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## Community-Based, Caregiver-Implemented Early Language Intervention in High-Risk Families: Lessons Learned

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### Abstract

**Background:** High-quality, early caregiver-child interaction facilitates language, cognitive, and health outcomes. Children in low socioeconomic status households experience less frequent and lower-quality language interactions on average than their middle to high socioeconomic status peers. Early caregiver-implemented intervention may help to improve outcomes for these children.

**Objectives:** This article describes how we used community-based participatory research (CBPR) to develop and implement a community-based, caregiver-implemented early language intervention, including the challenges, solutions, and lessons learned in the process of CBPR.

**Methods:** We adopted an ethnographic approach to document and analyze our CBPR experiences in multiple phases of the project, including intervention design, training, implementation, and evaluation.

**Lessons Learned:** Developing the CBPR partnership, co-designing and implementing the study, and managing systems-level concerns like obtaining funding were central challenges for the researcher–community team.

**Conclusions:** The CBPR model enhances early language intervention research by facilitating understanding of families in underserved communities and increasing the cultural relevancy of intervention materials.

### Keywords

Community-based participatory research, early language intervention, caregiver-implemented intervention, at-risk community, language development

Frequent, high-quality early interaction is critical for language development and later academic, social, and health outcomes.<sup>1–8</sup> The frequency and nature of early language interactions can be influenced by a variety of environmental and developmental factors. Here we focus on children who are at risk for language delays due to low socioeconomic status. Approximately 21% of U.S. children live in poverty.<sup>9</sup> Despite the large intra-group variability,<sup>1,10</sup> children in poverty tend to have fewer and less rich early language experiences.<sup>5,6,11</sup> Differences in early language skills

can manifest as long-term achievement gaps.<sup>12</sup> Improving child outcomes by supporting high-quality early language interaction represents a public health need.

Caregiver-implemented early language intervention is an evidence-based approach for supporting language development.<sup>11,12</sup> Designing and implementing effective interventions is challenging, particularly with underserved or high-risk populations. The families with the greatest need for services are often the hardest to reach.<sup>13,14</sup> Furthermore, there is a need for balance between efficiency and individualization;

interventions must be scalable, but also individualizable for diverse families.<sup>15</sup> Although many early language interventions support short-term gains, the long-term effects are relatively small.<sup>16</sup> Long-lasting improvements require the maintenance of gains over time.

We adopted CBPR as an innovative model to address these challenges. CBPR is defined as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings.”<sup>17</sup> Involvement of the research team and community members in the design, implementation, and dissemination of the research is crucial to CBPR. The CBPR model has been frequently used in areas of public health research like smoking cessation,<sup>18</sup> obesity/diabetes prevention,<sup>19</sup> and HIV prevention.<sup>20</sup> However, CBPR is an underused model within early language intervention, with only a few studies using this approach to enhance early communication and children’s language outcomes.<sup>21–23</sup>

This article describes how we used CBPR to design and implement a community-based, caregiver-implemented early language intervention for children—The Duet Project. We chose to use the CBPR approach to facilitate family engagement in the hard-to-reach community and increase the ecological validity, effectiveness, and sustainability of the intervention. Through Duet, we learned about establishing a partnership, balancing the needs of research and community members, finding well-suited funding mechanisms, and negotiating the institutional review board (IRB) approval process. We detail the challenges, solutions, and lessons learned in the process of CBPR. In particular, we focus on three phases of The Duet Project: 1) intervention design, 2) advocate training, and 3) implementation and evaluation.

## METHODS

The research team developed and piloted an early language intervention for primary caregivers and their 12- to 24-month-old children, in collaboration with a community partner, the Maternity Care Coalition (MCC). The MCC provides home-visiting services for pregnant women and mothers with children under 3 years of age. The intervention was implemented by MCC home visitors, called “advocates,” working with families enrolled in Healthy Start, Early Head Start, or Healthy Families America programs. All participating

families fell below 200% of the federal poverty line, and many of them faced a variety of other challenges, such as unemployment, overcrowded households, and lack of access to childcare. Although there were individual differences, as a whole these families faced many barriers to frequent, high-quality early language interaction. The majority of the caregivers had high school or lower educational level (51%), and self-identified as African American (41%) or non-White Hispanic (46%). Approximately 69% of the caregivers spoke English at home, 23% spoke Spanish, and the rest spoke both English and Spanish. All families received regular MCC services in English, although most advocates working with Spanish-speaking families were bilingual. This research was approved by the Temple University IRB.

