Youth-Based Participatory Research: Lessons Learned From a Transition Research Study

abstract

Transitions to postsecondary education for youth with disabilities, special health care needs, or both are often challenging. Adults design most interventions aimed at assisting youth in the transition process. In this article, we report on how youth can enhance transition interventions and research. Youth representing a variety of community-based organizations that serve diverse immigrant populations served as co-researchers in a randomized controlled study called OPT4College, a program that provides postsecondary education transition support for youth with disabilities, special health care needs, or both. This youth-based participatory study used an iterative process that is quite different from the traditional research-study flow. The involvement of empowered youth and communities, in concert with academic and public health partners, increases the probability of creating interventions that ensure successful postsecondary transitions for youth with disabilities, special health care needs, or both. Pediatrics 2010;126:S177–S182
Successful transitions to postsecondary education (PSE) are especially challenging for students with disabilities, special health care needs, or both. This challenge may be particularly complex for students who must contend not only with the potential disenfranchisement that often accompanies a disability but also with the marginalization that culturally and linguistically diverse youth typically experience. Some research findings have indicated that for youth from culturally or linguistically diverse backgrounds, the rates of enrollment in PSE are significantly lower and unemployment rates are disproportionately higher than for their peers with and without disabilities.

In this article, we describe the process we used to design an online transition curriculum with youth from diverse backgrounds. We also discuss our approach to evaluating the curriculum’s effectiveness in assisting students with disabilities, special health care needs, or both from urban public schools in the greater Boston, Massachusetts, area in making the transition to PSE.

We used youth-based participatory research (YBPR), defined for this project as a collaborative partnership between researchers and youth, to help achieve the project’s goals. Similar to community-based participatory research, YBPR focuses on engaging the youth (or community) in all phases of the research, including project design, implementation, analysis, and dissemination of results.

We describe here the process we used to co-design and implement the project with youth, with a focus on the study’s design and recruitment phases. We also describe the differences between this process and the traditional research process.

**COMMUNITY PARTNERS**

The participatory research team consisted of 4 researchers and educators, 2 youth leadership trainers from the Institute for Community Inclusion at the University of Massachusetts and Children’s Hospital Boston, 10 youth from area public schools, 2 college students, and 3 graduate students. Several team members had physical or learning disabilities or special health care needs, and some were caregivers of youth with special health care needs, disabilities, or both. The team was ethnically and linguistically diverse; members were aged 16 through 50 years, and approximately half were female.

In addition, ~15 parents who were members from the 12 different community-based organizations (CBOs) representing diverse immigrant populations provided consultation on OPT4College. Many of these parents have children with disabilities, special health care needs, or both. The 12 CBOs each have leaders who have served on the project’s community advisory board. The community members of these CBOs, together with the community advisory board, have guided much of the work on OPT4College and the center’s activities in general. Some of the communities represented by these CBOs include the Somalian, Ethiopian, Eritrean, Latino, Chinese, Asian/Pacific Islander, and Portuguese communities. In addition to the youth previously mentioned, there was a youth advisory board (YAB) that convened on a quarterly basis and was composed of youth who were disability advocates in the Massachusetts area. Members of the YAB agreed that the project should address the needs of a broad group of students, including students who take special education courses and those who take mainstream courses, as well as those with and without a 504 plan. The program also needed to target students who may not be “disabled enough” to qualify for services and ultimately fall through the cracks in many schools.

Many members of the YAB were part of the project’s target population and shared anecdotal evidence on the unique set of academic, social, and health challenges that these young people face. The YAB also provided feedback on the potential interventions identified by the researchers and youth leadership trainers.

**PLANNING PROCESS**

Figure 1 illustrates the framework for this YBPR study compared with the traditional research approach of any given study. From a cursory glance, it is apparent that the YBPR approach requires several added steps that are not seen in the traditional research approach and an iterative process that is necessary for working alongside community youth. The basic elements of study design, measurement, intervention, and data analysis are included as primary elements in both of these approaches. However, how these elements are completed vary between both approaches. In this study’s youth-based approach, the 12 CBOs were engaged in the grant application writing process, and concerns for each of their communities became the focus of the study. Researchers did not identify focus study on the basis of literature, theory, epidemiologic data, or funding priorities. In designing the study, there were instances when the research team had to go back to square one and completely redesign curriculum, individual lessons, and recruitment strategies. At the end of this process, CBOs and youth from the YAB assisted with interpretation, dissemination, and translation of findings versus researchers who complete these steps in isolation. Figure 1 provides an overview of the framework that guided this study.
however, a detailed description of the procedures is described below.

Initially, the researchers conducted extensive reviews of articles (~50) in the published literature on precollege outreach programs for urban youth and PSE transition planning for students with disabilities.

