutions require participants to sign detailed informed consent forms, investigators and staff may regard the informed consent process as a formality rather than a fundamental component in establishing trust between a participant and the research team (Washington, 2006).

Distrust may also come from lack of study transparency. BIPOC families have cited the failure of investigators to spend sufficient time explaining the risks and potential benefits as a substantial barrier to participation (Ford et al., 2013). While often considered low-risk, ethical concerns are present in autism research. Autism researchers have been inculpated for insufficiently assessing the adverse events and negative consequences of early monitoring and assessment studies (Bottema-Beutel, Kapp, et al., 2021; Rodgers et al., 2020; Zorzela et al., 2016). Invasive procedures like electric shocks are rarely used in modern autism research, but medication trials certainly have risks to participation (Bottema-Beutel, Kapp, et al., 2021). Other historical procedures such as “facilitated communication” where a clinician manipulates a patient’s bodies are now considered harmful (Mostert, 2010). The most common type of behavioral therapy for autism (Adaptive Behavioral Analysis, or ABA) has been widely criticized due to its use of repeated provocation and reinforcers like unhealthy food (M. Dawson & Fletcher-Watson, 2022).

Early intervention studies carry the potential for negative consequences to participants, such as emotional distress and poor self-esteem (M. Dawson & Fletcher-Watson, 2022). There are numerous positive effects of communicating early concerns about autism through a research study (i.e., earlier diagnosis, access to intervention, validation of parent concerns, informed family planning), but some have argued that research reports can unnecessarily elevate family concern for autism, resulting in hyperattention to child development and autism symptomatology (Crane & Winsler, 2008; MacDuffie et al., 2021). False positives for autism are not uncommon, particularly for complex clinical presentations (Greene et al., 2021). While a clinical evaluation may include a multimodal approach, research evaluations may be limited in scope. As a result, a family may needlessly commit substantial time and financial resources to obtain treatment for a child who does not have autism. These alerts can also redirect scarce resources in the community away from children with greater need (MacDuffie et al., 2021). This ethical question is particularly salient in low-resource settings where interventions might not be available, leaving newly concerned families without treatment options (Daley et al., 2013). Additionally, there are challenges to conveying results from genetics studies, particularly for individuals with lower levels of health literacy (de Vries et al., 2011). While these adverse events are not life-threatening, they may have long-term consequences that are insufficiently evaluated and reported in research literature (Bottema-Beutel, Kapp, et al., 2021). Families may also fear the consequences of revealing sensitive information like their immigration status (Ford et al., 2013). Lack of access to other treatment options can also introduce concerns about coercion (Daley et al., 2013).

BIPOC communities may also have experienced displacement by institutions themselves, as occurs when universities require space for expanded facilities (Dancy et al., 2004). Individuals and communities who have experienced marginalization may contrast the substandard infrastructure in their neighborhoods with the expensive facilities at a research institution and determine that the researchers or the institution at large has a limited interest in truly improving the lives of their research subjects. Further, systemic barriers to equal education may mean that some BIPOC children are unable to gain admission to the universities adjacent to their own community. These experiences may perpetuate anger, distrust, and disinterest in research participation amongst BIPOC communities (Dancy et al., 2004).

The process of addressing historically based distrust in research institutions is not a small feat. The goal of these efforts should not be to convince BIPOC families to trust research; instead, policymakers, institutional leaders, and individual investigators should aim to make research trustworthy and relevant. As author Harriet Washington describes, there should be a clear and accessible procedure for elevating concerns about misconduct, followed by independent investigation and actions to establish accountability (Washington, 2006). Institutions must also publicly acknowledge the role that they have played in historical misconduct and their plan to change policies to address existing concerns within the BIPOC community (Washington, 2006). Additionally, researchers should consider strategies to better evaluate the potential risks of participation in autism research by transparently conducting more longitudinal follow-up of families and collecting specific data on family mental health and financial wellbeing (Bottema-Beutel, Crowley, et al., 2021).

Efforts to address distrust must involve training for both researchers and participants. Researchers (including staff, trainees, and faculty) should be knowledgeable about the history of research misconduct in America and aware of how this may continue to impact BIPOC communities. One intervention (Strengthening Translational Research in Diverse Enrollment, or STRIDE) implemented a three-pronged approach to address barriers to diverse research enrollment (Danila et al., 2021). Recognizing that barriers are rooted in historical injustices, this intervention trained research staff using an online training module to address cultural sensitivity and communication. The goal was to prepare staff to respond to questions and comments during recruitment and empower them to identify problems and potential biases if they arise. Simultaneously, research participants were automatically enrolled in a training module during the online consent process. This training included vignettes from previous research participants describing their experience. While the effectiveness of this intervention has not yet been reported, other "navigation" interventions have been developed to convey culturally sensitive information about the structure of research studies, confidentiality, the rights of participants, and protective safeguards to potential BIPOC research participants (Ford et al., 2013). These models have demonstrated greater BIPOC recruitment compared to clinical trials without navigation interventions (Fouad et al., 2016). Reviews have also concluded that the initial resource investment needed to implement a navigation program can have financial benefits for institutions (Bernardo et al., 2019). A similar intervention could be developed for BIPOC autistic individuals and their families. Widely accessible or required training materials translated into multiple languages would improve the quality of informed consent and increase the confidence of participants in making decisions about enrollment.

Some experts suggest that informed consent should be conducted by independent personnel who are not affiliated with a research study. This could help to address concerns about coercion during the consent process, particularly for high-risk or sensitive studies. Written or visual summaries of the risks and benefits could also increase comprehension during the consent process (Heerman et al., 2016). Another option could involve increasing cultural representation and language diversity amongst recruitment staff, thereby decreasing some barriers for participants to ask questions about research involvement (Daley et al., 2013). Researchers should facilitate diverse family structures by allowing adequate time for caregivers to discuss potential participation with other family members. Ultimately, buy-in across the family can help to establish a positive relationship between researchers and participants and acknowledges the multifaceted decision-making structure often seen in BIPOC families.

Distribution of benefits

The motivation to participate in a study is an important consideration for any investigator because it directly informs recruitment strategies and materials. Whether or not the research provides direct benefits to the participants (e.g., behavioral intervention, medication), many studies endorse the future benefits that may follow increased knowledge. Many investigators understand altruism (i.e. selfless concern for the well-being of others) to be the primary motivator for research participation, and indeed, families often enroll in studies to improve future treatment options for themselves and their communities (Jansen, 2009; Tromp et al., 2016). Altruism is made easier in communities where evidence about the positive impact of past research is abundant. In many BIPOC communities, the benefits of research discoveries are often inaccessible or decades delayed due to structural barriers like availability, proximity, and insurance coverage (Shaia et al., 2020). Furthermore, researchers frequently fall short of sufficiently informing community members about the knowledge gained from a study or its impact a study on a community, leaving many BIPOC participants to feel abandoned, ignored, and exploited by researchers.

It is imperative to disrupt the existing belief in communities that investigators collect data without positively impacting the community (Zamora et al., 2016). This requires investigators to reflect on whether research appropriately benefits communities and addresses real-world needs. Researchers should consider how their interventions can be made sustainable for a community by providing training and leveraging existing strengths and resources, rather than introducing interventions that cannot be integrated after funding ends. Before initiating a study, researchers should consider whether the costs a community would carry to sustain a program are worth its relative advantage and whether a community has the necessary staff and resources to fully implement a program beyond the research cycle (Dingfelder & Mandell, 2011). Researchers must focus on feasibility with specific populations in order to measure and modify implementation in community settings. This attention to translational research can reduce the extensive research-to-practice gap and increase the likelihood of real-world benefit for a community (Dingfelder & Mandell, 2011). Research for the sake of research is not appropriate or ethical and may perpetuate mistrust between communities and researchers.

Investigators should also consider the significance that an assessment report can hold for a family of an autistic child. Cognitive and psychological evaluations can be very expensive for a family regardless of insurance coverage. Waitlists for these evaluations may take months or even years and often require a referral from a physician (Stahmer et al., 2019). Often, services are delayed until a formal evaluation is conducted. While it is important to ensure that research-generated reports provide information to parents responsibly and ethically, parent concern also has substantial predictive validity in autism diagnosis (Sacrey et al., 2018). A parent who participates in an autism research study is likely to have legitimate concerns about their child's development. Whenever possible, investigators should provide assessment reports to participating families, which may help families advocate for further evaluation and additional services to their school or healthcare system. When reports are not available, community resource guides should be offered to participants.

Without an accurate understanding about the motivation of BIPOC families to enroll in research, investigators may rely too heavily on a family's passive altruism rather than promoting factors that are more likely to engage BIPOC minoritized families, such as knowledge about autism as it applies to their child or information about community interventions and services (Ford et al., 2013). It is critical that investigators recognize participants motivation for enrollment and highlight the direct impact that a study can have on a family and their community in recruitment materials. Materials should explicitly state the benefits and risks that a family can expect from participating in research and not assume that this information is commonly known in the community. Studies focused on minoritized populations should result in benefits for these populations. It is important to consider who makes decisions about benefit and ensure that BIPOC populations are represented throughout decision-making processes. Researchers must also think about how to disseminate results of studies in a way that benefits communities.

2.2.2 Community Level

Logistical challenges

There are many logistical barriers that prevent autistic individuals from enrolling in research studies. Participation in research takes ample resources, including time off of work, childcare for other children, meals during the appointment, and transportation to testing sites (Comis et al., 2003). These barriers are described in the community level of the SEM because they relate to the resources available in a person's physical environment or neighborhood. While logistical challenges exist for all research participants, BIPOC communities may be disproportionately impacted by geographical location and transportation barriers, particularly when institutions are located far from BIPOC neighborhoods due to discriminatory housing practices (Mandell & Novak, 2005). Marginalized families are more likely to work for hourly wages with inflexible scheduling, so taking time off from employment to attend assessment visits during restricted hours of operation can negatively impact their income (Derenoncourt & Montialoux, 2021). Scheduling can be especially problematic when a parent must organize childcare for other children who are not participating in the study. Some families rely on schools to provide healthy meals to their children, leading to additional expenses when children miss school to attend research visits. While some families are easily be able to navigate the various hurdles to participation, other families cannot afford the necessary resources. Research studies are intended to help families either directly or indirectly, but there are many burdens associated with attendance, particularly for studies that involve multiple lengthy appointments. The decision to participate therefore requires families to balance the benefits of participation (which may be poorly defined or inadequately motivating) with their own needs and those of their child and family, which often results in a decision to not participate in research (Burkett et al., 2015).