## Intervention Design

The intervention design was iterative and collaborative—providing multiple opportunities for community partners to give feedback throughout the process.<sup>24–26</sup> First, the research team conducted an extensive review of existing early language interventions. We incorporated some of the strengths of existing programs into our intervention design including regular home visits (e.g., Nurse–Family Partnership,<sup>27</sup> Parents as Teachers<sup>28</sup>), video models (e.g., Video Interaction Program<sup>29</sup>), content related to the quantity and quality of language input (e.g., Providence Talks,<sup>30</sup> Thirty Million Words Initiative,<sup>31</sup> Play and Learning Strategies intervention<sup>32</sup>), information to increase parental knowledge (e.g., VROOM<sup>33</sup>), and examples of language stimulation situated in everyday activities (e.g., Talking is Teaching: Talk, Read, Sing<sup>34</sup>). However, we also realized that no existing program met all of the needs of our target population. For instance, Duet needed to align with MCC families’ cultural beliefs, priorities, practices, and schedules (e.g., familiar routines, culturally relevant wording). Duet also moved beyond the existing programs by facilitating the back-and-forth interactions between caregivers and children—setting the communication foundation for language development.<sup>1</sup> Together, the joint team of researchers and community partners designed Duet by incorporating the most up-to-date developmental science and the specific needs of our community.

Next, we evaluated MCC’s existing services and programming to determine if and how much of the content supported early language skills. The research team conducted a systematic

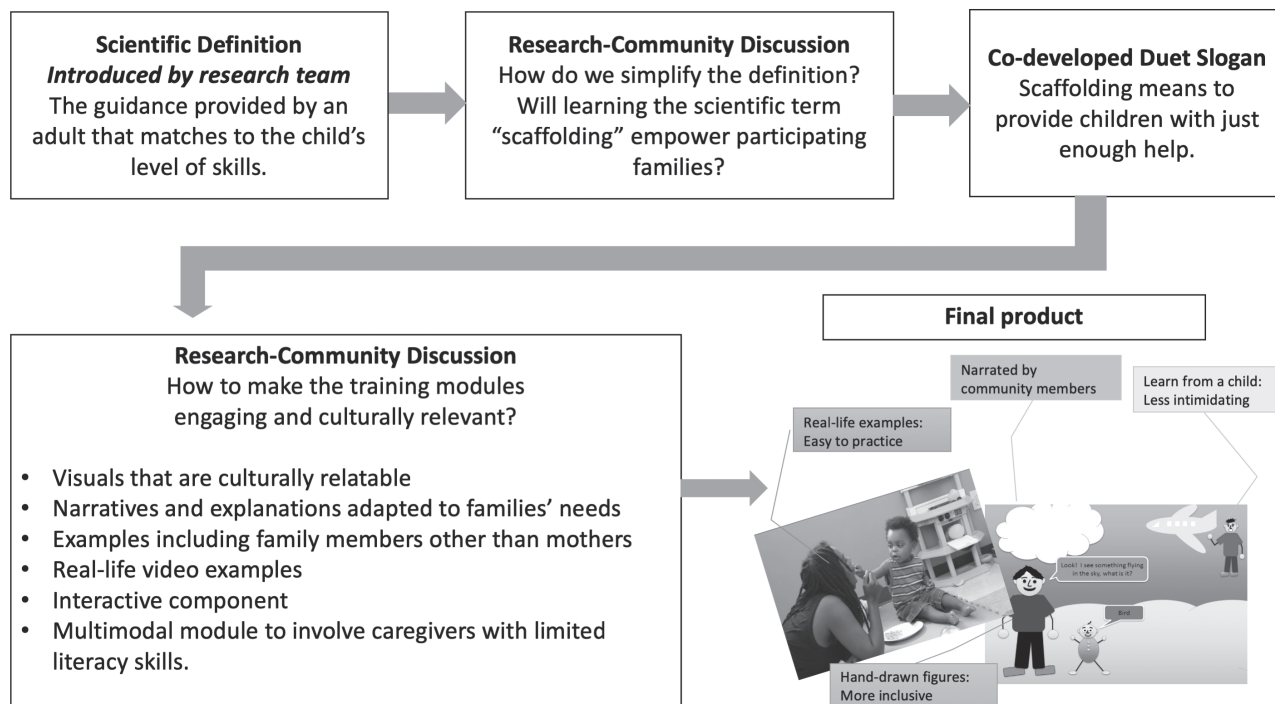
program review by observing home-visiting sessions, examining MCC curricula, and interviewing MCC staff. Ultimately, the research team and community partners agreed that although the curricula varied across different programs, MCC's strengths lay in health and safety-related topics like breast feeding and child abuse prevention. However, there was a need for programming to support early language and communication.

