PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.

Building a community partnership to meet the needs of parents of neurodivergent children

Elyse R. Park, PhD, MPH[1,2], Brett Goshe, PhD[1,2], Isabelle Miranda, BS, BA[1], Lucy Finkelstein-Fox, PhD[1,2], Pam Nourse, MBA[3], Renee Williams, MBA[3], Gabriella Nicolosi, BA[4], Karen Lopez, BA[3], Ruth de la Cruz, BA[3], Esteban Barreto, PhD[5], Rachel A. Millstein, PhD[2], Giselle K. Perez, Ph.D[1,2], Brittain Mahaffey, PhD[6], Carolina Abuelo, MD, MSc[2], Brian Winklosky, MA[7], Rosalie Rippey, MDiv[3], Karen A. Kuhlthau, PhD[2,8]

Affiliations:
[1]Mongan Institute, Massachusetts General Hospital, Boston, MA
[2]Harvard Medical School, Boston, MA
[3]Federation for Children with Special Needs, Boston, MA
[4]St. John's University, New York, NY
[5]Disparities Solution Center, Massachusetts General Hospital, Boston, MA
[6]Stony Brook Medicine, Stony Brook, NY
[7]Boston Children's Hospital, Boston, MA
[8]Department of Pediatrics, Massachusetts General Brigham, Boston, MA

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ABSTRACT

Background: Massachusetts General Hospital (MGH) and Federation for Children with Special Needs (Federation) staff partnered to conduct the Supporting Parents Raising Kids (SPARK) trial. SPARK compares a mind body intervention, Stress Management and Relaxation Training (SMART) Learning and Attentional Disabilities (LAD), and a comparison health promotion intervention, Health Enhancement Program (HEP), for parents of children with LAD.

Objectives: We describe how the partnership collaboratively adapted the proposed trial and treatments.

Methods: MGH and the Federation staff contributed professional and lived experience expertise of families of children with LAD. This was done through collaborative leadership, shared learning about institutional differences, listening sessions, treatment manual review sessions, and a shared decisions process.

Results: Bridging cultural differences and engaging in a shared decision-making process resulted in trial design and treatment adaptations that resulted in a successful collaboration.

Conclusions: Co-creation of a study requires commitment and partnership. Collaboratively developed trial improvements will strengthen community-based implementation of an open pilot trial and subsequent full trial.

KEYWORDS: Community health partnerships, Learning and attentional disabilities, Children, Health promotion, Community health research

INTRODUCTION

Parents, guardians, and caregivers of children with learning and attentional disabilities (LAD) face ongoing stressors that can negatively impact their emotional and physical health outcomes. Parents of children with LAD may experience more stress than those of neurotypical children, including heightened emotional distress that impacts the family, high rates of mental health disorders, and experiences of social isolation. Specifically, prior research found high levels of stress, related to issues such as navigating the educational and health systems, social isolation, familial concerns, and financial and professional sacrifices.[1,2,3] Parents' ability to engage in self-care may be limited due to time spent caring for familial needs and managing children' appointments, as well as a dearth of supportive resources to help parents manage their own stress.[4,5,6] Additionally, levels of stress among parents of young children are higher among Latino parents compared to white parents.[7]

Parental stress, particularly for parents of children with LAD, has been linked to emotional and physical exhaustion, social isolation, maladaptive parenting practices, and strained familial relationships, which can directly impact the child's wellbeing.[4,5,8,9,10] Short-term interventions have been beneficial to help parents manage stress[11] including interventions for Spanish speaking parents,[12] but there is a need for more programs and long-term follow up to support parents in their resiliency and stress-management.[13]