Investigators must make every effort to reduce other logistical barriers to participation. While monetary incentives are not the primary motivation for enrollment in research studies, adequate compensation can offset the cost of participation due to travel expenses, lost wages, and child care (Shaia et al., 2020). It is important to work with community partners to identify adequate compensation, which is not equal in all communities. Appropriate compensation may differ across cultures; for example, some communities may prefer direct payments or gift cards, while others may prefer informational webinars or newsletter about study findings (A. Graham et al., 2015). Compensation should be guided by community engagement (Tiwari et al., 2014). Researchers should also consider ways to increase the flexibility of scheduling by permitting evening and weekend visits or reducing the length and number of visits. Offering childcare can also make a substantial impact on a family's ability to enroll in research (Zamora et al., 2016).

Some logistical challenges of research can be overcome through study design. Interventions that are conducted in the community have shown better success in recruiting BIPOC participants (Carr et al., 2016). Others have demonstrated that while community intervention can promote high levels of enrollment, high levels of drop-out remain a problem (Carr et al., 2016). Therefore, it is important that community-based studies still utilize culturally-based interventions informed by community engagement.

Telehealth also shows promise to bridge geographical barriers and reduce travel demand (Hyde et al., 2020). Some BIPOC populations are more reachable online than in-person (Heron et al., 2019). Shifting assessments online can be helpful for families to reduce logistical barriers and can also provide more accurate information to assessors about a child's behavior in a real-world setting. Collecting questionnaire data online can also allow parents to self-pace completion of forms. Some caregivers may prefer to consult with other family members about their responses or may require more time to complete forms due to their language and literacy level.

However, some evidence suggests that BIPOC communities do not utilize telehealth at the same rates as White populations (Harju & Neufeld, 2022). Uptake is higher for higher-resourced communities and areas with fewer BIPOC patients, which is related to reimbursement rates and broadband coverage (Harju & Neufeld, 2022). Patient preference may also very by race, though trends are not consistent across literature (Harju & Neufeld, 2022; Predmore et al., 2021). Further research on telehealth preferences across populations would inform whether this is an appropriate avenue for autism treatment.

There are some ethical challenges associated with online research. For example, it can be impossible for researchers to ensure privacy during study procedures, which is especially important during discussion of sensitive topics. It can also be impossible to guarantee the accuracy of results when clinicians and trained examiners are not able to conduct assessments themselves but rely instead on parent reports and remote administration. Anonymous data collected through online surveys can facilitate diverse and representative participation, but this method does risk poorer data quality. Additionally, researchers may be unable to follow up with participants. While many families across BIPOC groups own smartphones, not every family will have access to the necessary devices or stable internet connection (Bushar et al., 2019). Studies must have alternative solutions (i.e. internet hot spots, loaned tablets) to address potential telehealth challenges. Finally, online studies are at great risk of low participant engagement and loss to follow-up (Roberts, 2015). Remote assessment has expanded substantially in the last two years due to the COVID-19 pandemic, but researchers must focus on the implementation of these projects in order to understand data quality and validity. Once these methods are understood and enhanced, they could bridge logistical barriers for BIPOC families.

Not all participants will require the same accommodations; some may prefer to complete all components of a study in one visit, while others may prefer to extend their contribution over multiple shorter visits. Some families may prefer to complete research assessments in-person due to their internet connectivity or home distractions (i.e., other children). Ultimately, flexibility is key to reducing logistical barriers. This flexibility should be highlighted in recruitment materials so that families are aware of the types of accommodations they can request. Study coordinators should also include questions about accommodations during the screening process, rather than relying on families to request logistical support. It is also critical that studies publish their recruitment strategies and the corresponding enrollment demographics. This will aid researchers in selecting appropriate recruitment models and identifying promising strategies for a particular geographic region, population, or health concern.

Stigma, denial, and fear

Autism is considered by scholars to be a high-status diagnosis due to the associated service support and positive characteristics popularized in media such as creativity and intelligence (Giwa Onaiwu, 2020). However, these "privileges" are often unequally distributed in marginalized communities due to race-based stereotypes. BIPOC autistic people may be mislabeled as aggressive, obstinate, or lazy, rather than offered the understanding and accommodation increasingly afforded to White autistic people. Education and employment for BIPOC autistic individuals are also limited by racialized stigma (Blanchett, 2010).

Disability threatens the safety of BIPOC children and adults, particularly when they experience difficulties communicating, interacting with strangers, or maintaining hazard precautions in public settings. Autism is sometimes associated with violent behaviors or social exclusion, and this stigma is often compounded by racism. BIPOC autistic people frequently encounter dangerous situations with significant risk for abuse. Consider, for example, that 50% of the Americans killed by police have a disability and more than 50% of Black people with a disability have been arrested by the age of 28 (McCauley, 2017). Simultaneously, autistic individuals are more likely to encounter the criminal justice system compared to non-autistic people (Woodbury-Smith & Dein, 2014).

Many BIPOC caregivers strive to protect their autistic child from violence and discrimination by encouraging "normal" behaviors that can help them camouflage in society. This might dissuade caregivers from enrolling their children in intervention services, special education programs, or research in an attempt to protect them from stigma both outside and within of their community (Burkett et al., 2015; Shaia et al., 2020).

Autism is plagued by misconceptions, and some communities perceive disability as religious punishment that shames families (Kandeh et al., 2020). Some religious leaders emphasize prayer as an exclusive strategy to "overcome" autism, which can reduce social acceptance of autistic people as well as the acceptability of evidence-based interventions used to treat autism symptoms (Kandeh et al., 2020). Lack of community awareness and education about autism can lead caregivers to hide their autistic loved ones from view. Further, BIPOC voices are often absent from public discourse and media portraits of disability (N. L. Jones et al., 2019). Many caregivers are therefore surprised to learn that autism is equally distributed across race and ethnicity because they might not see autistic people in their own community (Burkett et al., 2015). Because of the lack of awareness and discussion of disability in BIPOC communities, there are fewer community networks to discuss treatment and research options (Burkett et al., 2015). Without sufficient guidance and support, caregivers must weigh the cost of seeking treatment that could address challenging behaviors against community stigma. However, these experiences are not universal across BIPOC communities; some families have anecdotally described the relative strength of Black families in including their autistic children during family and community events. A strengths-based approach to social inclusion in some families could reveal avenues to address stigma and fear in other communities.

Barriers related to fear and stigma are particularly difficult to overcome due to their deep integration into communities. Further research is needed to identify interventions for stigma about autism. However, researchers should always reflect on how their findings may impact marginalized communities, particularly if they are conducting research focused on BIPOC populations. Some publications may unintentionally promote stereotypes. For example, a genetics paper that discusses racial differences for autism and intellectual disability could be read to imply that certain races have different biological capacities than others. Authors may be unaware of inflammatory undertones of this suggestion or may presume that readers understand their good intention. To avoid this, it is important that BIPOC senior investigators, collaborators, or community members are involved in the dissemination of results. While review does not guarantee that publications are free from potential harm, it is important that community members are consulted about their portrayal in academic literature. Demonstrating that positive outcomes are possible with treatment and increasing positive experiences with intervention can help to assuage complex psychological barriers to intervention, including shame and denial about autism.

Additionally, it is critical that researchers focus on problems that are a high priority for BIPOC communities (Frazier et al., 2018). Some BIPOC caregivers of autistic children have expressed deep frustration for the lack of prioritization of life-threatening problems like police violence against BIPOC autistic individuals, stereotypes and stigma in BIPOC communities, and lack of awareness and network opportunities for BIPOC caregivers (D. R. Jones et al., 2020; Shaia et al., 2020). BIPOC caregivers have articulated a desire to engage with culturally responsive researchers and amplify community voices in autism research in order to impart understanding about the needs and expectations of diverse communities (D. R. Jones et al., 2020). More BIPOC people in leading investigator roles will further enhance the ability of the field to meaningfully integrate the needs of communities into research. Current researchers should also make every effort to study the problems voiced by BIPOC populations, which may require interdisciplinary research teams and new grants.

2.2.3 Organizational Level

Representation in staffing

Potential BIPOC research participants have discussed a desire to engage with representative and culturally responsive research teams who have a specific understanding of their community’s needs and experiences (Shaia et al., 2020). There are also power dynamics involved in all research interactions where researchers and participants have unequal levels of authority and influence (Hilton et al., 2010). The perceived power imbalance is greater when investigators belong to a racial or ethnic group with more social capital than a participant’s community. Power imbalance is related to a participant’s perception of exploitation (grounded in historical and current discrimination) or their belief that a researcher can influence their opportunities for employment, education, housing, or healthcare (Yeager & Bauer-Wu, 2013). Participants may withhold important questions about a research study, resulting in tenuous informed consent or even coercion to participate (Rogers-Adkinson et al., 2003). Power imbalance can bias data collection, particularly if respondents modify their responses to align with what they perceive as socially desirable or expected by an investigator. This imbalance can also perpetuate distrust between researchers and participants (Dancy et al., 2004). These power dynamics also exist between BIPOC communities and institutions on a larger scale, particularly if a marginalized community believes that an institution has power over healthcare delivery, community funding, or policy (Dancy et al., 2004). Hiring bicultural staff can enhance cultural responsivity during recruitment, leading to more successful engagement of underrepresented populations (McClure et al., 2013).