Based on the literature and a program review, the research team worked closely with MCC partners to establish intervention goals. Together, the joint team identified four measurable objectives that addressed the needs of both researchers and the community: 1) increase knowledge of language development, 2) empower caregivers as communication partners for their children, 3) enhance the quality and quantity of early language interactions, and 4) improve child language outcomes.

We developed five evidence-based principles to target these objectives. The first principle, general awareness,

emphasized that knowledge of child development supports high-quality communication interaction.<sup>11,35</sup> The second principle, creating opportunities, highlighted that meaningful communication interaction can take place anywhere and any time—not just during play and reading.<sup>36</sup> The third principle, conversational duets, described that rhythmic and reciprocal early language interaction supports child language development.<sup>1,8</sup> The fourth principle, scaffolding, underscored the importance of providing just enough support to help children succeed.<sup>37</sup> Finally, harmonizing detailed how all of these principles could be combined.

A digital training module was designed to showcase each principle and its accompanying strategies that translate the principle into practice. The modules incorporated real-life and animated examples, interactive scenarios, and built-in stopping points for discussion (Figure 1). The advocates showed the modules to the caregivers during home visits.



**Figure 1. An illustration of the process of co-developing a multi-media training module: Scaffolding.** Several features make the Duet training modules unique. These modules: 1) are informative, engaging and enjoyable. A child offers the narration and describes the interactions between family members, making the training more fun and less intimidating; 2) are culturally appropriate, as they are narrated by community members and presented by stick figure characters; 3) integrate behavioral strategies and real-life examples recorded with community members, allowing participants to translate their new knowledge into daily practices; and 4) are interactive. Built-in stopping points and interactive questions allows participants to discuss the modules with the advocates.

The intervention sessions included opportunities for real-life practice of the target strategies with video feedback.

### Advocate Training

Advocate training was critical to Duet's success. Our program review revealed that advocates' existing knowledge and experience varied greatly. Thus, we needed to ensure that all advocates had the foundational knowledge and skills to maintain intervention fidelity. We minimized the didactic instruction and maximized active participation with practice and individualized feedback.<sup>38</sup> All training sessions were facilitated jointly by researchers and community partners.

During training sessions, advocates reviewed the modules, created prompts to engage caregivers with the materials, and role-played their interactions with families. Additionally, the advocates were trained to provide strengths-based feedback on caregiver-child interaction. Specifically, caregivers were filmed practicing the target strategies with their child and then watched the videos with the advocates. Feedback focused on what went well and opportunities for continued improvement. The advocates also learned to use motivational interviewing tools when setting goals with caregivers.<sup>39</sup>

### Implementation and Evaluation

Advocates providing home-visiting services to families with 12- to 24-month-old children were randomly assigned to either the intervention group ( $n = 7$  advocates, 18 families) or a comparison group ( $n = 11$  advocates, 23 families). Advocates in the intervention group delivered Duet to their eligible clients; advocates in the comparison group continued their business-as-usual services with their clients. Randomization was conducted at the level of advocates, because reassigning advocates to different families was not feasible in MCC's service delivery model. Furthermore, asking advocates to deliver Duet only to some of their clients might have introduced confounders. Duet was designed to be delivered in 6 biweekly, hour-long sessions. Before and after the intervention, the research team assessed children's language and cognitive skills, the quality and quantity of caregiver-child interactions, as well as caregiver and advocate knowledge of early language development. The results and evaluation of the program will be described in another article.

