


# Utilizing Community-Based Implementation Trials to Advance Understanding of Service Disparities in Autism Spectrum Disorder

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The Centers for Disease Control and Prevention estimates up to 1 in 59 children have autism spectrum disorder (ASD),<sup>1</sup> and the annual cost of ASD in the United States is estimated to be \$236 billion.<sup>2</sup> Evidence-based interventions (EBIs) have been developed and demonstrate effectiveness in improving child outcomes. However, research on generalizable methods to scale up these practices in the multiple service systems caring for these children, especially those in low-resource settings, has been limited and is critical to meet this growing public health need. The purpose of this commentary is to describe how a new project, described in *Implementation Science*<sup>3</sup> that includes 2, coordinated studies testing the effectiveness of the Translating Evidence-based Interventions for ASD: Multi-Level Implementation Strategy (TEAMS) model, can provide an example of how community implementation trials can support our understanding of service disparities. All procedures in this study have been approved in accordance with the ethical standards of the University of California, San Diego (161234SW), with reliance approval from University of California, Davis, and the University of California, Los Angeles, institutional research boards. The TEAMS project aims to improve scale up through a focus on improving implementation leadership, organizational climate, and provider attitudes and motivation in order to improve 2 key implementation outcomes—provider training completion and intervention fidelity, and subsequent child outcomes. The TEAMS Leadership Institute applies implementation leadership strategies, and TEAMS Individualized Provider Strategies for training (TIPS) applies motivational interviewing strategies to facilitate provider and organizational behavior change.

Two, linked, cluster randomized implementation/effectiveness hybrid, Type 3, trials with a dismantling design are being used to understand the effectiveness of TEAMS Leadership Institute and TIPS modules and their effect across publicly funded settings (educational and mental health), participants (teachers and clinicians), and

interventions (AIM HI: An Individualized Mental Health Intervention for ASD; and CPRT: Classroom Pivotal Response Teaching; see original article or [teamasdstudy.org](http://teamasdstudy.org) for additional information on the specific practices). If found to be effective, the TEAMS implementation strategy has the potential to increase quality of care for ASD in publicly funded settings by improving effectiveness of intervention implementation. The process and modules may be generalizable to multiple service systems, providers, and interventions, providing broad impact in community services.

The TEAMS large-scale, multisite trials includes a large sample of providers (200 mental health providers, 200 teachers) and 400 children drawn from multiple geographic areas in California. Of note, the children represent a highly diverse sample. Thus, the TEAMS trials provides a unique opportunity to examine mechanisms of the well-documented disparities in quality of care for traditionally underserved children and families and understand the role of evidence-based practice implementation in reducing disparities. The Interagency Coordinating Committee Strategic Plan for Autism Research highlights the increasing documentation of disparities in access to diagnosis and treatment and has included a key objective since 2009 to conduct research identifying reasons for health disparities in ASD.<sup>4</sup> Conducting implementation trials in community settings often increases participation of racial/ethnic minority and low-resource populations in comparison to typical clinical trials. For example, in the TEAMS school sample thus far, over 60% of

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participating school districts serve a high proportion of students living in poverty and/or minority students, 39% of enrolled families identify as Hispanic/Latinx, and 41% identify as another minority. In the current TEAMS mental health system sample, over 60% of children and 53% of parents identify as Latinx, with 30% of parents indicating Spanish is their preferred language. This highly diverse population of families and organizations provides an opportunity to examine mechanisms of disparities in service quality within the context of EBI implementation in public service settings.

Disparities in access to care have been documented in ASD. For example, African American, Asian, and Latinx children are less likely than non-Latinx white children to receive special education services.<sup>5</sup> Furthermore, Latinx children with ASD receive fewer specialty services and have higher unmet service need and problems getting referrals to specialty care.<sup>6</sup> For those individuals who do access care, ethnic minority families are less likely to receive high-quality, evidence-based care. For example, Latinx children with ASD are less likely to receive guideline-concordant care than non-Latinx white children with ASD on almost all indicators.<sup>7</sup> In particular, parents of Latinx children reported that providers were not sensitive to family values/customs and were more likely to report that providers did not make parents feel like a partner or provide enough information. Importantly, these quality indicators have been found to mediate health care utilization.<sup>8</sup> Inequalities also exist in education where program quality, as defined by a combination of teacher working conditions, training, leadership, facilities, materials, caseload, and time, is lower in districts with high racial/ethnic minority or low-income student populations, likely due to limited district resources and this affects student learning.<sup>9</sup> This is likely to lead to disparities in access to quality care because more minority students attend high-poverty public schools.