Bilingual staff are also critical to increase both recruitment and retention of BIPOC participants (Taani et al., 2020). While only 5.9% of White children and 7.4% of Black children speak a language other than English at home, the rates are substantially higher for Asian and Hispanic populations (56.3% and 60.4%, respectively) (US Census Bureau, 2021). Caregivers who speak a language other than English may not respond to English-only recruitment materials or may experience difficulties coordinating a research visit with English-only staff. Hiring bilingual research staff and providing study information in other languages can greatly facilitate diverse recruitment, particularly for Hispanic, Asian, and Pacific Islanders (Kelly et al., 2005). Staff can also activate their own social networks to identify interested participants, which may be one of the most cost-effective mechanisms for targeted recruitment (Milo Rasouly et al., 2019).

There remain too few BIPOC autism researchers at all levels of training. Despite efforts by the International Society for Autism Research (INSAR) to diversify its professional membership, the group has not published any reports of measurable achievement in this area, and currently, there are no BIPOC autism research caucuses or committees, though there is a committee for cultural diversity (D. R. Jones & Mandell, 2020). While cultural diversity committees do important and necessary work, they do not necessarily support BIPOC researchers. Funding exists to address staffing diversity concerns in autism research, but these grants are limited to research focused on healthcare disparities. This problematically pushes BIPOC researchers towards diversity-related work, rather than encouraging diversity across all areas of research (D. R. Jones & Mandell, 2020).

Given the underrepresentation of BIPOC investigators in autism research, it is critical that organizations commit to recruiting and hiring more diverse faculty and staff. This requires mentorship of BIPOC students throughout their education to foster an interest in academic research broadly and autism research specifically. There are numerous strategies to elevate diverse autism researchers, including: providing funded research opportunities for BIPOC undergraduates, developing programs to support mentorship and networking for BIPOC students and early career researchers, separating efforts to diversify research institutions from efforts to conduct culturally inclusive research, and fostering inclusive and comfortable environments by seeking and listening to concerns from BIPOC employees (D. R. Jones & Mandell, 2020). Institutions and professional organizations should also be transparent about their own demographic distribution.

White investigators can certainly be responsive and sensitive to minoritized communities and cultures. However, efforts towards cultural responsivity require significant motivation and careful collaboration with stakeholders to understand the complexities of community needs and expectations. This investment can take substantial time and training to generate recruitment results. Investigators who do not properly consider the culture of their target population may not adequately address community concerns. They also risk perpetuating stereotypes and distrust if they do not engage in self-reflection and transparency about their objectives when specifically targeting minoritized groups (Maye et al., 2021). Recognizing the strengths and expertise of diverse populations better enables researchers to engage community partners in shared decision-making. Cultural humility is a key component of establishing trust with communities, reducing barriers to research, and responsively improving the health and wellbeing of diverse communities (Maye et al., 2021).

Restrictive and single-subject research design

Study design can greatly impact the success of an organization in its effort to conduct representative research. For example, some studies might include strict inclusion and exclusion criteria that unintentionally but systematically disqualify BIPOC families (Comis et al., 2003). A study may exclude participants who speak languages other than English, omitting many culturally and linguistically diverse families. Some clinical trials in other medical disciplines require that participants have health insurance in order to offset the cost of expensive procedures, and coverage is occasionally denied by insurers (Klamerus et al., 2010). BIPOC families of autistic families, who have higher rates of public insurance coverage, are more frequently excluded (Anderson et al., 2022; Brown et al., 2000). Some studies exclude participants with co-occurring diagnoses such as intellectual disability, which is diagnosed at a higher rate in Black populations (Constantino et al., 2020; Russell et al., 2019). Additionally, many autism genetic studies require that either one or both biological parents or a full sibling be available for data collection, which excludes BIPOC families at a higher frequency if a parent is unwilling to participate or unavailable due to geographical distance, incarceration, or death (Hilton et al., 2010). In a large study about genetics in Black children with autism, 67% of reachable BIPOC families were excluded from participating due to their family structure (Hilton et al., 2010).

While this study did not provide a comparison for non-Black exclusion, 54% of Black children in the US reside with a single parent compared to 20% of White families, suggesting that this criterion would more frequently impact Black families (Data Center, 2021). While some genetic studies require triangulation only achievable with two biological parents, newer case-control methods are able to overcome this constraint and should be considered when designing genetics research (Hilton et al., 2010). Investigators across autism research disciplines must consider how their research designs might systematically exclude some participants and make every effort to reduce the barriers to enrollment. Certainly, some investigators will feel that the loss of controlled study design outweighs the benefit of diverse participants. However, the inclusion of more diverse participants is likely to reveal new findings based on the heterogeneity of research cohorts.

Another challenge to inclusive research is the prevalence of single-subject designs, which account for 90% of published autism intervention studies (West et al., 2016). Single-subject research design, which usually includes more than one subject, involves repeated measurement of a research subject before and after intervention along with careful observation manipulation of specific variables. This allows researchers to establish causal relationships, but this strategy also limits the generalizability of findings because the research environment is carefully controlled (Horner et al., 2005). Most single-subject research publications fail to thoroughly describe the treatment environment or participant characteristics; race and ethnicity are omitted from 83.2% of single-subject publications on autism (West et al., 2016). As a result, these studies have poor replicability.

In contrast, group design research involves randomly assigning a representative sample of the population to a treatment group and drawing group-level inference. Group design research is fundamentally oriented to emphasize participant characteristics in order to inform findings about a larger population (Shadish et al., 2002). External validity (i.e. generalizability in other populations and settings) is the goal of group research design. Race and ethnicity are reported at a higher frequency in these studies compared to single subject designs, though demographic data is still missing from 71.8% of group research publications about autism (West et al., 2016). The challenge which makes group design less common in autism research despite its potential for higher external validity is that substantial sample size is required in order to capture the full heterogeneity of autistic populations. Without sufficient size and representation, it is challenging to understand variable response to treatment (West et al., 2016). However, improving participant diversity through the methods outlined in this paper could make group study designs more feasible for investigators. Regardless of research design, it is critical that investigators examine the influence of race and ethnicity during analysis and report demographics in publications so that findings can be generalized and repeated.

Implementation science is another field that could facilitate health disparity research (Chinman et al., 2017). The goal of implementation science to understand and improve the quality and effectiveness of evidence-based intervention in real-world practice (Eccles & Mittman, 2006). This approach could widen the scope of research by integrating system-level factors into study design (Chinman et al., 2017). However, this methodology only addresses issues related to inadequate or inequitable healthcare delivery; it will not directly impact other issues that contribute to health disparities (Chinman et al., 2017).

Many research studies require a participating family to attend multiple assessment visits, which is resource intensive for both families and investigators. The carefully collected data is then used to answer one particular set of research question. Therefore, the burden of increased representation in research would ultimately fall on BIPOC families to participate in more studies. Maximizing the use of participant data would address this problem, although data sharing faces an abundance of challenges. While NIH requires data be made available for use by other investigators, data quality is unpredictable. Researchers who want to utilize information across studies often encounter an absence of descriptors about data collection, challenging collaboration and minimizing the impact of participants' contributions. Some organizations have established consortiums to share data, but investigators still encounter a mismatch of assessment measures. While some repositories exist, more attention must be paid to data quality and standardization of measures. This might require investing significant resources to establish and maintaining repositories. Researchers should also consider ways to utilize "big data" to address knowledge gaps. Breen et al. (2019) describes several approaches to studying health disparities in BIPOC populations, including linking structured data, harmonizing data elements, developing large and comprehensive cohorts, and mining novel data (Breen et al., 2019). Investigators also need to consider storage, ownership, and ethics (Breen et al., 2019). In particular, this solution also requires careful consideration of the ethical use of data without a participants' direct consent.

Investigators should also consider the assessment tools that are used in their study. Researchers rely on stable baseline measurements and assessments that are sensitive to change. If the baseline measurements are not appropriate for a marginalized population, the results of a study will be inaccurate. Some assessments may be systematically biased in scoring for underrepresented populations. Most research materials are only administered in English, but many measures have been validated in other languages. Investigators should consider selecting measures that can be read by linguistically diverse participants and should provide descriptions for culturally specific terms.

The need for more evidence about the impact of race and ethnicity on experiences of autism should require methodological creativity from researchers, rather than increased demand on research participants. However, none of the suggested approaches to inclusive research design eliminate the potential for bias. Therefore, researchers should employ reflexivity and document their successes and failures.

2.2.4 Interpersonal Level

Referral networks

Referral gaps inhibit research participation regardless of a family's motivation to enroll. Many BIPOC families are simply not aware of research studies (Andrasik et al., 2021). Identifying gaps in the recruitment process is a key component of improving representation in autism research. Research studies often utilize physician referrals from clinics within their hospital system due to advantages like patient proximity, medical record availability, and easy coordination between clinical and research staff (Hudson & Momperousse, 2005). This recruitment method can be highly effective for increasing participant numbers, but it also results in participant pools that reflect the patient population in a health system, either an advantage or disadvantage for research diversity depending on the hospital's demographics. BIPOC patients are more likely than White patients to receive care in safety-net urban hospitals and clinics for the uninsured or federally insured (Hasnain-Wynia, 2007). When research studies are conducted at universities and other highly resourced hospital systems, physicians in low-resourced settings may be unaware of the research studies available to their patients.

Providers in low-resourced settings face additional barriers that can interfere with recruitment. Packed clinic schedules and prioritization of care over research can disincentives providers from spending time discussing research opportunities (Joseph & Dohan, 2009). Without comprehensive understanding about a research project, providers themselves may be distrustful of the study or aware of their patient's distrust in research (Salihu et al., 2015). Providers may be dissuaded by the perceived logistical burden associated with referring a patient to another hospital system (i.e. paperwork, follow-up communication) or may be reluctant to sacrifice personal control over the patient's treatment (Tanner et al., 2015).