Accessible remote resiliency and stress-coping interventions have the potential to be an important resource for these vulnerable parents.[14] As such, researchers at Massachusetts General Hospital (MGH), based in Psychiatry, Pediatrics, and Medicine partnered with staff from the Massachusetts-based Federation for Children with Special Needs (the Federation) and the Health Promotion and Resiliency Intervention Research (HPRIR) Center to learn how to adapt a mind-body stress-management and resiliency intervention for English and Spanish speaking parents and guardians (hereafter we will use the term parent for brevity) of children with LAD. The Federation is the leading parent organization in Massachusetts, providing support through the Parent-to-Parent program among other services for children with special health care needs. The Federation network reaches a representative sample of parents due to their community connections, including BIPOC (Black, Indigenous, and People of Color), Latinx, low-income, rural, and parents from other underserved groups. The Stress Management and Relaxation Training-Relaxation Response Resiliency Program (SMART-3RP), originally developed by Dr. Park and colleagues, is an eight session program that was adapted in 2017 to specifically meet the needs for parents of children with LAD (SMART-LAD).[15,16] A pilot waitlist-control trial demonstrated the feasibility, acceptability, and preliminary efficacy of SMART-LAD for improving parents' distress, resiliency, and stress coping.[16,17]

Building upon this promising pilot trial, essential next steps for this work include refining the intervention, based on lessons learned from the original pilot trial, as well as adapting program content for a post-pandemic environment, developing a linguistically and culturally-appropriate version of the SMART-LAD protocol for Spanish-speaking parents, and, similarly, adapting a health education program, the Health Enhancement Program (HEP).[18,19,20] HEP is a manualized eight-session health behavior change program, specifically designed to match the health education, but not mind-body, content delivered in other mind-body programs.[5,15,16,17]

Toward these goals, MGH and the Federation staff partnered to modify the intervention for English and Spanish speaking parents of children with LAD and address issues raised in the first pilot study. The Supporting Parents Raising Kids (SPARK) trial was thus initiated to compare the adapted SMART-LAD and HEP.[18,19,20] This manuscript describes lessons learned in the formation of the SPARK team partnership during the initial qualitative phase of the SPARK trial (Phase 1). During this initial phase, the study team developed initial frameworks for cross-site collaboration and collected key feedback about program adaptation for Spanish-speaking participants, parents from the Federation staff, and parents of children with LAD in the community.

OBJECTIVES

Specific objectives of this paper are to describe: 1) methods and challenges in start-up, recruitment, bridging institutional differences, and identifying the target population; 2) the process of harmonizing team input from academic and community partners and parents of children with LAD; and 3) study design decisions for the two-treatment program (i.e., SMART-LAD and HEP) manual modifications in English and Spanish.

METHODS

Start Up -- Description of Partnership and Roles

Initially, the MGH investigative team worked with the Federation Executive Director and the Associate Executive Director to conceptualize the project and co-develop the study proposal for federal funding. Once funded, and at the start of Phase 1 (the qualitative intervention and study adaptation phase described here), additional staff joined the MGH research team -- including bilingual qualitative experts and clinical interventionists -- and the Federation team --

including leadership staff and staff that worked directly on programs that served Spanish-speaking families.

In addition to co-designing the study logistics with the MGH team, the Federation staff contributed professional and lived experience expertise of the needs of families of children with LAD. Through weekly meetings they helped refine the interview protocol, recruited individuals for qualitative interviews, reviewed findings from the interviews and helped modify the planned intervention. An overview of the Federation's role as lead community-based partner is summarized in Table 1. As lead academic partner, MGH staff oversaw regulatory aspects of the project, conducted participant interviews, performed data analysis, and integrated qualitative feedback to make changes to the SMART-LAD and HEP intervention manuals. The Federation shaped the study design and intervention to fit the community's perspectives and oversaw enrollment and retention.

Details of MGH-Federation Collaboration

A detailed description of the MGH-Federation collaboration on study formation, regulatory approval, data collection, and intervention refinement is below. Overall, the MGH-Federation SPARK team worked together to assure that the study was optimized to meet the needs of families of children with LAD as well as maintaining scientific and regulatory excellence.

