abstract

Community-based interventions have greater relevance and a greater chance of success and sustainability when the community is collaboratively involved in the research process. Opening Doors: Project Adventure is a research project designed to evaluate the impact of community-based inclusive recreation, using supportive mentoring, on children and youth with disabilities and special health care needs (CYDS). The project has a central goal of engaging CYDS who are members of underrepresented minorities, including those who face linguistic, cultural, and/or financial barriers to participation. In this article we describe the process of working with community partners and the lessons learned in the development and implementation of Project Adventure. Pediatrics 2010;126:S165–S169
In recent years there has been increased recognition of the importance of involving the community directly in health intervention research. Community-based participatory research is a rubric for various research methods that incorporate community collaboration in the design and testing of new health initiatives. When investigators partner with community members in the research process and draw on their strengths and experiences, interventions become more relevant to the true needs of the community and, therefore, more sustainable.

Community-based participatory research is of particular importance for interventions directed toward traditionally underserved communities. People whose cultural backgrounds differ from the dominant culture have complex needs, and an intervention may not succeed unless these needs are understood. Distrust of researchers and perceived cultural bias may pose a barrier to participation. Language barriers may impede the consent process. Even with translation, the terminology used in consent forms can have a legal feel, which may generate further feelings of distrust. Direct involvement of the target communities from the start is vital for overcoming these barriers.

In this article, we discuss the process of working with a diverse group of community-based organizations (CBOs) to develop and implement an inclusive recreation program. Analogous to education in the least restrictive environment, the guiding principle for Opening Doors: Project Adventure is to foster inclusion in community-based recreation so that any child with any disability can choose any activity and participate with support alongside peers in the general community.

Involving participants from traditionally underserved communities was an explicit goal of Project Adventure.

Based in Boston, Massachusetts, Project Adventure is part of Opening Doors, a national rehabilitation research and training center funded by the National Institute on Disability and Rehabilitation Research. To implement Project Adventure’s model in a multicultural urban context, Opening Doors formed partnerships with 9 CBOs that serve members of ethnic and linguistic minority groups in the Boston area (Table 1). From the beginning, it was clear to us that the perspectives and input of our CBO partners would be critical for creating a strong program and bringing in participants from underserved communities.

To aid the implementation of Project Adventure, we established professional partnerships with Partners for Youth With Disabilities, a nonprofit service organization with experience forming mentoring relationships between youth and adults with disabilities, and with the Greater Boston YMCA, a network of 13 YMCAs that serve many Boston-area neighborhoods. Input from both our CBO and professional partners guided project development from its conception onward, and we learned many lessons in bringing the program to fruition.

**PROJECT DESCRIPTION**

In Opening Doors: Project Adventure, children and youth with disabilities and special health care needs (CYDS) aged 6 to 15 years met for 1 to 2 hours per week at a local YMCA with a 1-to-1 mentor, or “coach,” who provides support for the child to engage in recreational activities. In contrast to recreational programs exclusively for children with disabilities that function separately from recreational opportunities for peers without disabilities, this inclusive, supported, community-based program allows children to engage in any activity on the basis of the preferences of the child, the parents, or both, side by side with peers (with or without disabilities) in their community. Each child’s pediatrician ensures that the chosen activities are safe and appropriate for the child, and program staff members evaluate activity feasibility. Pairs of coaches and children meet at least 20 times over the course of the program, which lasts ~6 months. To date, 47 children with a wide range of neurodevelopmental and physical disabilities have participated, including children with an autism spectrum disorder, cerebral palsy, Down syndrome, hearing loss, and genetic disorders.

Project Adventure’s use of trained volunteer mentors to support inclusive recreational activities was designed to provide respite for the participating child’s caretakers and to increase the stream of people entering the workforce who have an interest in serving individuals with disabilities. An in-depth selection process and training program for coaches, who typically have no previous training or experience working with CYDS, has been developed. All coaches undergo thorough in-person training, online case-based training, and cardiopulmonary resuscitation and first aid certification offered by Project Adventure staff. Trained coaches are carefully matched with child participants by using the expert assistance of Partners for Youth With Disabilities.

**TABLE 1** Project Adventure’s Community Partners

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<tr>
<td>Boston Chinatown Neighborhood Center</td>
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<td>Eritrean Community Center</td>
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<td>Ethiopian Community Mutual Assistance Association</td>
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<td>Haitian American Public Health Initiatives, Inc</td>
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<td>Massachusetts Alliance of Portuguese Speakers</td>
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<td>Massachusetts Asian and Pacific Islanders for Health</td>
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<td>Somali Development Center</td>
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<td>Soul Touchin’ Experiences</td>
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<td>Sudanese American Integration and Development Center</td>
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WORKING WITH THE COMMUNITY

For Project Adventure, we defined “community” broadly as children and families from underserved populations, those who face financial, linguistic, and cultural barriers to participation in recreation and who often are vastly underrepresented in research. Project Adventure established trust by repeated contacts with champions in a diverse array of CBOs, encouraging involved families to speak at events to pave the way for others in their communities, addressing language barriers through translation of materials, matching children with coaches who speak their language, and allowing for flexibility in the recreation model. Using these approaches, Project Adventure has been able to enroll children from increasingly diverse backgrounds and to learn from their experiences. Of the 47 children who have participated to date, 17 are low-income, inner-city youth; 18 are immigrants to the United States from countries such as China, Eritrea, the Philippines, and Iran. Six of these children come from immigrant families whose members do not speak any English.