### Documenting CBPR Experiences

We adopted an ethnographic approach (i.e., participant observation) to document and analyze our CBPR experiences. This approach allows researchers and community partners to participate in the collaborative process, observe one another, and self-reflect about beliefs, behaviors, and changes. This approach provides an in-depth understanding of the CBPR process—particularly regarding identifying challenges and solutions at the beginning of a project. Specifically, we took field notes during each team meeting, gathered feedback from MCC advocates through focus group and one-on-one debriefing sessions between the MCC research director and individual advocates, and openly discussed the strengths and challenges of our CBPR experiences as a joint team. We also interviewed participating families on their satisfaction of the intervention.

### LESSONS LEARNED

#### Developing the Collaboration

An essential component of CBPR is establishing and maintaining the researcher-community connection.<sup>25</sup> CBPR often takes place in at-risk neighborhoods and communities to reach people with the greatest needs. Although most researchers have good intentions—and are bound by ethical guidelines—there is often wariness or mistrust of research in historically marginalized communities.<sup>40</sup> This wariness may stem in part from lack of familiarity with the research system (e.g., privacy, confidentiality, informed consent), previous negative experiences, or both. Researchers need to devote time and resources to establishing trusting partnerships. Trust is built in part by maintaining open, frequent, and bidirectional communication.<sup>25</sup> We used several approaches to establish trust and communication between the research team and community partners. Based on our experiences we present suggestions for the future.

*Building a Team.* It is imperative to build a CBPR team that includes researchers and community partners with diverse roles, backgrounds, and perspectives.<sup>41</sup> The Duet team included directors, supervisors, and advocates from MCC, as well as professors, postdoctoral fellows, graduate students, and a project coordinator from the research side. Each team member contributes uniquely to the project. For instance, the

Duet researchers helped to ensure scientific rigor, whereas the advocates provided invaluable insights about their day-to-day interactions with families.

Additionally, it is critical to have a team member with whom both the research team and the community partners feel comfortable expressing their needs and concerns. This bridge person must have a deep knowledge in both research and the community and is willing to help facilitate a trusting CBPR partnership. In The Duet Project, the senior director of research (hereafter research director) at MCC served as the bridge person. Her training as a researcher, including a Ph.D. in social science, plus more than 10 years of community experience enabled her to relate to all members of the joint team. Specifically, she facilitated understanding and shared participation amongst the members of the joint team—including researchers, advocates, and families. For instance, the research director ensured that the MCC advocates' concerns about random assignment (see *Balancing Rigor and Reality* for details) were understood and considered by the researchers.

*Creating a Shared Language.* A critical step in building the relationship involved developing a shared language. The diverse backgrounds of the Duet team presented strengths and challenges in developing a shared understanding. What does “scaffolding” mean in developmental psychology? Why are people assigned randomly to groups in intervention research? What do advocates do in a home-visiting program? What strategies and language do MCC staff use when interacting with MCC families? Understanding the language and concepts used was critical to establishing effective, clear communication.

*Maintaining Trust and Communication.* Relationship building is a continuous component rather than a temporary stage of a CBPR project.<sup>26</sup> Maintaining trust and communication takes diligent effort by all involved. The research team spent over six months designing the intervention with MCC partners, mostly program directors, and developed a strong relationship with them. However, when the research team started training MCC advocates—who were new to Duet—we learned that the trust between the research team and MCC leaders did not transfer automatically. For instance, even though we co-developed the intervention goals and principles through research–community partnership, the advocates were not aware of the collaborative process and did not have much influence over the intervention design

in the planning phase. Thus, the advocates still viewed the researchers as outsiders who wanted to pour their knowledge into the community. To address the advocates' concerns, the research team worked with MCC leaders to introduce our collaborative journey, show the researchers' efforts to learn about the community, and make the advocates feel part of the team. One lesson we learned from this was to plan more time for relationship building. Furthermore, we learned to approach each new group of MCC partners (or researchers) with the mindset of building new relationships as opposed to relying on existing goodwill.