Provider bias can also interfere with referrals; physicians may make inaccurate assumptions about a family's qualification for or interest in a study (Neuhaus et al., 2018). BIPOC families may not see their provider as a trusted source of information due to lack of receptivity to their concerns during visits, a dynamic that limits the capacity for collaboration (Burkett et al., 2015). Although useful for eliminating the reliance on physician referrals, queries of diagnostic codes in medical records may be biased against BIPOC children, who are underdiagnosed with autism due to numerous barriers previously described. Without a formal diagnosis for their child, these families may simultaneously face obstacles in accessing community-based services, making their inclusion in research studies particularly consequential.

Acknowledging these referral barriers, researchers must identify alternative recruitment pipelines outside of health systems and leverage the strengths of community networks (Joseph & Dohan, 2009). Some BIPOC communities seek advice from trusted friends, family, and elders about their child's development before discussing concerns with medical professionals (Burkett et al., 2015). Therefore, parent-centered recruitment strategies have proven effective for many BIPOC communities, though this success is also related to an investigator's commitment to building relationships over time (Ratto et al., 2017). Efforts for collaboration should involve community partners trusted within a BIPOC community (e.g., clergy, community health workers, teachers, childcare providers) as well as in-person settings not traditionally used in recruitment (e.g., resource fairs, recreation centers, churches, salons, and grocery stores) (L. A. Graham et al., 2017). It is necessary to cast a wide geographic net for recruitment if the neighborhood around a research institution is not demographically diverse. Investigators should also consider the readiness of an organization to provide recruitment aid, as well as how they can reciprocate the effort required to recruit for a study (i.e., payment, information) (Zamora et al., 2016). Community leaders may have similarly distrustful perspectives of research, so academic partnerships must be established with careful attention to reciprocity (Hughes et al., 2017). The materials and process of participation should be adequately explained to community partners so that they are also knowledgeable about the study. This can facilitate better buy-in from the community.

The most successful strategies for recruiting Black mothers for one autism research study were referrals from community healthcare providers, personal recommendations, and Facebook (Shaia et al., 2020). In general, the size of a parent's peer network predicts the number of autism services a child receives and can also impact referrals to research studies (Gulsrud et al., 2021). Patient advocacy groups are critical recruitment pipelines for many investigators (Merkel et al., 2016). However, patient advocacy groups engage mostly White patients and families (Stahmer et al., 2019). In collaboration with existing patient advocacy groups, researchers should explore why BIPOC families are less interested in participating in these groups.

Recruitment materials and methods

Responding to recruitment materials requires that BIPOC population identify with the terms used on flyers. Autism is a socially constructed term coined in the United States in 1970 to describe specific social communication challenges and restricted/repetitive behaviors (Treffert, 1970). However, some cultures use other translated terms interchangeably or in lieu of "autism". For example, "reactive attachment disorder" is used synonymously with autism in Korea, although this comparison does not align with American diagnostic criteria (Kim, 2012). Other cultures use autism to describe any type of developmental delay and is not specific to social communication (Kim, 2012). Autism does not have a direct translation in some languages, and families might use alternative descriptions for their child such as "social communication challenges." Studies that recruit across racial and ethnic groups may need to use either focused recruitment materials for individual groups or list multiple terms to describe the inclusion criteria.

The mode of recruitment is equally important to participant diversity. Individuals have variable preferences about recruitment, but there are also group trends for successful strategies by race, ethnicity, language, and geography (Zamora et al., 2016). A plethora of resources exist to guide investigators on developing better recruitment materials. These resources address how materials should be formatted and distributed in order to reach more diverse potential participants. For example, the Simons Foundation Powering Autism Research for Knowledge study (SPARK) successfully recruited a representative sample of 50,000 participants for a genetics study (Ahmed et al., 2020; Feliciano et al., 2018). Their recruitment resources are available online, with details on both in-person hand-offs in the clinic setting and online recruitment. There are also some well-documented successful strategies for recruiting targeted racial and ethnic groups that can be leveraged as appropriate for a research study. Recruitment plans that rely solely rely on one method are unlikely to gain diverse enrollment, so investigators should deploy multifaceted methods.

The goals of a research study may require specific interpretation for a community. Therefore, it is critical that communities are consulted on appropriate recruitment materials and methods. There is also a literature gap for successful recruitment strategies of BIPOC populations in autism and pediatric research, which may differ from studies of adults. As autism studies achieve representative enrollment, it is important that they publish their successes and challenges for replication in addition to scientific findings.

2.2.5 Individual Level

Cultural beliefs about autism and disability

While some BIPOC families may be interested in research participation, they may find a specific study incompatible with their cultural preferences, treatment practices, or beliefs about autism. Caregivers hold a wide array of beliefs about the origin of their child's autism, which directly impacts decision-making about treatment and influences enrollment in research studies (Mandell & Novak, 2005). White caregivers are more likely than BIPOC caregivers to describe their child's autism using the medical and biological terminology often reflected in research studies, inspiring immediate familiarity and understanding between some researchers and participants (Bussing et al., 1998). In contrast, BIPOC families are less likely to attribute their child's developmental challenges to genetic causes, an idea that dominates research literature and knowledge (McLeod & DiSabatino, 2019). When a genetic origin for autism is not understood or endorsed by a family, early intervention and genetic studies, which allude to the inherited causes of autism symptoms can be stigmatizing. Caregivers enrolled in these studies may also have increased rates of autism traits due to autism's heritability, which should be considered sensitively in the design of recruitment materials and assessment selection (West et al., 2016).

Compared to White caregivers, BIPOC caregivers are more likely to affirm alternative frameworks as the cause of autism, including that metal toxicity, physical or spiritual environment, immunizations, diet, or psychosocial causes such as family issues, stress, or trauma (Bussing et al., 1998). Families may also seek religious, spiritual, or other “folk medicine” treatments to address their concerns, though utilization of alternative treatment in autism is infrequently researched and poorly understood (Levy et al., 2003). Investigators should consider asking families specifically about spiritual or folk medicines as part of standardized intervention history forms in order to better understand compatibility with evidence-based practice.

Some caregivers may disagree with the idea that their child’s behavior is related to an underlying disorder, instead attributing symptoms to personality that they consider within the bounds of typical child behavior (Castillo et al., 2020; Mandell et al., 2002; Yu et al., 2002). Investigators should consider that the optimal trajectory for child development differs across cultures, as do the indicators of child accomplishment and atypicality (Fletcher-Watson et al., 2019). BIPOC populations might find existing interventions, which aim to correct naturally occurring behaviors, to be offensive. Better characterization of the variation in perspectives of “typical” development across populations and cultures can inform interventions that are effective for BIPOC families.

Beliefs about the need for intervention also vary between cultural groups. White caregivers are more likely than BIPOC caregivers to switch between intervention methods or seek additional care if a treatment fails to alleviate symptoms as expected, including alternative options that may be available exclusively at research institutions (Levy et al., 2003). One review of pediatric drug trials found that caregivers were frequently motivated to participate in research when they felt they had no other options or desired closer contact with expert medical teams

(Tromp et al., 2016). Alternatively, some BIPOC cultures recognize the importance of "fatalism," the belief or acceptance that fate cannot be changed (Flores, 2010). Some families believe that their child's delays are temporary and will reconcile without intervention. One qualitative study of Hispanic mothers of autistic children found that parents saw their role as caregiver and nurturer rather than therapist, which may reduce attention paid to their child's specific treatments (Luelmo et al., 2020). While these beliefs do not mean that families are unmotivated to seek care for their child, it may impact their treatment selection and adherence or disincentivize enrollment in studies (Tek & Landa, 2012). Rather than viewing disengagement from intervention as evidence that a family is not interested in addressing their child's autism symptoms, investigators should seek to understand cultural strengths that ease perceived burden for families.

If a family perceives fewer negative consequences resulting from a child's autism symptoms, they may be less motivated to participate in intervention services or research studies. A key study by Bishop et al. (2007) demonstrated that Black mothers rated the level of impact they experienced from their child's symptoms as lower compared to White mothers of autistic children despite similar levels of symptoms severity (Bishop et al., 2007). The authors suggest that this difference in perception could be due to differing cultural values that shape family dynamics and relationships, including family member interdependence, which is prioritized in many BIPOC communities (Brooks et al., 2021). A caregiver might view their child's symptoms as an accepted family obligation, rather than a burden. Strong kinship networks may also protect against the negative impact of stress, which is a substantial strength for minoritized families across a number of health problems (Brooks et al., 2021; Chiang et al., 2019). In the Bishop study, lower parent perception of symptom impact was also associated with lower income and education for Black mothers, but not White mothers (Bishop et al., 2007). The authors suggest that higher education among Black participants imparts greater understanding about the difficulties that autistic people will likely face across their lifetime and increases desire for a child's independence, resulting in higher level of concern and greater motivation to seek intervention and services.

While resiliency and connectedness of BIPOC families may have protected caregivers from negative perceptions of impact early in their child's life, longitudinal follow up of these families revealed that Black mothers identified more negative impacts from their child's autism over time (Carr & Lord, 2013). The families who initially perceived less personal impact from their child's autism had also enrolled in fewer hours of intervention early in their child's life. This certainly relates to the number and quality of services available to families based on their race, income, and education, but increased parental concern later in life poses a significant problem because services and research studies are extremely limited for autistic adults (Hendren, 2021). By the time concern elevates, treatment options may be more difficult to access. Additional research about the strengths of BIPOC families over the course of an autistic person's lifespan may help researchers identify more applicable and appealing mechanisms for early intervention.

Many BIPOC households are multigenerational, where multiple adults are involved in a child's education and socialization. Many existing autism interventions rely on a single caregiver or therapist to implement the skills in therapy sessions and at home, which leverages the structure of the Western-idealized nuclear family. Identifying a primary caregiver to participate in a research study may not be congruous for multigenerational households. However, dismissing these families as poor fits for parent-mediated intervention neglects an opportunity to leverage the connectedness of complex family structures (Tomczuk et al., 2022). While there may be opportunities to enhance treatment options for BIPOC families, studies on the role of family units in delivering autism interventions are limited by lack of racial and ethnic representation (Factor et al., 2019).