The TEAMS study has the potential to increase our understanding of how to increase quality care in community programs by improving the use of EBIs in programs serving a high proportion of minority students. A meta-analysis of over 500 community prevention and health programs for children and adolescents indicated that better program implementation leads to better child outcomes.<sup>10</sup> In fact, programs that are carefully implementing new strategies, especially when fidelity or dosage are tracked, lead to mean effect sizes that are 2 to 3 times higher than in programs with implementation challenges. Similarly, in school programs for students with ASD, training in EBIs to fidelity standards has been associated with significant increases in student outcomes.<sup>11</sup>

Data from our initial community-based effectiveness trials illustrate the promise of using community trials to

better understand disparities. AIM HI therapist training and clinical intervention targets both therapist and parent within-session behaviors. Specifically, providers learn evidence-based strategies to actively engage parents in sessions in order to teach them strategies aimed to reduce a child's challenging behaviors and facilitate a child's acquisition of positive alternative skills. Similarly, parents attend sessions and actively participate to facilitate their own acquisition of skills as well as their child's skills. Therefore, examining any differences in parent/therapist interaction is especially important for this intervention. Data from the AIM HI effectiveness trial indicated that, while there were no differences in client outcomes or therapist fidelity by ethnicity or primary language, qualitative data examining in-depth experiences of therapists and parents reveal differences in process for Latinx families.<sup>12</sup> Specifically, therapists indicated that they adapted AIM HI delivery for specific families.<sup>13,14</sup>

Qualitative interview data with providers and Latinx families who participated in AIM HI identified the following therapist-reported factors as influencing treatment process: (1) level of parent mental health literacy, including expectation regarding parent involvement; (2) parent understanding of ASD; (3) parent limited English proficiency; (4) cultural factors including the value of *respeto* and parent deference to providers, the influence of extended family members expectations of treatment, and the alignment of culturally specific parenting values and a behavioral approach. Latinx parents reported having low ASD knowledge and highlighted the need for increased psychoeducation about autism. In addition, Latinx parents overwhelmingly identified a relationship of trust, connection, and safety with the therapist as a significant factor influencing their involvement in their child's treatment. Parents reported the need to establish this type of relationship with their therapist before they would feel comfortable participating in their child's treatment.<sup>10</sup> These data were used to inform the development of enhancements to AIM HI to address the 2 targets identified, ASD knowledge and the therapeutic relationship.

Classroom Pivotal Response Teaching involves training teachers to use naturalistic behavioral strategies to increase student motivation for learning activities and therefore examining factors that affect teacher implementation of CPRT may guide future implementation. In the original CPRT school-based effectiveness study, data indicated disparities in classroom quality (using an observational measure of classroom environment, teaching strategies, etc, specifically designed for classrooms serving students with ASD) associated with the proportion of students served in the district who had either

minority or poverty status.<sup>11</sup> Specifically, we examined classroom quality in relation to the percentage of students receiving free and reduced-price lunch, children in the district living in poverty, and Latinx students. All risk categories were negatively related to classroom quality. In contrast, having a higher percentage of white/non-Latinx students in the district was associated with higher classroom quality. Importantly, classroom quality at the beginning of the school year significantly and positively predicted intervention fidelity after training. Additionally, teaching in a high poverty/high minority district was associated with lower intervention fidelity on specific CPRT components. Despite these challenges, working in a high poverty/high minority district was significantly and positively associated with teacher report of frequency and duration of CPRT use in the follow-up year. These data suggest that pretraining in general classroom strategies to support students with ASD may be an appropriate target for improving implementation of CPRT in low-resource districts, and that attitudes toward evidence-based practices does not need to be emphasized.

These preliminary data have led to 2 additional lines of study. First, current TEAMS implementation study offers the unique opportunity to build directly on the previous AIM HI trial process data by developing and pilot testing an intervention, AIM HI EQUIPO, that targets the mechanisms identified as influencing AIM HI treatment process differences within the context of publicly funded outpatient and school-based mental health services. Specifically, *AIM HI EQUIPO* will be designed to address 2 key targets to improve AIM HI delivery: (1) increased parent understanding of ASD diagnosis and the role of parents in their child's mental health care; and (2) development of a collaborative and trusting relationship between the parent and clinician to facilitate active parent engagement. This AIM HI enhancement is being developed and pilot tested in the context of the TEAMS trial using a mixed method design, which begins with collaborative development of the educational materials and pilot testing the feasibility, acceptability, and effectiveness of the intervention. Data will be used to support a larger test of the training module, which will be designed for use across multiple EBIs used in ASD clinical care.

In the CPRT study, we are just beginning to further explore several potential mechanisms of action at multiple system levels that affect use of evidence-based treatments in low-resource districts. These include classroom quality, teacher stress and burnout, implementation leadership and climate, and district resources. We will use the TEAMS study to examine racial/ethnic and income disparities in key areas that affect CPRT

fidelity, identify barriers and facilitators to positive CPRT outcomes in these districts, and develop additional supports (teacher or leader) to reduce disparities. This information will lead to the identification of factors (resources, teacher training, stress, student factors, and leadership support) that explain differences in classroom quality and implementation climate to develop potential adaptations to CPRT training or TEAMS enhancements to reduce disparities.

The TEAMS project provides examples of how a community trial can add to the understanding of how to promote service quality. First, we will have the capacity to examine the impact of the TEAMS implementation strategies (leadership and provider level) in agencies serving a high proportion of traditionally underserved children and families. Additionally, in the mental health project, which includes a high level of parent participation, we are capitalizing on the diverse and representative sample of the parent study by partnering with community therapists and parents to develop and pilot test the *AIM HI EQUIPO* enhancements to support providers in working with Latinx families. We are hopeful that conducting large trials in diverse community settings will increase our broader understanding of ASD services.

### Author Contributions

AS, LBF collaboratively conceptualized this article; AS drafted the article based on discussion and prior work on the project; LBF substantially edited multiple drafts. The final paper represents both their work.

### Declaration of Conflicting Interests

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