Formation of Partnership and Overview

From September 2023 to May 2024 the MGH and Federation teams met 22 times to establish the study name and design, protocolize outreach and enrollment strategy, and iterate the treatment modification process. To gather feedback about necessary refinements to the SMART-

LAD and HEP intervention manuals, the team hosted 7 parent listening sessions (4 English, 3 Spanish), 1 full Federation staff listening session, and 8 Federation staff manual review sessions. Rapid thematic analysis was applied to notes from team meetings and sessions with parents in English and Spanish.MGH obtained IRB approval and established a single IRB agreement to allow Federation staff to participate in human subjects research***. Kickoff and Initial MGH-Federation Study Development Meetings***

Intervention refinement.

Federation and MGH staff collaboratively reviewed and revised the SMART-LAD and HEP manuals through a series of structured feedback sessions, with edits informed by rapid qualitative analysis (see rapid analysis below)[19].

Study Branding. During smaller weekly team meetings, the MGH and Federation teams brainstormed study names and acronyms. Given the study's focus on expanding services to meet the needs of Spanish-speaking parents, it was imperative that the study name would translate to Spanish. Ultimately, the team chose the name "Supporting Parents Raising Kids (SPARK)," or "CHISPA" in Spanish. After selecting the study name, they co-created a study logo. **Eligibility and Recruitment Design.**

Based on feedback from Federation staff members and parents (Table 2), the team collaboratively established study eligibility criteria as "parents/caregivers of children with learning and attentional difficulties" (recognizing cultural variation in family structure and caregiving norms) and used the wording "neurodiverse" to acknowledge concerns about ableism and creating a shared understanding of the eligible population. In addition, the SPARK team worked together on recruitment strategies. One challenge included consistently using the same definition of the eligible population; therefore, a one page reference guide helped support messaging across the team.

Sociodemographics (Table 3)

In the full sample, participants were predominantly female (97.3%) and average age 46 years. The majority were white (69.0%) but the sample had substantial racial and ethnic diversity, with 10.3% identifying as Black or African American, and 24.1% reporting Hispanic/Latino ethnicity. Many participants had completed college or graduate work (75.9%), were employed full-time (51.7%), and held either private (69.9%) or Medicaid/Mass Health (31.0%) insurance coverage. See Table 3 for a breakdown of sociodemographic characteristics between parents and providers.

Conducting Listening Sessions for Parents of Children with LAD

Concurrent with the MGH-Federation manual review sessions described above, listening sessions were intended to elicit feedback on the SMART-LAD and HEP program manuals from individuals with lived experience supporting children with LAD. Participants in these listening sessions included: 1) Federation clients who are parents of children with LAD (7 listening sessions) and 2) Federation staff members, many of whom are parents themselves, who provide services to families of children with LAD as part of their professional role (1 listening session).

Recruitment. Federation staff recruited participants through word of mouth, conferences, email listserves, newsletter and their social media postings. Federation staff also recruited via direct outreach to known members and connections within the Federation community. Recruitment challenges, including fraudulent responses (e.g., individuals who did not have a child with LAD), were addressed through targeted outreach and improved participant screening."

Data collection. Group sessions included between 2 to 9 participants each, with 4 English-speaking parent groups, 3 Spanish-speaking parent groups, and 1 Federation staff group. There were 28 women parents (21 English speaking; 7 Spanish speaking) in 7 listening sessions. The professional group had 9 participants (1 male) and were also all parents, see Table 3 for sociodemographic information. Listening sessions lasted approximately 60 minutes. Participants were compensated with a $50 gift card. A semi-structured interview guide, developed during weekly MGH-Federation study meetings, was used to frame the conversation, see Table 2 for a list of domains covered. Listening sessions were recorded and transcribed. The MGH team used rapid analysis to identify recommendations for intervention modifications.[21]

LESSONS LEARNED

Methods and challenges in start-up and recruitment

Overcoming recruitment challenges when faced with likely fraudulent inquiries required a deeper understanding of the Federation programs by the MGH staff and of implementing guardrails around recruitment and consent while adhering to the language in the approved IRB protocol.