### Collaborative Study Design and Development

*Evidence-Based, Culturally Sensitive Materials.* The influence of the CBPR model on Duet was visible in all materials and procedures. The cultural relevance of an early intervention is essential to its success.<sup>15</sup> Tailoring interventions to the individual needs of the target population improves participation, compliance, and outcomes.<sup>42–44</sup> Even the strongest scientific evidence is only powerful when it is delivered in a meaningful and accessible way. The expertise of the research team and community partners was necessary to develop evidence-based, culturally sensitive materials. Each Duet module was built around solid scientific evidence, but the wording choices, imagery, and examples were molded to the community. Figure 1 shows how the CBPR model informed the iterative development of the scaffolding module. This process included developing a shared understanding of the concept, creating the take-home message, and designing a module that accurately conveyed the target content. The community partners provided line-by-line feedback on the script for each module—focusing on making the modules relatable to families. The community partners also suggested changing the characters' voice to ensure that it matches the dialect used in the community. To do so, members of the community and research team voiced the characters in the modules. The stick-figure characters with non-human skin colors were designed for maximal inclusivity. We also integrated real-life video from MCC families to increase the relatability of the modules.

*Balancing Rigor and Reality.* Another challenge when translating basic science into practice is balancing experimental rigor with real-life needs and priorities.<sup>45</sup> A well-controlled experimental design allows researchers to make causal inferences, yet

might not be feasible or optimal in the real world. The trade-off between internal and ecological validity in CBPR can cause conflicts between researchers and community partners. We present two examples of such conflicts and discuss what we have learned from the process of negotiation and compromise.

*Random assignment.* Randomly assigning advocates and their associated families to treatment and comparison groups was critical to managing variability and demonstrating intervention effectiveness. However, randomization was concerning for the community partners, who were eager to provide the Duet training to all families. Furthermore, the community partners were concerned that families and advocates in the comparison group would feel excluded and therefore less invested in the study. To address these concerns, we initially randomly assigned advocates and their clients to the intervention and business-as-usual groups, but at the end of the study we gave everyone access to the intervention materials.

*Intervention implementation and evaluation.* After addressing the concerns about randomization, we moved on to intervention implementation. Community-based research introduces many more uncontrolled variables than laboratory research. The priorities of the community members—like concerns about housing and food—frequently took precedence over the completion of research tasks. The same reasons that initially motivated our work in the community—like the ability to reach and serve underserved, high-need families—presented implementation challenges. It was particularly difficult to schedule and complete visits with the participants, who frequently canceled or were not present upon arrival. Coordinating and completing baseline and follow-up data collection required flexibility and persistence. Therefore, Duet data collection was streamlined to gather all of the necessary information, while minimizing the burden on the community partners and participants. Intervention sessions were designed to accompany existing home-visiting services. Research assistants were responsible for data collection, but the advocates helped to build rapport and maintain contact with families. Nonetheless, coordinating and facilitating data collection still required extra efforts from the advocates.

### Systems-Level Challenges

Balancing scientific needs with community priorities in CBPR also generates systems-level challenges like obtaining

funding and navigating the IRB.<sup>46</sup> The traditional research infrastructure may not meet the needs of the community partners. For instance, the intensive, hours-long Collaborative Institutional Training Initiative program required by the IRB may not fit into community partners' busy schedules. Thus, creativity and adaptation are critical to CBPR success.

*Funding.* CBPR requires unique capacities, time, and resources, which are often underestimated by researchers, community partners, and funding agencies. For instance, we learned that having a project coordinator who could spend time at the university and at the community sites would have facilitated communication between the partners. Furthermore, the amount of time spent by the Duet team vastly exceeded the effort funded by the grant budget. In an academic climate where effort is such an important metric of productivity, it is critical to build in the appropriate amount of support for CBPR projects. CBPR projects—particularly those focused on at-risk communities—may be more expensive than traditional research of a similar sample size. It is also important to recognize and compensate the often unseen work done by the community partners. Establishing and maintaining the existing relationship between the community partners and the target population requires enormous time, effort, and resources, especially when there is an add-on research project. Thus, it is incumbent upon the research team to identify funders who can support these projects and to illustrate the benefits of CBPR despite the increased cost. These needs may not be met entirely through one funder. The Duet Project was co-funded by several agencies, yet was still underfunded.