There is further variation in the preferences for treatment structure, content, and delivery between cultural groups. Many empirically validated autism interventions focus on "joint activity" routines during which parents and children engage in turn-taking, shared attention, back-and-forth communication, positive affect, and child-directed activities. However, these interventions are often based on Western child-rearing practices and may not be generalizable to other cultural frameworks (Ramseur II, 2018). Further, a caregiver's cultural background can inform the relative value they place on authority, structure, conformity, and privacy. Treatments that promote politeness and responsiveness may be preferred by caregivers who value authority (Rodriguez & Olswang, 2003). Interventions organized around rules and repetition are more culturally appropriate for families who value structure (Tait et al., 2016). A caregiver who values conformity around social norms may prefer to engage in a treatment that address social difficulties (Dancy et al., 2004). Parents who value privacy may prefer parent-mediated or at-home interventions over group therapy or lab-based services (Burkett et al., 2021). While some of these values may relate to race and ethnicity at the population level, there will always be variation amongst individuals. Researchers must generate better tools to characterize participants' culture and values outside of their race and ethnicity, as these constructed labels are insufficient to document the complexity of family characteristics that might interact with intervention adherence or efficacy.

Understanding pertinent values and strengths can aid in the development of new, culturally-based interventions (Vivanti et al., 2017). This knowledge can also facilitate adaptation of current interventions. While cultural adaptations are beginning to emerge, there is extensive work to be done in this area. Investigators should engage communities to aid in modifying existing interventions to include culturally appropriate pictures, characters, sayings, and storylines, adapted delivery structures to focus on peer- or expert-delivery, additional tools to allow self-tracking of quality, and flexible content depending on the specific challenges and strengths of the population (Magaña, 2021). Rather than attempting to build universally inclusive interventions, there is value in developing precise interventions personalized to families across cultures. Researchers must also identify the "key" ingredients of current interventions in order to assess the tradeoffs between cultural fit and preservation of treatment fidelity. Establishing this foundational knowledge will maximize the ability of providers to ensure that an intervention is consistent with the expectations, goals, challenges, and resources of diverse families.

Health literacy

Health literacy is another substantial barrier to research. Nearly 40% of Americans have limited health literacy, and half of these individuals are from minoritized groups (Timmins, 2002). In addition to reducing participation in clinical trials, low health literacy amongst caregivers can result in a number of negative consequences for their autistic children, including delayed detection, less effective treatment, and reliance on information provided by the internet or social networks that may not be accurate or safe (Ford et al., 2013). Limited health literacy can also affect how parents navigate healthcare and education systems and make decisions about their child's care. Many caregivers have minimal engagement with published research articles, which are often dense with jargon. This issue is amplified for non-English speakers who may find information in their native language difficult or impossible to access (Zamora et al., 2016). This can be attributed to lack of integration between academia and culture for BIPOC families, as well as general educational barriers for minoritized populations (Skinner, 2008). These factors further contribute to the lack of knowledge about the potential benefits of participation for both themselves and their community.

Addressing disparities in health literacy requires better translation of scientific findings. The successful "Science Briefs" intervention program disseminated summaries of key scientific literature to Hispanic caregivers of autistic children, increasing their knowledge about autism and interest in continued education both immediately after and five months post-intervention (Lajonchere et al., 2016). Community members contributed to the selection of high-priority topics and culturally-informed design of the Science Briefs, which included graphics and audio recordings of the text. Following their participation, caregivers expressed appreciation for the research being done, relief that their child's autism was not their fault, and desire to learn more about their child's diagnosis. Additionally, investigators found that 86% of participants discussed their new knowledge with family and friends in their community. In practice, it is important for investigators to ensure that their research findings are disseminated to research participants and their communities more broadly. There are existing programs that translate and disseminate community-friendly science research through articles and podcasts (e.g. Science Friday en Español), which should be a focus of community dissemination efforts. Improved dissemination about the results of research studies could encourage higher levels of participation in BIPOC communities.

2.2.6 Community advisory boards

Perhaps the most notable strategy that can be utilized by researchers to recruit more diverse participants is community engagement, including community advisory boards (CABs) (Maye et al., 2021). CABs engage a representative group of community stakeholders in all phases of research, including study design, recruitment, data collection, analysis, and dissemination of results (Kuhn et al., 2020). CABs are well-documented to reduce power differentials between community members and researchers, particularly around sensitive topics like health disparities (Dancy et al., 2004). Shared decision-making empowers collaborators to mutually invest towards achieving communal goals (Gomez et al., 2021). This approach notes that partnership between academic institutions and communities must be iterative, equitable, collaborative, mutually beneficial, and sustainable (Andrews et al., 2012). The structure can be adapted towards the needs of stakeholders, and members of a CAB can act as liaisons between community members and researchers.

Many of the barriers to representative research described by the Social-Ecological Model (SEM) can be addressed by integrating community expertise through CABs (Magaña, 2021; McCloskey et al., 2011). At the individual level of the SEM, a community advisory board can support the development of culturally and linguistically appropriate materials and study design. At the interpersonal level, a CAB can identify community events and liaisons through which to bridge recruitment gaps. Board members can also advise on recruitment materials and strategies. At the organizational level, a CAB can facilitate relationships between an academic institution and trusted community partners. At the community level, a CAB can help to identify strategies to reduce logistical and psychological barriers to research participation. And finally, at the policy level, a CAB can collectively advocate for important domestic and national regulations that might affect BIPOC communities. Board members can also contribute to setting agendas for high-priority research questions to inform future investigations.

While CABs are common in many academic disciplines and successful in promoting community engagement for BIPOC populations affected by other health problems, they are not widely implemented by autism researchers and rarely with specific attention to racial diversity (Nicolaidis et al., 2011). In fact, they are not required by NIH for large studies, and only a small number of NIH-funded autism institutes have recently implemented CABs. Research institutions are not designed for participatory research (Maye et al., 2021). Researchers experiences pressure from institutions and funding agencies to produce rapid results, and community engagement is time-consuming. Grant timelines do not always support the iterative nature of community engagement nor potential revisions to measures, interventions, and recruitment materials. Funding for committee member payment is limited by grant budgets. Committee members may request rapid implementation of interventions in their community, but funding institutions may require preliminary data not yet available in an underrepresented population. Additionally, autism researchers are primarily educated in neuroscience, clinical psychology, and biology, but may lack the expertise to operationalize a CAB, or may view the process as difficult or unnecessary (Hollin & Pearce, 2019). When CABs are used by autism researchers, there are wide variations in methods and limited reporting of specific community involvement (Jivraj et al., 2014). Certainly, there are challenges to managing diverse interpersonal relationships and power dynamics (den Houting et al., 2021). However, community-advisory boards offer sustainable support for local action towards reducing disparities, a critical goal that deserves comprehensive effort.

CABs have been used successfully in select autism studies, particularly because autistic individuals and their advocates have been a “driving force in advocacy for research” (Elsabbagh et al., 2014). A case study of a community advocacy board describes a collaborative workshop where stakeholders discussed bi-directional knowledge, service needs and community resources, and current barriers and policy transformations to improve the quality of life for autistic individuals and their communities (Elsabbagh et al., 2014). Through similar discussions, autism researchers at other institutions may identify ways to make their studies more trustworthy and relevant to underserved communities. Careful implementation and documentation changes should then be disseminated back to communities through progress reports. When implemented, successful autism CABs have created specific guidelines in order to equalize power distribution of autistic adults, caregivers, and providers across varying communication ability, but organizations must further ensure representation from BIPOC communities.

Attempts by researchers to address disparities without engaging communities’ risks and perpetuating distrust between communities and academic institutions. Research institutions are uniquely situated to conduct scientific studies, establish foundational knowledge, and advocate for appropriate policies, but addressing these problems ethically and transparently requires community engagement through CABs. If an organization cannot realistically support a community advisory board, smaller scale community engagement through focus groups may be achievable. Other forms of community engagement (i.e., community-based participatory research, community-academic partnership, etc.) should also be considered.

2.3 Conclusion

This section used the Social-Ecological Model (SEM) to summarize a number of barriers to representative research in the field of autism research as well as existing and promising solutions. At the policy level, grant institutions can incentivize diversity efforts by funding methodological studies. Academic journals can standardize and require demographic reporting in publications. Investigators can demystify research and reduce community mistrust through patient navigation programs administered to both participants and staff. Selecting appropriate research projects, providing assessment reports, and disseminating results to communities can ensure bi-directional benefits for researchers and communities. At the community level, researchers can address logistical barriers by integrating child care, transportation assistance, flexible scheduling, and increased compensation. Telehealth and community-based research can be leveraged to reduce barriers to enrollment. Researchers can investigate and establish evidence-based and strength-based strategies to reduce community stigma and increase knowledge about autism and treatments. Studies should also focus research on high-interest topics in communities (e.g. police violence, employment, safety). At the organizational level, institutions can increase diversity throughout research membership, including trainees, staff, and faculty. They can also address language capacity and interpreter costs at research institutions. Investigators should reflect on the usefulness of current research designs, exclusion criteria, and measures, and identify opportunities for group design, data consortiums, and implementation science. At the interpersonal level, diverse recruitment can be enhanced through better referral pipelines with trusted community partners and locations developed over time. Successful methods for replication across projects, populations, and disciplines can be replicated. At the individual level, researchers should investigate “key ingredients” that may influence success of a treatment and establish measurement tools to document the impact of culture on health. Community-based approaches can aid development of culturally-specific interventions. Health literacy can be addressed through broad dissemination of research findings to communities to bridge science and practice. Across these solutions, community engagement can enhance accuracy of diversity efforts.

Section 3: Research Aim 2 & 3

The SEM provides a framework for designing interventions to address barriers to enrollment for BIPOC research participants. In this section, the SEM will be applied to one research institution, the UCLA Center for Autism Research and Treatment (CART). First, an evaluation of enrollment demographics will provide insight on specific areas of focus to guide future CART efforts. Second, the SEM will be utilized to identify specific interventions that could address enrollment barriers at CART.