Bridging cultures and overcoming institutional barriers

As is common with new academic-community collaborations, specific growth opportunities arose in start-up and recruitment, such as bridging institutional cultural differences and identifying the target population. Identifying consistent meeting times and explicit delineation of team roles (e.g., identifying project “champions” who would lead specific initiatives), proved essential for building a cohesive team. Time spent communicating both work cultures and building a coherent team yielded positive results.

Identifying the target population

The target population was identified with input from the Federation on community need for this intervention as well as the MGH members' prior research studies.

Harmonizing team input

Shared decision-making is essential to intervention improvements and research processes. The project included several perspectives: a community-based organization and an academic medical center; service providers and researchers; and Spanish and English treatment development. In modifying both intervention arms and refining research procedures, careful listening and learning resulted in an improved SPARK study. For example, our study title, SPARK works well in both English and Spanish and does not overlap with any relevant existing programs or studies at the institutions.

The perspectives of the parent focus groups compared to the staff focus groups differed slightly and provide valuable input for planned changes. Parents sessions (SMART and HEP) focused on practical tools for stress relief, simplified language, culturally relevant visuals, and flexible group material formats (e.g., manual PDFs and mindfulness audio recordings). Parents emphasized emotional support and accessibility, especially around sensitive topics. Staff, meanwhile, highlighted systemic barriers such as advocacy fatigue and lack of school support, recommending resources that help parents model behavior and navigate institutions. While both groups valued inclusivity and relatable group facilitators, parents prioritized immediate coping strategies, and staff leaned toward structural improvements.

The English-speaking groups emphasized mental health challenges, time constraints, and the need for clearer communication about available resources, while the Spanish-speaking groups focused more on language barriers, trust-building, and culturally relevant outreach. Both groups expressed a desire for more accessible programming and stronger community engagement, but their specific concerns reflected distinct cultural and logistical realities. Notably, the English-speaking participants tended to suggest digital solutions, whereas the Spanish-speaking participants leaned toward in-person support and relationship-based approaches.

Study design modifications

Shared endorsement of the intervention modifications is critical to its feasibility and acceptability. By including formal listening sessions with parents and service providers, as originally proposed in the funded grant, as well as additional sessions to incorporate Federation staff input, this project resulted in several meaningful enhancements to the SMART-LAD and HEP interventions. Major changes to the intervention protocols (Table 2) included: 1) agreement that the 8-session programs would be shortened from 1.5 hours to 1 hour per session to accommodate busy parent schedules, 2) reliance on virtual delivery to reduce timing and transportation-related barriers to attendance, 3) refinement of in-session exercises which focused on managing common stressors specific to LAD parents, 4) simplification of language for both English- and Spanish-language manuals, and 5) diversification of illustrations of multiple family types (e.g., grandparent as primary caregiver, same-sex parent teams), races, and ethnicities. Additionally, we developed a resource list of Federation-sponsored programs to address concerns that parents shared regarding their children's well-being (e.g., how to have conversations with teachers and medical professionals, nutrition, exercise), to address parents' desire for structured problem-solving tools as well as the self-focused stress-management skills that the SMART-LAD and HEP programs traditionally emphasize. These changes were only possible because of the collaborative work of the collective SPARK team and a deep commitment to parents of children with LAD and the importance of effective resiliency interventions.

CONCLUSIONS

Conducting research with community partners can be challenging due to academic regulatory barriers and structural differences in work norms. These can be overcome through ongoing meetings with a collaborative spirit and structure, including team members with varied experiences/specialties, as well as clear delineation of team priorities and roles. Co-creation of a study and treatment design requires commitment and partnership. The study was refined to improve recruitment strategies, bridge institutional cultural differences, and edit the program content to fit the parents' needs. The feedback from the parent and staff groups reinforced and informed the manual content in terms of 1) context and examples for coping strategies and 2) provision of resources to address systems-based and structural barriers frequently encountered by parents of children with LAD. In particular, feedback from the Spanish speaking listening sessions, which highlighted trust and relationship building, was emphasized in the adapted manual sessions. Feedback obtained also influenced the acceptability questions to be used in the pilot groups, specifically the group logistics and, in particular, group trust, as well as psychological and physical measures.