The participatory research team created a series of videos that simulated news shows. These videos, called Transition News, featured 2 youth with disabilities who were members of the YAB and served as lead anchors. The videos were 30 minutes long and included information on medical transition for students beginning college. The team showed these videos to other youth who were members of the CBOs that represent the Ethiopian, Chinese, Portuguese, and Somali communities, and these members served as evaluators for the show. The youth evaluators expressed concern that the videos would encourage students to take a passive role in the transition process by simply listening to the “news reporters” present information about making the transition to college and that the videos might repeat some of the messages already conveyed to youth through more formal school-based guidance services. The evaluators also said that the videos were infantilizing and not “cool.” These youth encouraged the project team to replace the news-show format with a format that is more familiar to students, such as textbook chapters, classroom lessons, and activities or quizzes at the end of each to test the students’ knowledge.

Between September 2008 and January 2009, the research team conducted in-depth interviews and focus groups with youth, parents, and professionals from local programs that assist students in applying to college. These informants indicated that the types of training and resources for PSE transitions in local public schools varied across and within schools, which indicates a need to design the intervention so that students could complete it independently or in collaboration with their counselors, parents, or both. The interviews and focus groups also taught the research team that every school has its own ecosystem; the type of intervention that is appropriate for a school’s students might not be appropriate for another school’s students. Furthermore, youth with disabil-

**FIGURE 1**

Ities, special health care needs, or both were comfortable using the Internet and spent a substantial amount of time on social networking and other Web sites; also, youth preferred learning over Internet. Parents and youth reported in the interviews and focus groups that computer access is not a barrier for most area students with disabilities, special health care needs, or both because many schools assign a computer to each student, schools have computer laboratories that students may use, or students may use computers at public libraries and/or community centers.

On the basis of this feedback, the participatory research group designed OPT4College, an online curriculum with 6 comprehensive lessons on PSE options, college applications, financial aid, and the medical and educational transition steps required before a student with a disability, special health care need, or both leaves high school. Each of the 6 lessons consisted of at least 1 video, self-test questions, animated slide presentations, instructional text, and a resource page with links to relevant Web sites. The youth from both the YAB and the CBOs recommended providing much of the information through videos that feature youth “like them” (ie, similar race/ethnicity, class, disabilities, and/or special health care needs). The newscast format of the videos was replaced with different hosts located in a relevant setting such as a financial aid office, classroom, or campus student center. Each host(s) presented information to the viewers in a more informal, conversational format. In some lessons, there were additional videos that consisted of a host interviewing a college disability services counselor; students with disabilities, special health care needs, or both; and an adult with a disability who works with youth with disabilities.

The research team produced the first video of the new series and hosted pizza parties for youth and parents from the CBOs (Somalian, Ethiopian, Eritrean, Asian/Pacific Islander, Portuguese, and Chinese CBOs) to screen the video and provide feedback. The directors of these organizations and some of their staff members also viewed the video and gave feedback. These youth, parents, and CBO staff members commented that the actors in the video came from families with higher incomes and were not racially or ethnically representative of the target population, the majority of the actors did not have a visible disability, and the overall language and tone were more appropriate for younger students. It is interesting to note that all of the youth stated that the first video, which introduced the curriculum, needed to clearly indicate that the video series would provide information on PSE financing because the target population might not complete the lessons if they did not know that this topic would be adequately addressed.

On the basis of this feedback, the research team made many changes to the video. First, the team expanded the video cast to feature youth from the CBOs and several community and state colleges. The team devoted an extraordinary amount of effort to working with college student disability service offices and clubs to hire racially and ethnically diverse actors. The research team arranged to have the video script rewritten to use a higher language level and to indicate that the series would include a lesson on how to finance PSE and acknowledge that this was a critical concern for students and parents. Several youth reviewed the script before filming for the next version began. All of the videos for the curriculum were produced and pilot-tested with a variety of youth.

The partnerships established with youth, their families, and the CBOs continue to be strong, and we are working with these partners to develop plans for disseminating the findings.

**STUDY DESIGN**

On the basis of the research principles that the study needed to follow to make it possible to test the curriculum’s effectiveness, the research team decided that the study would include a control group and an intervention group, with a projected total sample of ~200 participants. The sample would consist of sophomores and juniors from public high schools in the greater Boston area, because many youth from the various CBOs indicated that senior year might be too late to have a significant impact.

The parents and youth from the various CBOs believed strongly that all participants, including those in the control group, needed to have access to the information provided in the curriculum. Consequently, the research team decided that the intervention and control groups would be exposed to the same curriculum, but the intervention group’s activities would conclude with 4 action steps that were based on the content of each lesson (eg, the financial aid lesson included an action step that directed youth to request a copy of their parent’s previous-year income tax return and start a draft of a financial aid application) and guidance on how to complete these steps. The study hypothesis was that a gap existed between knowledge about the general college-application process and action. If the necessary steps to apply to college were broken down into smaller surmountable tasks, and the participants were asked to report on their success in completing these tasks, those in this group would probably have better transition outcomes than those in the control group, who
were not guided via smaller steps and asked to report on progress. The intervention group would also report on the supports they received and challenges they faced in completing the activities.

