Developmental Brain Research With Participants From Underprivileged Communities: Strategies for Recruitment, Participation, and Retention

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ABSTRACT— Challenges associated with recruitment and retention of participants from underprivileged social communities, in addition to neuroscience researchers’ unfamiliarity with these communities, possibly explain the limited number of individuals from these communities who participate in neuroscience research studies. The consequence is a scarcity of data in this fast-growing segment of the population. In particular, developmental research involving children from ethnic minorities has yet to catch up with the number of studies available for middle-class White children (Flores et al., 2002). This underrepresentation can lead to disparities in health and social services for children from these communities, as well as to a nonrepresentative knowledge base of child neurodevelopment. Developing and utilizing innovative and culturally sensitive approaches to recruiting participants from underprivileged communities can maximize their participation in research, as behavioral researchers have known for some time. Here, based on our experience recruiting low-socioeconomic status (SES) Latino children from Los Angeles, we offer strategies to improve recruitment, involvement, and retention. We have a special focus on techniques relevant to recruiting for neuroimaging, which is associated with new challenges not faced to the same degree in research historically. Better inclusion of underrepresented children in research can ultimately lead to the development and improvement of effective public policies to support their needs, ranging from education to health care.

The first information session to recruit child participants for a longitudinal brain study had begun at a community center in downtown Los Angeles. Anxious parents and children of Latino descent sat quietly and listened to what we, the researchers, had to say. An awkward silence filled up the air every instance when there was a gap between our words and those of the Spanish translator. Some parents appeared to avoid making eye contact with us. The awkwardness continued until one father broke the silence and asked a question. Others followed, and, pretty soon, there were many conversations going on. All of a sudden, a beautiful young woman, who was holding a sleeping baby in her arms, spoke with indignation (in Spanish) to the person sitting next to her:—“What? No way someone is going to cut my child’s head open!” She stood up discreetly and left the room.

Some weeks went by and we began testing children in the community center. We would often see the young woman there, but she avoided any type of contact with us. But as our visits to the facility became more constant, we also became more integrated in the community. Children greeted us with smiles and hugs, and parents and grandparents often shared everyday stories. It didn’t take long for Martina,1 the 6-year-old daughter of the woman, to express her wish to participate in the study. She wanted

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to play the same “cool” games that the other children had played, visit the university and get a picture of her brain. After many conversations with the researchers and the program director, as well as consultations with family members and friends, Martina’s mother finally agreed to have her child participate and signed consent forms.

On the day of the brain scan, while Martina appeared to be both excited and nervous, her mother was clearly scared. Martina did well on the mock scanner; chose her favorite movie, grabbed a Minnie Mouse doll from the lab and marched happily to the scanner with one of us. The other researcher stayed outside the scanner room to provide support to the mother, who was now whispering prayers in her mother tongue while repeatedly making the sign of the cross. All went well with the scanning. Martina came out of the scanner with a big smile, asking for a cookie. Mom hugged Martina and then us.—“You know the truth? I was really scared when she went inside. But I am so proud of my Martina; she is a very brave girl. I am glad that we came.”

(Researcher notes)

As in the opening vignette, members of minority groups from underprivileged communities typically participate less frequently in research studies, and this is particularly true where children are concerned (Cauce, Ryan, & Grove, 1998; Yancey, Ortega, & Kumanyika, 2006). This situation has likely worsened in the last decade with the increase in the use of neuroimaging methods, such as magnetic resonance imaging (MRI) and electroencephalography (EEG) for research purposes. A range of reasons including trust, lack of access to information about research opportunities, ineligibility to participate, and individual circumstances such as child care needs, geographic proximity to the research site, and job flexibility, all undermine these individuals’ participation (Wendler et al., 2006; Yancey et al., 2006). However, in order to provide scientists, educators, and policy makers with scientific evidence that is relevant to all segments of the population, it is necessary to include participants from diverse ethnic, socioeconomic, and racial backgrounds in research.

While issues surrounding recruiting and engaging research participants from diverse cultural and economic backgrounds are by no means novel to many research areas, it is especially relevant to neuroscience as our methods and focus may be especially intimidating to children and individuals traditionally outside of formal scientific inquiry. To address this issue, our aim here is to discuss the lessons we learned by reporting on the strategies that have proven to be successful in ensuring the participation and retention of 72 participants, as young as 6 years of age, from predominantly Latino and underserved communities in the Los Angeles area. Details of this longitudinal developmental neuroscience study have been published in Habibi et al., 2014. Without the intent of being overly prescriptive, we have incorporated a general protocol for each step starting with recruitment, followed by laboratory visits, data collection and study participant retention, as well as recommendations for addressing the challenges specific to pediatric neuroimaging endeavors with participants from low-income communities. Although many of our strategies are not new and have been utilized for decades to conduct behavioral research, we nonetheless describe them here because they are generally unfamiliar to neuroimaging researchers. When applicable, we also describe ways that we and others have specifically adapted these strategies to use with recruitment for neuroimaging.