Role of Partners

Enrolling so many children from underserved populations would not have been possible without our community-based partners, who shaped the project at all points of development and provided invaluable guidance. A focus group of youth with disabilities from a variety of backgrounds chose the name “Project Adventure” and encouraged use of the term “coaches” rather than “mentors” for greater acceptance by youth participants. Family members from the community who function as liaisons to the Opening Doors program reviewed and edited drafts of the consent forms to improve phrases that were ambiguous or disconcerting. CBO staff identified and helped the project use the most commonly accessed and trusted mechanisms of communication within each community, which ranged from consultation with leaders to describing the project on a local radio show.

More critically, our community-based partners provided important information and ideas that shaped the project. The first year of Project Adventure was dedicated to planning and openly exchanging ideas with our community-based partners. We approached the work with some initial constructs in mind but worked with our partners to understand how to best promote the participation in the diverse communities of the child participants we hoped to serve and the volunteer coaches. As our relationships with our community partners developed and they shared more information with us about their cultures and communities, we were able to see the flaws in many of our initial assumptions.

Barriers to Recruitment and Participation

Our community partners identified recruitment as a potential obstacle. They shared with us the views held by many members of their communities regarding disabilities and indicated that it would take time and trust for parents in our partnering communities to bring their child with a disability forward for participation in the project. For example, in some communities there is parental denial of a child’s disability. Members of some groups believe that children with disabilities should be sheltered or hidden. Some parents who have a child with a disability do not identify their children as such or believe that the disability will disappear in time or already has. Parents may believe that their child’s condition was a result of something they or their ancestors did. Similar culturally based views of disability have been reported in the literature.6-9

Other concerns raised by our community partners were in response to Project Adventure’s model for inclusive recreation. For example, in some cultures, recreation is not a formal activity, and engaging in physical activity at an unfamiliar, indoor public facility such as the YMCA is a concept not easily embraced by parents who did not grow up in countries where this type of formal recreation is the norm. In other cultures, recreation is a social event with extended family and others from the same community. Therefore, having a child with disabilities participate in recreation away from the family or the community and with assistance by a stranger may be at odds with fundamental cultural practices and values. Although we have not moved the project out of the YMCA, we are exploring new and expanded options, in consultation with our community partners, for a wider range of recreational activities in settings that are more familiar to participants, such as neighborhood walks or neighborhood soccer games.

Some concerns raised by our community partners are more difficult to address. Because our participants are “research subjects,” the project must follow certain institutional regulations governing participant safety. For example, public swimming classes or sports teams do not, in general, require caregivers to remain on site, but Project Adventure does. Some parents interpret this requirement to mean that the coach is not trustworthy or competent. Others do not have the time needed to meet this type of requirement. Unfortunately, we are not able to waive this requirement as long as Project Adventure remains subject to regulations for human subjects protection.
Research-Design Issues

Additional needs identified by community representatives had an impact on the research design and approaches to promoting participation. Our initial design called for random assignment of CYDS to either an active participation group or a control group. However, our community partners voiced concerns about families enrolling in a project that might ask them for information but offer nothing in return. Therefore, we changed our design to use a waitlist control group that would participate after a fixed, comparison period of nonparticipation.

We soon found that multiple complexities were associated with this design in practice. We intentionally recruited children to represent a wide range of ages, disabilities, and ethnic and linguistic backgrounds. As a result, we had to consider multiple issues when matching a child and coach, such as matching personalities, providing gender balance, aligning schedules, and, most challenging of all, finding coaches who spoke the appropriate language. All of these factors influenced our ability to find the right match in time for a child to begin active participation by a fixed date. Consequently, the 47 children who have participated in Project Adventure to date have waited a range of 15 to 446 days (median: 166 days).

Because of our limited control over the time between initial enrollment and participation in the project, we were unable to randomly assign half of the children to a fixed waiting period. Therefore, we implemented a within-subjects design and compared each participant’s measures before and after participation. The primary outcomes became the achievement of an individually established set of goals and changes in feelings of recreational self-efficacy. This new design provides a more meaningful way to accommodate children with widely varying disabilities and backgrounds while addressing the concerns raised by our community partners. The within-subjects design also gives us the flexibility to meet the changing recreational interests of the participants, which is important for sustaining participation over many months.

CONCLUSIONS

Project Adventure was undertaken as a field research project in Boston to measure the impact of mentored inclusive recreation for CYDS from typically underserved populations. From the start, it was clear that we would need to address multiple challenging issues simultaneously, including a lack of pre-existing inclusive community-based recreation programs, the need for trained mentors who were willing to volunteer their time, and cultural and linguistic barriers to participation in research and recreation. Implementing the project required a flexible and collaborative approach. The Project Adventure–community partnership has provided the ideal forum for discussing and creating an approach that can be tailored individually to the children, families, and coaches who participate in the project.

Project Adventure continues to evolve. The partnership with the local YMCA network has blossomed to include membership support for the participation of whole families in exercise, and the YMCA has called on the Project Adventure team to help educate staff members who work with people with disabilities across the life span. Parents of Project Adventure participants are taking advantage of their time at the YMCA to exercise, relax, or spend time with siblings. Coaches are learning about the needs of children with disabilities, and many of them have reported that it has had an impact on their career aspirations. Partners for Youth With Disabilities is providing ongoing support for child-mentor pairs who want to continue to meet after their participation in Project Adventure has ended. We have been able to secure funding for some low-income families to continue their YMCA memberships for an additional year. Ongoing and deepening relationships with the CBOs have allowed community members to openly share barriers and successes with project staff and to work together to continue to identify ways to involve more CYDS in recreation.

Through collaboration and the willingness to adapt to meet the needs of the participants, Project Adventure is now effectively serving children with a wide range of disabilities from numerous immigrant and inner-city communities. Ultimately, the Project Adventure team plans to literally open doors and provide a variety of opportunities for children with disabilities to participate in inclusive recreation in their communities in novel ways.

ACKNOWLEDGMENTS

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REFERENCES

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