The participatory researcher team decided to give all participants $2 gift cards that they could use to download music or videos from the Internet at the end of each lesson. After some research and discussion, the participatory research team selected this incentive because it would motivate the youth to complete the 6 lessons, was small enough to avoid being coercive, was easy to distribute, and was of interest to and easy to use for students regardless of disability (deaf students could use the codes on the cards to download videos and blind students could use their screen readers to read the codes and download music). Subsequently, the YAB indicated that these gift cards were not suitable for all participants, because some do not have digital music players to play the downloaded music, others have needs that would best be met with a supermarket, pharmacy, or subway gift card, and some use shareware sites to download music at no charge. Therefore, the project will offer additional incentives such as those previously mentioned to meet participants’ diverse needs and preferences.

The process for participants is the following:

1. Undergo screening for eligibility by research staff.
2. Provide parental consent or student assent.
3. Complete baseline survey by e-mail.
4. Receive personal user identification and password for logging onto study Web site.
5. Complete each lesson, including a survey at the end (and, for intervention-group members, complete 4 action steps).
6. Receive a gift card and an access code for the next lesson.

Participants repeat this process for all 6 lessons and then complete the final survey.

Research staff members and the YAB began recruiting and screening participants in May 2009. To date, 182 participants have been recruited. Research staff experiences with these procedures indicate that qualitative interviews with some of the participants would be crucial for understanding the effectiveness of the curriculum and the complex transition process for these youth (interviews with 10 participants from the intervention and 10 from the control group will be conducted in the fall of 2010). The participatory research team will design an interview protocol with youth staff to gather data on these issues.

**RECRUITMENT PROCESS**

Initially, the participatory research team had hoped that research staff could easily recruit participants who were patients at some of the Children’s Hospital Boston clinics and local college preparatory programs and by distributing flyers in libraries, community centers, town centers, and popular hang-out spots for youth. Unfortunately, these efforts yielded few positive results and were time-consuming. The team therefore decided to work with Boston public school teachers, counselors, and administrators to identify potential participants, and this approach has been more successful. Guidance counselors and special education teachers, in particular, have been particularly valuable recruitment partners.

When this recruitment approach was used, we had to alter our presentation focus slightly by stressing the importance of transition planning and possible use of OPT4College as part of individualized education program plans. This tactic has facilitated communications between the researchers and the schools but has created barriers to targeting potential study participants, because study staff are no longer identifying the potential participants directly; this is now done by special education teachers and counselors. Often, gatekeepers’ (ie, teachers and counselors) perceptions of who might benefit from or be eligible for OPT4College differ from our definition. As a result, these teachers and counselors might unintentionally screen out individuals because of a lack of documentation or English-language fluency or by categorizing a student as “not college material” because of the severity of his or her cognitive impairment, although such students might not only be eligible for the study but could ultimately benefit from the extra assistance that OPT4College offers.

However, each initial meeting with school administrators has prepared us to better handle future encounters with other school personnel, and we have received suggestions for new avenues for successfully reaching out to youth and their families. For example, 1 school administrator suggested that we present the material at parent-teacher association meetings or larger gatherings that parents and teachers attend. We gave presentations at 2 parent-teacher association meetings in 2 different schools and were able to recruit ~20 students with this approach. In addition, we hired 6 youth aged 16 to 21 years from the CBOs to assist in recruitment during the summer of 2009. These youth visited parties, clubs, concerts, hair salons, libraries, and summer job corps program meetings, where they distributed flyers and spoke to potentially eligible youth about the project. The youth also discussed the project with teachers and principals from their schools. Some of their efforts paved
the way for us to enter several schools during the first week of classes in the fall of 2009 and recruit some participants. We hired one of the youth recruiters to continue assisting with recruitment, following up with students and keeping them engaged in the project, and securing parental consent on a part-time basis while he attends college.

CONCLUSIONS

Projects that use YBPR can impose heavy demands on team members’ time and lead to frustrations with the process, missed opportunities, and loss of control. However, we firmly believe that the benefits of this approach far outweigh its challenges. Our experience has shown that YBPR can help ensure that the research questions are relevant to the community, increase data use and dissemination, and establish partnerships that could be pivotal in expanding the project.

The academic researchers on this project experienced a healthy tension between the project’s service component and its research imperative. The nonacademic team members learned about the complexity of conducting research and the challenges with recruitment and retention. The YBPR methods that the team used facilitated the flexibility that fostered this healthy tension. For the participatory research team, OPT4College has provided a foundation in YBPR that will facilitate team members’ future work in this field.

We share the results of this pilot project to illustrate the potential of YBPR to establish long-term partnerships between universities and communities and to generate high-quality data that will translate into more effective interventions and policies to improve outcomes for youth with disabilities, special health care needs, or both. We invite other scholars to evaluate the merits of this form of inquiry for their own work.

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