

Community-Partnered Research With Urban School Districts That Serve Children With Autism Spectrum Disorder



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ABSTRACT

OBJECTIVE: To illustrate the process of community-partnered participatory research to develop and evaluate interventions for children with autism in urban school districts.

METHODS: We formed partnerships of school personnel, parents, and researchers to guide the project. We then conducted focus groups, key informant interviews, and town halls to explore how public schools currently serve students with autism. We used findings from these activities to adapt interventions for public schools. We then tested interventions in randomized clinical trials (RCTs).

RESULTS: Community input indicated a particular need for interventions to improve children's social interaction and instructional supports to promote their success throughout the day. On the basis of this input, we adapted 2 interventions: Remaking Recess for improving peer engagement during social times; and Schedules, Tools, and Activities for Transition (STAT) for facilitating successful transitions between activities throughout the daily routine. Results of the RCT of Remaking Recess are

not yet available. The RCT of STAT involved 150 children and 56 teachers. Teachers reported high buy-in and increased their proficiency at implementing STAT; children with ASD reduced their disruptive behavior and made progress toward teacher-nominated goals. However, teachers' implementation remained inconsistent, and children did not reliably improve in academic engagement or independence.

CONCLUSIONS: The findings suggest that although community-partnered participatory research has limitations, it can assist in selecting interventions to address community priorities and produce some favorable outcomes for children with autism in public schools. An important next step is to evaluate the sustainability of the interventions introduced in this project.

KEYWORDS: autism; community pediatrics; community-based participatory research; schools

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A PRIMARY AIM of community pediatrics, pioneered by Robert J. Haggerty and colleagues at the University of Rochester, is to improve services for children who are receiving inadequate care.¹ This process often involves collaborations between researchers in academic institutions and stakeholders in underresourced communities. The collaborations can be mutually beneficial, promoting dissemination of effective practices from specialized centers into diverse practice settings while increasing researchers' awareness of community priorities and ability to address them. However, there are many potential pitfalls. Researchers may be unfamiliar with the cultural, ethnic, and linguistic background of community members, and naive about community needs, resources, and preferences.² Communities may face funding shortfalls and other challenges such as administrators reluctant to change the status quo, providers who have little training in research-based interventions and may have strong allegiances to

their current practices, families with limited means to identify and access services, and children whose needs differ from (and are more complex than) those of children already receiving appropriate services.³ For these reasons, efforts to improve services risk being ineffective or short-lived.⁴

The divide that commonly separates research from community practice has given rise to implementation science, which examines the best ways to implement interventions in which they will take place so that they are effective and sustained.^{5,6} One strategy that has been adopted by implementation scientists and may be especially useful in community pediatrics is community-partnered participatory research (CPPR).⁴ The guiding principle of CPPR is coequal partnership between academic researchers and community stakeholders in all phases of research development, implementation, and dissemination. This partnership is fostered by an infrastructure that brings researchers and community stakeholders together for shared decision making and

capacity building. The infrastructure usually includes a standing committee of researchers, influential community members, and those affected by implementation efforts, including administrators, practitioners, and families. Ideally, each committee member has an equal voice in providing information, making recommendations, and choosing next steps for the partnership.

We illustrate the process of CPPR by describing one project that involved a population with large discrepancies in access to services across income classes and racial/ethnic groups: children with autism spectrum disorder (ASD). Here we provide a rationale for focusing on this population, give an overview of the CPPR project, outline the steps in the project, and summarize findings thus far. Steps in the project included forming a partnership, gathering information on community needs, piloting an intervention, conducting randomized clinical trials (RCTs), and evaluating the sustainability of the intervention.

RATIONALE

ASD is a behaviorally defined disorder characterized by impaired social communication and interaction, as well as frequent or intense repetitive behaviors or routines, or circumscribed interests. It is estimated to occur in approximately 1 in 68 children.⁷ African American and Latino children with ASD receive diagnostic and ASD-specific treatment services much later than white, non-Latino children and long after child delays are noticed.^{8–10} Children in low-income or low-education families also have substantially reduced access to services.¹¹ African American and Latino families tend to perceive less need to obtain some services for their children with ASD than do white non-Latino families.¹²

Although ASD is a neurodevelopmental disorder of prenatal origin, the primary interventions currently are behavioral and educational.¹³ Many of these interventions have substantial empirical support, such as applied behavior analytic interventions for language, social skills, and problem behavior; developmental interventions for social communication and play; cognitive behavior therapy for social skills or for anxiety reduction; and parent training to enhance the child's communication or improve discipline.¹⁴ However, the interventions are difficult to implement effectively and sustainably in community practice because they are complicated to deliver, intensive, and expensive. For school-age children with ASD, public schools are usually the main service setting, and the largest school districts, especially those in major urban centers, predominately serve low-income and racial/ethnic minority children and tend to have limited capacity to deliver behavioral interventions as designed.¹³ Prior attempts to transfer behavioral treatments to urban public schools have failed to produce consistent implementation by teachers or clear benefits for students.¹⁵ Because interventions that originated in research centers have been difficult to implement in schools, we initiated a CPPR project to identify which interventions were most relevant to priorities identified by community stakeholders and how these inter-

ventions might be adapted for use in schools. Benchmarks for success included high teacher buy-in and fidelity of intervention, improvements in student outcomes that were emphasized by community stakeholders, and ongoing engagement of community partners (eg, interest in continuing the partnership beyond the current project).

OVERVIEW OF THE PROJECT

This CPPR project was conducted over a 4-year period (2011–2015) by the Autism Intervention Research Network on Behavioral Health (AIR-B) with funding from the US Health Resources and Services Administration. The project involved 3 universities (UCLA, University of Pennsylvania, and University of Rochester) and stakeholders from local school districts (Los Angeles Unified School District, School District of Philadelphia, and Rochester City School District). All 3 school districts were under tight budgetary constraints and received Title I funding from the federal government to improve performance of economically disadvantaged students. They enrolled students from mostly low-income families (>75% meeting federal criteria for free or reduced-price lunch in all districts) from traditionally underresourced racial and ethnic backgrounds (9% African American and 74% Latino in Los Angeles, 55% African American and 19% Latino in Philadelphia, 61% African American and 25% Latino in Rochester).¹⁶

The first year of the project was devoted to developing community partnerships with the school districts and community stakeholders at each site and to improving our understanding of how public schools currently serve students with ASD. The second year involved adapting interventions for the school setting, piloting one of the interventions, and initiating RCTs to evaluate the deployment of these interventions in schools. The RCTs continued into the third year. The funder extended the project for a fourth year, giving us a rare opportunity to examine whether teachers continued to use the interventions after the conclusion of the RCTs.

PARTNERSHIPS

Each of the 3 sites formed a partnership group to develop collaborative relationships, guide the project, and assist with logistics such as recruitment of teachers and children for the research. The researchers consulted with the school district superintendent or a designee to seek agreement to collaborate on the study and determine which school personnel to invite into the partnership. These procedures resulted in somewhat different compositions of partnership groups at each site: administrators and the study team in Los Angeles; administrators and clinicians who served students with ASD in Philadelphia, along with the study team; and administrators, an ASD specialist, a general education teacher, parents, and the study team in Rochester. One issue that arose in selecting partners was that school personnel and study team members were less likely to be from low-income or underresourced racial/ethnic groups than were the students and families served by the school districts.

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