3.1 Case Study of UCLA CART

For more than 50 years, CART has been a national leader in autism research and treatment. CART brings together researchers across disciplines; it's eighteen faculty members have academic appointments in Psychiatry, Neurology, Genetics, Pediatrics, Education, and Biostatistics. The mission of CART is to understand the biological basis of autism in order to provide effective targeted interventions. CART also cites its focus on education and outreach in order to bridge gaps between science and community.

3.2 Aim 2

Aim 2: Assess BIPOC enrollment in research at CART.

CART is funded by a diverse array of grants, with a large proportion of support coming from the NIH Autism Center of Excellence (ACE) grant. The goal of these grants has been to understand the relationship between brain development and autism. Three consecutive ACE grants have been conducted at CART since 2007. Composed of three to five sub-studies related to intervention, bioimaging, and genetics, the ACE grants represent the breadth of research conducted at CART. While CART investigators conduct many more research projects than those described here, the data describes a sample of studies conducted across the last decade.

Aim 2 establishes a baseline for enrollment. Identifying historical enrollment distribution facilitates identification of areas for improvement. Continued tracking will also support monitoring of the impact of future intervention efforts.

3.2.1 Methods

CART demographic data was obtained from ACE enrollment reports submitted to NIH between 2007 and 2021. The ACE studies enroll children and adolescents with autism who were under the age of 18. Additionally, non-autistic controls were recruited for participation. All studies were conducted on the UCLA campus. Some provided intervention to participants, while others included genetic testing or bioimaging.

The enrollment reports summarize demographic distribution as reported by participant caregivers. Caregivers were asked to report ethnicity (Hispanic/Latino, Not Hispanic/Latino, or Unknown) and race (White, Black, American Indian, Asian, Pacific Islander, Multiracial, or Unknown). However, reporting discrepancies in race and ethnicity and subsequent misclassification of research data are particularly common amongst individuals who identify as Hispanic (Magaña López et al., 2017). To avoid misclassifying participants who might omit one aspect of self-reported race or ethnicity, this project collapsed data to one variable describing demographic group (Table 1). All participants who identified their ethnicity as “Hispanic” were considered Hispanic, regardless of their reported race (e.g. a person identified as Black/Hispanic was counted as Hispanic, not Black). All non-Hispanic participants were counted in their reported racial group (e.g. a person identified as Asian/Unknown was counted as Asian, not Unknown).

Table 1: Classification of race and ethnicity groups

	Hispanic	**Not Hispanic**	**Unknown**
White	Hispanic	White	White
Black	Hispanic	Black	Black
American Indian	Hispanic	American Indian	American Indian
Asian	Hispanic	Asian	Asian
Pacific Islander	Hispanic	Pacific Islander	Pacific Islander
Multiracial	Hispanic	Multiracial	Multiracial
Unknown	Hispanic	Unknown	Unknown

Within each demographic group, three measures were used to assess participant enrollment. First, demographic data from the enrollment reports were compiled to provide a snapshot of "Actual" participant diversity. Second, the "Planned" demographic distribution was calculated using recruitment goals set by investigators in the same enrollment reports. There is no standard procedure for calculating Planned enrollment, though some investigators consider recent census data and historical recruitment distribution. Third, a measure of Los Angeles "Population" was calculated using the average proportion of children under the age of 18 in each demographic group between 2007 and 2020 (*U.S. Census Bureau QuickFacts*, 2022).

The three measurements (Actual, Planned, and Population, all reported as percentages) were compared within each category to identify differences between 1) Actual and Planned, 2) Planned and Population, and 3) Actual and Population demographic estimates. A margin of error was calculated for each group using the sample size (n = 596), proportion percentage, and a 95% confidence interval (Table 2). Differences that were within one margin of error were classified as "Acceptable." Differences within two times the margin of error were considered "Low" or

"High." Differences more than two times the margin of error were classified as "Very Low" or "Very High."

Table 2: Acceptable range for groups based on lowest and highest population estimate between 2007 and 2021, including margin of error.

	Low % (Year)	**High % (Year)**	**Average %**	**Margin of Error %**
White	17.1 (2009)	20.4 (2020)	18.7	3.1
Black	7.5 (2020)	8.5 (2007)	8.0	2.2
American Indian	0.2 (2007)	0.2 (2020)	0.2	0.4
Asian	9.1 (2007)	12.7 (2020)	10.9	2.5
Pacific Islander	0.2 (2020)	0.3 (2007)	0.2	0.4
Hispanic	55.7 (2020)	62.7 (2009)	59.2	3.9
Multiracial	2.6 (2007)	3.4 (2020)	3.0	1.4
Unknown	0.0	0.0	0.0	0.0

3.2.2 Results

Figure 2 summarizes Actual, Planned, and Population measures for ACE studies between 2007 and 2021 (n = 596).

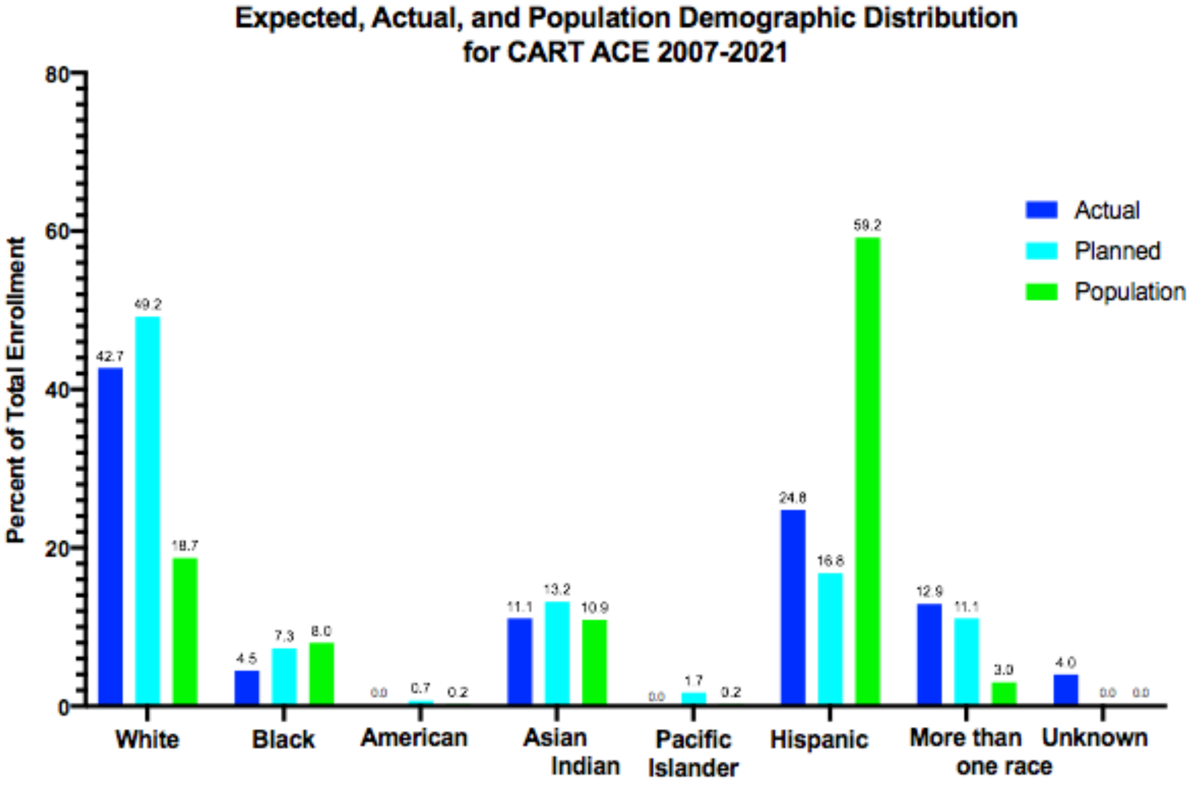


Figure 2: Proportion of participants in compiled demographic groups for CART ACE studies 2007-2021 and expected distribution based on average Los Angeles population between 2007-2020.

Table 2 summarizes the calculated differences for each demographic group. The ACE studies met planned enrollment goals for Asian participants and over-enrolled Hispanic and Multiracial participants. Black, American Indian, and Pacific Islander participants were under-enrolled. No participants identified as American Indian or Pacific Islander were enrolled in any ACE study. White participants were considered under-enrolled in ACE studies based on Planned estimates; however, the difference between Planned and Population estimates suggest that these goals may not accurately represent the Los Angeles population.

The difference between Planned and Population estimates provides insight about the accuracy of recruitment goals in representing the local Los Angeles population. Investigators planned to enroll a disproportionately high number of White, Pacific Islander, and Multiracial participants compared to the Los Angeles population. A smaller proportion of American Indians and Hispanics were planned than comprise the Los Angeles population. Planned recruitment for Black and Asian populations accurately represent the local population.

Finally, the third difference calculation between Actual enrollment and Los Angeles Population shows that Multiracial participants are over-enrolled in CART studies. While CART exceeded the Planned enrollment goals for Hispanic individuals, the Actual enrollment of Hispanic participants underrepresents local demographics. Inversely, White participants were overenrolled compared to Population estimates, despite apparent under-enrollment according to Planned goals. Black participants were under-enrolled compared to Population estimates. Enrollment of American Indian, Asian, and Pacific Islander groups were considered within the margin of error based on Population estimates. Additionally, 4.2% of participants did not have race and ethnicity data reported.