*IRB.* Human subjects protections are critical to CBPR, particularly in vulnerable communities. Although IRB regulations serve to protect human subjects, the language and procedures are often inflexible and not aligned with the CBPR spirit. Here we discuss how these challenges were manifest in Duet during the consent process as the research team and community partners negotiated the roles of the MCC advocates.

The official, mandatory language in IRB-approved consent documents was unfamiliar—and at times offensive—to the community partners. We worked as a team to adapt the IRB materials as much as possible within the narrow allowable range. However, given the limitations, the final version was reluctantly accepted by the community partners. Furthermore,

there were complications surrounding the process of informed consent. The MCC advocates would ideally have had three roles in Duet: 1) as researchers who consented and collected data from families, 2) as MCC staff and Duet team members who delivered the intervention, and 3) as participants who provided data on advocate training effectiveness. However, the IRB regulations prohibited the first role. The Collaborative Institutional Training Initiative training—required for all team members to consent participants, collect data, and conduct analyses—was too big of a burden to place on the advocates' time. Thus, we trained research assistants to consent participants and collect data, but had the advocates present for the comfort of the families. Although this had some advantages for preventing tester bias, the inability to include the advocates fully as researchers undermined their sense of ownership in the project.

CBPR aims to minimize the cognitive distance between researchers and community partners. However, the IRB procedures and documentation explicitly separate “researchers” and “human subjects.”<sup>46</sup> This wording caused confusion regarding the advocates' roles and was contrary to the spirit of CBPR. We learned that the research team needs to carefully prepare community partners for the challenges and limitations of the IRB process. In the future there needs to be a less burdensome way to include community partners as both researchers and participants. This will involve working alongside the IRB to modify the consent and Collaborative Institutional Training Initiative training process so that it is more accessible to community partners. Some strategies include 1) establishing a relationship with IRB staff and helping them to understand the principles of CBPR, 2) connecting IRB staff with community partners, 3) involving community representatives and researchers familiar with CBPR on the IRB committee, and 4) creating sample consent forms, protocols, and other IRB documents geared towards CBPR research.<sup>46–49</sup>

## CONCLUSIONS

Our experiences demonstrate that the CBPR model can facilitate early language intervention research in underserved communities in unique ways that traditional research approaches often cannot. Yet, benefits come with challenges that require effective strategies and joint effort of the team.

First, CBPR strengthens community–research collaborations and yields a rich understanding of children and families in hard-to-reach communities. However, the long, iterative process of CBPR, and the mistrust of research by community members, can be challenging. Strategies for meeting these challenges include building a diverse team, identifying bridge personnel to establish trust, devoting time and energy to each new relationship, and maintaining effective communication at all levels.

Second, CBPR increases the cultural relevancy and ecological validity of intervention design and materials. Yet, the trade-off between scientific rigor and practice relevance may cause research–community conflicts. Open-mindedness and humility are fundamental for negotiation and compromise. When both partners are adaptable and flexible, conflict resolution can become an opportunity to enhance mutual understanding and strengthen the partnership.

Third, CBPR empowers community members to address real-world problems through high-quality research. However, it is important to anticipate and address systems-level challenges related to funding and the IRB. A successful CBPR grant application needs to address the unique needs of establishing and sustaining a research–community partnership. For instance, it is critical to budget for a project coordinator who works at both the university and the community organization to facilitate communication between the two partners. Moreover, the current IRB process does not always align with CBPR spirit and can sometime cause friction with community partners. Researchers must prepare their community partner for these challenges in advance, while actively working with the IRB office to increase the awareness of CBPR and develop new IRB protocols and procedures that are sensitive to the needs of CBPR research.

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