RECRUITMENT

The first step in recruitment needs to include the gathering of information and the development of an understanding of the beliefs and behaviors representative of the community targeted to participate in the research. Several studies that have assessed participation of racial and ethnic minority groups from low-socioeconomic status (SES) backgrounds in research have suggested that low levels of participation have been largely related to mistrust of scientific institutions and of healthcare systems that can be traced back to past experiences of exploitation, such as the notorious case in the Tuskegee Syphilis Study (Edwards et al., 2013; Miranda, Azocar, Organista, Munoz, & Lieberman, 1996). In addition, fears of mistreatment, for example, feeling to be used as “guinea pigs,” concerns about immigration status, and fear that research findings would be largely used to benefit the careers of individual researchers rather than to address community problems are other reasons affecting recruitment and retention (Yancey et al., 2006). Recognizing these concerns and building a trusting relationship with the target community is necessary for effective recruitment when working with underserved communities. We outline here the strategies that we have successfully used.

- We collaborated with community-based organizations such as churches, schools, and community centers that proved to be vital when trying to connect with the community from which participants were sought (Moreno-John et al., 2004). Likewise, we sought endorsement and support of community leaders and social organizations. In our experience, providing a sample recruitment letter to leaders in the targeted community detailing the objectives of the study and the purpose of including participants from their community can facilitate the initial communication and increase the
perception of the congruence between community goals and researchers’ motivations (Bates & Harris, 2004; Fouad et al., 2000).

- We trained a diverse research group to have cultural and language competency as an effective strategy for building trust in our targeted population and for addressing sociocultural difficulties including language barriers (Swanson & Ward, 1995; Yancey, 1999). For example, when working with participants speaking a language other than English, having bilingual/bicultural staff, including members from the participants’ community, and using formal language to indicate respect while being warm and personable has proven to be a successful approach (see also Miranda et al., 1996).

- We developed an active recruiting strategy by bringing the staff, in particular “cultural insider” members of the team, into direct contact with prospective participants via in-person meetings, or even via telephone calls, as we found this to be more effective than communication via emails or through advertisement via flyers. In our experience, organizing meetings with prospective participants where they are given an opportunity to tour the research site, to ask questions and to engage in conversations about the objectives of the research has been very helpful. Of note, multiple attempts may be required to yield well-attended meetings given the busy work and family schedules of prospective low-SES families.

- Ensuring that all materials including recruitment flyers, consent, and assent forms are translated appropriately and are written in language that is accessible to lower literacy participants proved to be important. We found it to be imperative to engage in conversation with the participants to ensure their understanding of the procedures especially during the consent process, including issues of confidentiality and anonymity of collected data (Ojeda, Flores, Meza, & Morales, 2011), and safety of the neuroimaging methods and machinery.

- Highlighting personal advantages as well as benefits to society at large by their participation in the study was vital when talking to the families of young children. For example, among our Latino participants, we found it useful to emphasize the participants’ role as a community representative (Haack, Gerdes, & Lawton, 2012), as well as to emphasize the need for scientific research that represents children like theirs.

We found that employing these culturally sensitive approaches and building connections with communities of the targeted populations positively influenced the recruitment process. By implementing these strategies, we were able to successfully enroll a large group of participants between the ages of 6 and 7 from underserved Los Angeles communities in our longitudinal brain and behavior development study. Initially, 106 families signed up for the study. Within this group, 10 families later changed their minds about participation after the initial agreement. An additional three participants relocated before data collection and seven were deemed noneligible either due to the child’s age, pre-existing health conditions such as developmental delays, learning disabilities, or insufficient fluency in English (a condition necessary to undertake the tasks involved in the study). In all, 85 children and their families committed to the research project and successfully completed the first phase of data collection.