Table 3: Differences between Actual and Planned, Planned and Population, and Actual and Population estimates

Demographic group	Actual / Planned Difference	Planned / Population Difference	Actual / Population Difference
White	-6.5%	+30.5%	+24.0%
Black	-2.8%	-0.7%	-3.5%
American Indian	-0.7%	+0.5%	-0.2%
Asian	-2.1%	+2.3%	+0.2%
Pacific Islander	-1.7%	+1.5%	-0.2%
Hispanic	+8.0%	-42.4%	-34.4%
Multiracial	+1.8%	+8.1%	+9.9%
Unknown	+4.0%	0.0%	+4.0%

Very Low	Low	Acceptable	High	Very High

3.2.3 Discussion

When considering only the Planned enrollment goals as the benchmarks for diversity, CART met or exceeded its goals for Asian, Hispanic, and Multiracial populations. However, CART under-enrolled participants from every other BIPOC population. In fact, no participants who identify as Pacific Islander or American Indian were ever reported in a CART ACE study. Individuals from these groups may be difficult to recruit given their proportionally low numbers in Los Angeles, but it is concerning that they are not represented in CART ACE studies. This is particularly problematic given the lack of autism literature published on these marginalized groups (Johnson et al., 2009). These groups may face specific health disparities or concerns that warrant investigation, but without representation in population-wide research, there are fewer opportunities to identify health challenges or collect preliminary data for grant awards. It is critical that CART build partnerships with these marginalized populations in order to ensure that its studies are representative of the local population and also generalizable across populations.

ACE studies over-enrolled participants who identified as Multiracial. Multiracial participants may be important voices to consider when attempting to understand barriers to BIPOC research enrollment at CART. Alternatively, this over-representation may indicate a lack of specificity in data collection that obscured demographic categorization. For example, a participant who self-identified as both Black and American Indian would be categorized as Multiracial rather than both Black and American Indian. Additionally, the over-representation of individuals with Unknown or missing data suggests that CART researchers, like investigators across disciplines, should consider data collection strategies for race and ethnicity. This absence of data could be caused by participant confusion when completing demographic self-report surveys. Given the small enrollment numbers expected for some populations, it is important that CART conduct internal quality assessments to identify any consequential reporting errors. Without accurate reporting, it is difficult to fully assess the demographic distribution in CART research. Future research should seek to understand why participants choose not to report their race in demographic measures, as this might elucidate complex relationships between race and research participation.

Another important finding from this analysis is that Planned enrollment goals do not accurately represent the diversity of the Los Angeles population. However, representation of local the population is not necessarily an investigators' goal when calculating Planned recruitment. Investigators use variable methods to determine Planned enrollment, but many consider recruitment from past studies to guide their goals. Historical recruitment knowledge may lead investigators to expect greater numbers of White participants, in part because UCLA is located in a Los Angeles neighborhood that is majority White (LA County Public Health, 2019). Some investigators may consider prevalence rates of autism across populations or their ability to enroll diverse participants given access to interpreters or recruitment resources. There may be other legitimate reasons for differences between recruitment goals and the local population. This strategy makes their enrollment goals more accurate, but it also reduces motivation to recruit under-represented populations. Reflecting on this process may be an important step towards accountability in enrollment diversity. When comparing Actual enrollment to Population percentages, the problem of BIPOC underrepresentation becomes clearer. It is important that investigators reflect on their motivation for establishing the current recruitment goals to determine whether changes towards accurate representation are appropriate. Standardization of methods across CART studies could also improve the accuracy of Planned demographic numbers in future studies.

This analysis does face a number of limitations. Demographic distribution fluctuates from year to year, which may account for some differences in enrollment over the course of the ACE studies. Autism prevalence also varies across demographic groups. This factor was not included in population estimates because enrollment included both autistic and non-autistic children. In Los Angeles, most demographic groups have reported prevalence rate of 2.0-2.2%, but Hispanic children are diagnosed less frequently at 1.7% (Nevison & Parker, 2020). Therefore, we might expect proportionally fewer Hispanic children with autism to enroll in studies. This analysis was further limited because all enrollment data was self-reported with unknown accuracy, although some data points are known to be missing. Additionally, this analysis only includes participants from CART ACE grants; a large number of CART studies are not included due to data availability. Additional data could provide insight about the types of studies that achieve more racial and ethnic diversity and guide future recruitment efforts.

All CART ACE studies are conducted locally and research findings may impact local or national policies and evidence-based practice, so enrollment goals should closely represent the surrounding area (Gordy, 2020; Kasari, 2020). Each ACE grant is conducted over a five-year period, so investigators have the opportunity to periodically update Planned enrollment numbers. This regular attention to shifting demographics could help researchers to more closely consider current and future recruitment practices, community partnerships, and outreach. Standard and transparent assessment of recruitment demographics can build trust between researchers, funders, staff, policy makers, and community members. Further, understanding the efforts that led to successful recruitment of some BIPOC populations (including Hispanic participants) in past studies can build evidence for continued and improved diversity in the future.

3.3 Aim 3

Aim 3: Engage the SEM to identify opportunities to improve BIPOC enrollment in research at CART.

Results from Aim 2 demonstrate that while CART has met some of their diversity goals, there are opportunities for continued improvement. In the past decades, CART has made strides towards defining and accomplishing its diversity goal. In 2020, CART recognized the need to specifically address racial and ethnic disparity. The center's director published a statement describing his recognition that CART investigators must dedicate more effort towards working with underrepresented groups in order to minimize racial and ethnic disparities for autistic people and their families (Geschwind, 2020). Since initiating this conversation in 2020, CART has held two annual Equity, Diversity, and Inclusion (EDI) workshops, which included presentations from Black and Hispanic researchers and discussion about continued EDI efforts. CART has also promoted the efforts of staff and administrators who formed three working groups. The CART EDI working groups focus on Research, Clinical Care, and Mentorship within the center. CART has also funded several projects conducted by the EDI working groups, including two staff surveys and upcoming community focus groups. Additionally, strategies that have proven successful in recruiting BIPOC participants could be replicated across CART studies. Aim 3 provides an account of the current state of diversity efforts at CART. The results describe existing resources and successful strategies at CART as well as promising pathways for continued growth towards representative enrollment.

3.3.1 Methods

To address Aim 3, this project evaluated a number of sources to understand existing strategies and possible interventions solutions to address barriers for BIPOC participants at each level of the SEM. Sources included published intervention studies from autism centers and other research institutions, publicly available policies at UCLA, and a survey of CART staff (n=90). This survey was conducted by the CART EDI Research working group in December 2020. The goal of the project was to gather insight from staff about their experiences in recruiting and retaining participants for studies, identify key solutions that could improve perceived barriers, and inform the direction of future research efforts. The survey was designed in collaboration between staff, faculty, and administrators and conducted via Qualtrics over the course of three weeks. The demographics of CART staff, including undergraduate volunteers, staff, trainees, administrators, and faculty were assessed using self-reported data from the survey. This survey represented over half of the CART membership and can be considered a representation of perspectives at the center. Together, these sources informed this account of existing and promising solutions that could be implemented at CART, as well as limitations that each solution must consider.

3.3.2 Results

Policy-level interventions

Reporting demographic data

CART can standardize and centralize reporting of participant demographics within the center, including disaggregated data. These metrics are often collected and reported to funding agencies, but it is important to establish transparency and accountability within the center and the community. Closer inspection of data across studies could also reveal the impact of varied recruitment practices on enrollment and retention. In the future, data supporting the success of a recruitment strategy in increasing participant diversity could secure grant funding or justify additional recruitment spending.

Ethical research training

CART could integrate an evidence-based patient navigation program across research studies. Investigators could also develop autism-specific materials about ethical research and existing safeguards. These materials could be available in multiple languages at community events and online. When investigators approach community organizations for recruitment assistance, they could offer members a seminar about research ethics. Staff and trainees, who are most often involved in recruitment and consent, could participate in delivering this information to community members. Additional staff and faculty training could also promote understanding about the importance of comprehensive informed consent. CART should also ensure that required ethics trainings sufficiently cover historical misconduct in research so that staff can approach recruitment sensitively.

Increase direct benefit for research participation

Currently, the clinic associated with CART (Child and Adult Neurodevelopmental [CAN] Clinic) is able to offer only limited autism evaluations covered by insurance. While efforts are being made to expand insurance coverage for evaluations at the UCLA CAN Clinic, investigators should acknowledge their ability to assuage some disparity in access to expert evaluation through their research designs. Assessment reports should be provided to all participants. While this process requires staff time to write and review the reports, standardized templates and review pipelines can reduce the burden on researchers while ensuring that the reports are valuable to families. In the event that assessment reports are not feasible within an investigation, it is critical that families are still provided with support and resources when they exit a study. Resource guides should be made specific to communities across Los Angeles. These guides should be developed in partnership with community stakeholders in order to address the questions families may encounter when navigating the service landscape.

Community level interventions

Address logistical challenges at UCLA

In the CART staff survey, respondents identified a number of high-priority barriers that should be addressed for in-person visits. Parking was noted as a leading challenge by 60% of surveyed CART staff. Specifically, staff noted the difficulty of communicating with families about parking locations and directing families to study locations. Parking guides for coordinating staff could adequately address this concern. CART could additionally consider coordinating transportation for participants using Uber Health, a HIPAA compliant tool to facilitate healthcare appointments. HopSkipDrive is another rideshare platform that offers accessible and dependable transportation for children in Los Angeles and other cities around the country. This service has partnered with many Los Angeles schools to provide children with transportation with experienced and trained drivers. This could greatly enhance the ability of families to get to UCLA for research studies without negotiating parking or public transportation systems.

CART staff also identified childcare as a relevant barrier to research enrollment. 58% of respondents endorsed that providing childcare services would ease the ability of families to participate in research. However, UCLA policies complicate childcare capacity at CART. Undergraduate volunteers and interns are eager to gain experience working with children, but policy requires that they are supervised at all times by study staff. However, Work study students who have been on-boarded by the Human Resources department are able to provide childcare to siblings or research participants during study visits. Hiring several CART-wide work study students to support in childcare efforts could greatly reduce this barrier to research participation.

The EDI Research working group assembled a resource guide for staff with instructions for many other logistical accommodations that can be provided to participants, such as meal vouchers, snacks, and diapers (Appendix A). However, funding is a limiting factor and many studies do not budget for high levels of resource support, nor do all families require support. One solution would be for CART to use internal funds to offer research “scholarships” to qualifying families, which could include travel support, meal vouchers, and childcare as needed. Study staff could request support for families in order to ease the financial burden of participation and meet goals for representative enrollment. This solution would require CART to identify a goal for the number of scholarships offered and budget appropriately.