his strengthens the team's ability to conduct an open pilot in the next phase of the trial. These changes are important groundwork for widespread community-based implementation in the future.[22,23,24,25]

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Table 1: Study Phase and Engagement Activities

Phase	Massachusetts General Hospital Role	**Federation Engagement**
Study Grant Proposal	- Grant writing inclusive of initial plan for intervention arms and study methods - Co-wrote engagement sections - Reviewed sections about the Federation	- Reviewed grant documents - Co-wrote engagement sections - Wrote sections about the Federation
Phase 1	- Start Up - Weekly meetings - Co-developed intervention protocol, eligibility criteria, recruitment plan, study name - IRB submission and approval - Qualitative inquiry - Intervention and study adaptations	- Study kickoff - Weekly meetings - Manual review with Federation staff - Co-developed intervention protocol, eligibility criteria, recruitment plan, study name - IRB submission and approval - 7 Listening sessions for content feedback (4 in English and 3 in Spanish) - Review of listening session findings and suggested modifications

Table 2: Listening Session Findings and Planned Changes to Intervention

Domain	**Specific changes/endorsements**
Program Length and Delivery	- Shortened from 90 minutes to 60 minutes/session, keep 8 sessions - Continue to use virtual delivery to accommodate busy schedules
Intervention Plan and Manuals	- In-session exercises targeted to resolving common concerns for parents of children with LAD - Simplifying language to work for both English and Spanish speaking families - Modify images and examples to reflect diversity in race/ethnicity, gender, and family make up
Resources	- Developed a resource list of Federation programs for identified needs to keep the focus on parents

Table 3: Sociodemographic Information

Table 3			
Participant Sociodemographic Characteristics	**Total N=29 (%)**	**Providers n=9 (%)**	**Parents n=20 (%)**
Age	M=46.4	M=52.8	M=43.4
Sex			
Women	28 (96.6)	9 (100.0)	19 (95.0)
Men	0 (0.0)	0 (0.0)	0 (0.0)
Race			
Black or African American	3 (10.3)	1 (11.1)	2 (10.0)
White	20 (69.0)	7 (77.8)	13 (65.0)
Prefer not to answer	4 (13.8)	1 (11.1)	3 (15.0)
Hispanic/Latino	7 (24.1)	1 (11.1)	6 (30.0)
Education			
Less than high school graduate	0 (0.0)	0 (0.0)	(0.0)
High school diploma	1 (3.4)	0 (0.0)	1 (5.0)
Some college	5 (17.2)	1 (11.1)	4 (20.0)
College degree+	22 (75.9)	8 (88.9)	14 (70.0)
Employment			
Employed full-time	15 (51.7)	4 (44.4)	9 (45.0)
Employed part-time	8 (27.6)	5 (55.6)	3 (15.0)
Student	0 (0.0)	0 (0.0)	0 (0.0)
Unemployed	2 (6.9)	0 (0.0)	2 (10.0)
Other	3 (10.3)	0 (0.0)	3 (15.0)
Marital status			
Married	18 (62.1)	6 (66.7)	12 (60.0)
Single/never married	4 (13.8)	0 (0.0)	4 (20.0)
Widowed	0 (0.0)	0 (0.0)	0 (0.0)
Divorced/separated	6 (20.7)	3 (33.3)	3 (15.0)
Insurance			
Private health insurance	20 (69.9)	9 (100.0)	11 (55.0)
Medicare	0 (0.0)	0 (0.0)	0 (0.0)
Medicaid/Mass Health	9 (31.0)	1 (11.1)	8 (40.0)
Prefer not to answer	0 (0.0)	0 (0.0)	0 (0.0)

*Data may not add up to 100% due to missing responses or participants selecting multiple answers.