Identify strategies to reduce community stigma

In additional to addressing logistical challenges, investigators could consider ways to address community stigma. CART faculty are frequently consulted for media projects about autism and disability. This authority could be leveraged to diversify the face of autism in the media, which is primarily White and male. CART researchers have participated with the Los Angeles Police Department to identify ways to address violence in BIPOC communities, but nationally, violence against BIPOC autistic people as well as community fear are prevalent. Researchers could integrate community perspectives into developing improved solutions for police training or other policy responses. Additionally, researchers should continue to disseminate their work within BIPOC communities. Knowledge is an important aspect to of destigmatizing autism in BIPOC communities.

Organizational level interventions

Increase staff diversity and language capacity

CART lacks diversity across its membership, including students, trainees, staff, faculty, and administration. Less than 2% of CART staff are Black, and none of the 18 faculty members are Black. However, CART leadership recognized the importance of nurturing diverse trainees through the EDI Mentorship working group, which is led by senior investigators. Currently, the group is collecting internal data about the mentorship environment in CART. From here, the group can establish mentoring pipelines to improve CART's capacity to train students. However, CART must commit to hiring BIPOC faculty. It is critical that in our efforts to improve the diversity of our participants, we also address the diversity of our center. Other UCLA departments have implemented high-quality trainings that could be replicated at CART.

Los Angeles is the second most linguistically diverse city in the country, with 185 languages spoken. 56.6% of children over the age of five hear a language other than English at home, and 10.7% of children live in a limited English-speaking household (US Census Bureau, 2021). The most commonly spoken languages are Spanish, Korean, and Tagalog (US Census Bureau, 2021). However, the staff survey demonstrated that "multilingual staff members are overburdened but their efforts are often overlooked and not supported enough." Hiring clinicians, staff, and faculty who speak these languages would enhance the ability of CART to serve linguistically diverse families.

It is also imperative that CART address gaps in translation services. As documented by the 2020 CART survey, most research staff have not used interpreters for research nor had training to use these services. While ensuring that staff are equipped to use these services when needed, CART should also consider addressing the high cost of translation services for non-Medical appointments. Researchers are currently required to pay up to $85 per hour for interpreter services, while these services are provided at no cost to medical departments. When research appointments take up to 5 hours per visit, the cost prohibits many studies from enrolling families who speak limited English, thereby excluding a number of BIPOC families. Additionally, many psychometric assessments are not validated for use with interpreters. It is therefore important that investigators consider their capacity to enroll non-English speaking participants throughout study design, including measurement selection and budgeting.

Expand data-sharing capacity

Currently, CART is establishing a repository for center data. This will expand the ability of researchers to utilize data across research studies. Throughout research studies, investigators should consider alternative research designs that reduce the demand on BIPOC participants. This might require integrating expertise from other disciplines, such as public health. Currently, no faculty from UCLA's Public Health department participate in CART research.

Interpersonal level interventions

Engage community partners across studies

CART investigators have spent decades building partnerships with BIPOC communities. However, these partnerships are not integrated across labs. In the 2020 CART survey, 40% of staff endorsed that research accessibility would be improved by enhancing outreach in underserved communities. This suggests that a substantial proportion of CART staff are not aware of current recruitment efforts, that these efforts are not being enacted across all research studies, or that these efforts are not sufficient to address diverse recruitment needs. Investigators may be reluctant to publicize their recruitment efforts due to reasonable concern for exploitation of their community partners or worry about oversaturating organizations with research requests. They might not be confident in the cultural sensitivity of research materials and procedures across labs. However, unity across CART can help to improve recruitment and retention across a range of disciplines. Any degree of cultural insensitivity can damage the perception of CART research within communities. Documenting the recruitment process can further inform which projects attract certain populations, helpful information that can only be gathered if participants are invited to a wide array of research opportunities.

Identify new recruitment pathways

Although investigators can rely on the resources developed across disciplines and locations, an ideal recruitment manual would be specific to CART. Staff should collaborate to standardize best practices. Studies which have successfully recruited diverse populations should be highlighted in order to enhance center-wide recruitment. Additionally, staff should be trained on these successful methods. Due to frequent turnover, this training should be offered annually or biannually, or recorded as part of a staff training attestation. This should also involve training coordinators on culturally responsive interviewing.

Compiling successful recruitment methods will be important to ensure efficient efforts and reduce replication of failed strategies. However, it is important that strategies integrate the perspectives of community members. Ultimately, having a list of community members who are able to quickly provide feedback on materials would help streamline this review process. CART could consider providing financial compensation for this effort. For example, gift cards could be provided to the first 15 responders from an approved list who provide feedback about materials. For a more intensive review process, focus groups should be assembled. If successful, this strategy for rapid community feedback could be replicated in other fields of research.

Individual Level interventions

Share strategies for cultural adaptation

Investigators at CART have engaged in cultural adaptation of existing interventions. Dr. Connie Kasari works closely with a number of community organizations to design an intervention (Mind the Gap) for Black and Hispanic populations focused on navigating the arduous process of screening, evaluation, and treatment for autism (Iadarola et al., 2020). Dr. Elizabeth Laugeson has led several cultural adaptations for her adult intervention program PEERS®, which have been guided by surveys in local contexts (Shum et al., 2019; Yamada et al., 2020). These investigators have made great progress towards improving the cultural fit of interventions. However, it is important that the knowledge gained from these studies is broadened for use across research fields. CART studies in neuroimaging could greatly benefit from information about cultural adaptations. Standardizing these practices could enhance cultural sensitivity across studies and facilitate improved understanding about cross-cultural perspectives.

Utilize dissemination to address health literacy gaps

Dissemination is a core principle to community-engaged research. CART frequently provides webinars to the broader community through the “Coffee CART” meetings. Faculty and staff also provide free trainings to community providers as well as educational programs for parents and caregivers. However, CART should consider additional ways to ensure that research successes are disseminated to BIPOC communities. CART could engage with existing projects like Science Friday en Español, provide newsletters with lay-summaries to partnered community organizations, or conduct more community seminars and workshops, newsletters, or podcast appearances. Regardless of the mode of dissemination, it is critical to ensure that these efforts are distributed in multiple languages with attention to varying literacy levels. Community partners will be critical collaborators for this process. This effort can be further enhanced by involving staff and trainees who could gain valuable experience with scientific writing and presentations in the community.

Community advisory board

CART has not previously had a center-wide community advisory board (CAB), though CAB’s have been used in some individual studies. CART researchers intend to launch the center’s first CAB in June 2022. There are a number of considerations that CART researchers should make when establishing a CAB. The formation of a CAB requires selecting appropriate partners. To account for the dynamic family hierarchies in some BIPOC communities, it is advisable to include parents, grandparents, and siblings, as well as social workers, clinicians, educators, and legal advocates, though smaller groups of 3 to 8 active members are generally more productive than larger groups (Dababnah et al., 2018; Wheelan, 2009). Engaging BIPOC students can support meaningful mentorship for those interested in advocacy work. Researchers should also ensure that partners are provided the necessary materials to be productive and contributing members (Ortega et al., 2016). Respect between partners is critical to the success of a CAB, so it is important to emphasize to partners that the goal is bi-directional collaboration (Gomez et al., 2021). Researchers should aim to learn from community members, rather than promoting their achievements and successes. In order to achieve high-quality leadership, both senior and early-career investigators should attend CAB meetings. It is critical that all CAB participants communicate their visions and goals for the collaboration. The CAB should identify how and when achievements will be evaluated, as well as strategies for decision-making and conflict resolution (Brock et al., 2019).

Logistical considerations should be made, including clearly structuring meetings, defined roles, and common terms to equalize across content knowledge and health literacy (Drahota et al., 2016). In order to engage committee members outside of formal meetings and sustain momentum, it can be helpful to provide regular updates through newsletters (Ortega et al., 2016). To engage autistic community members who may require longer response times or less social engagement, the board should consider online, text-based communication. However, this must also be balanced with literacy and language needs of other stakeholders. Autistic researchers recommend the Five-Finger method as a non-verbal tool to support communication and decision-making for individuals with diverse needs (Nicolaidis et al., 2011). Translators should be integrated throughout CAB meetings. Community advisory boards are well-documented in medical literature, including autism research, but successful implementation will require careful planning and consultation from community engagement experts (Elsabbagh et al., 2014; Magaña, 2021).

3.3.3 Discussion

This project summarized a number of barriers to representative research in the field of autism research as well as the local context of UCLA CART. The solutions offered can be implemented simultaneously but should be closely monitored and documented. Ultimately, CART must work with community partners to identify goals to measure the success of diversity efforts.

Current suggestions to address logistical barriers utilize the perspective of staff; however, the next step is to investigate the perspectives of potential participants. Currently, CART is recruiting BIPOC caregivers of autistic children to participate in focus groups. These discussions will help researchers to better understand which perceived barriers are the most salient to communities in Los Angeles.

3.4 Conclusion

Investigators must recognize the need for continued attention to these efforts and take accountability for ensuring that adequate funding and support is offered to staff and community members. Success requires that investigators to reflect on CART's goals towards diversity and the appropriate measurements for achievement. It is possible that simple metrics like race and ethnicity of research participants are not sufficient to understand how successfully researchers are engaging the community, or that these measures are not directly important to researchers or community members. Perhaps other measurements of diversity should be considered in the future, such as the quality of community partnerships, quantity of disseminated research findings, or distribution of staff demographics.

As progress is made towards building capacity to better address health disparities and respond to the needs of community members, researchers must maintain ensure that results are available to diverse readers. Achievements in this domain will propel the local community towards health equity, and documented efforts can be replicated by other institutions. Ultimately, these efforts can better identify, address, and reduce health disparities encountered by the BIPOC autistic community and their families.

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