LABORATORY VISITS

Participating in a developmental research study involves taking time off from often inflexible work schedules and/or busy families, traveling with children to the laboratory for data collection (oftentimes without access to personal transportation), and finding childcare for children left at home. Because of this, anything that researchers can do to accommodate diverse personal circumstances can be helpful. This will not only encourage participants to further support the research, but can also increase their willingness to promote the research to other members of the community (Yancey et al., 2006). Furthermore, it is also important to remember that many participants who come from underserved communities may never have visited a university campus. A visit to a research laboratory may be filled with both expectations and anxieties, as some of our study participants have expressed. Below are some of the strategies that we have developed to accommodate these personal barriers and alleviate participants’ anxiety:

- Offering flexible scheduling including evening hours and weekends.
- Offering assistance with transportation in the form of compensation for personal transportation, prepaid parking permits, taxi vouchers, or passes for public transportation.
- Arranging for child care at the research site or offering additional financial compensation to family participants who need to pay child care expenses while participating in the study.
- Establishing a welcoming and comfortable environment to foster strong relationships. In our experience, having bilingual staff to meet arriving participants at the parking lot, or taxi drop off, and to direct them to the research site, has helped alleviate participants’ concerns with navigating an unfamiliar environment.
- Arranging for family-friendly waiting areas equipped with toys, snacks, and reading materials in the preferred language of the target population to provide a comfortable and friendly environment for the adults and children.
• Respecting traditional gender and family roles appropriate to the culture of participants is of great importance, especially when children are involved. Many cultural communities place great importance upon traditions associated with extended family. In our experience, working with Mexican American families, including both the mother and the father as well as extended kin in the research process has been an important step to assure the child’s participation (see Haack, Gerdes, Cruz, & Schneider, 2012; Valencia, 2004). For example, we have learned to be sensitive to issues of familismo, or the high level of importance attributed to family members including grandparents, aunts, uncles, and the like in everyday decisions, attitudes, and experiences (see Calzada, Tamis-LeMonda, & Yoshikawa, 2012). To illustrate this point, we have had cases in which more than one parent signed the consent forms, and did it only after discussing participation with the matriarch of the family, often the grandmother.

• Once at the laboratory for the research visit, maintaining an active engagement with the accompanying family members while their child is being assessed, by frequently updating them on the progress and inquiring about their needs and addressing their concerns, has helped put the family at ease and increased both comfort and participation rates.

DATA COLLECTION IN DIVERSE PEDIATRIC POPULATIONS

Innovative approaches and accommodations are necessary when collecting data from pediatric populations. Other innovative efforts to involve underrecruited populations in research include online studies that allow families and their children to participate in online activities from their convenient location (see lookit.mit.edu). In our brain and behavior development study, we are using a comprehensive battery of neuroimaging and behavioral assessments that can last up to three hours and cannot be performed outside of the lab. In the following section, we highlight specific considerations that we have found helpful to successfully complete these sessions with children. A number of articles have previously provided hands-on step-by-step guidelines for conducting MRI and EEG studies with young children (Bookheimer, 2000; Raschle et al., 2009; Trainor, 2012). We add the strategies we found useful in order to address sociocultural and individual barriers to pediatric neuroimaging.

The Use of Rewards and Snacks During Behavioral Assessment

Designing child-friendly testing rooms by placing toys and stuffed animals, providing parent-approved snacks and drinks, using positive language that is easily understood by children (e.g., “playing games” instead of “testing sessions”) and providing children with stickers or small prizes in between assessments are important factors to consider as they help keep children engaged. Of note, children from underserved populations often have limited access to toys, books and, in extreme cases, even food. Therefore, it is important to be mindful of the value that such rewards could provide for this group in comparison to participants from more privileged backgrounds. Furthermore, when selecting rewards, it is important to be attuned to age-specific references. As an example, at the onset of our study, we found that many 6-year-olds were particularly interested in stickers and small toys from Dora the Explorer and Diego. Yet, a year later, several children expressed that rewards representing these cartoons were “too childish” and thus unappealing. These issues may appear unimportant, but they do play a role in children’s willingness to participate in behavioral tests.

Electroencephalography

EEG is a noninvasive method to measure electrical activity of the brain. EEG has an excellent temporal resolution (milliseconds range), is quiet, and is more tolerant to movement artifacts. Compared to MRI, collecting EEG recordings from children poses fewer problems but, as with every testing situation involving children, it is especially important to consider and accommodate participants’ specific needs (Trainor, 2012). We have found the following steps to be helpful in facilitating the process:

• Given that attention-span in children is short and that they tend to tire more quickly, we keep experiments as short as possible and divide the experiments into multiple runs (5–7 min in length) with breaks in between.

• We have found it helpful to introduce the EEG process to the children by using child-appropriate choice of technical terms—for example, we refer to the multichannel EEG cap as a swimming cap with buttons and wires that act like microphones to pick up activity of the brain. In addition, we have put together images of different stuffed animals wearing the EEG cap which the children appear to experience as a fun ice-breaker during the introduction of the EEG recording process, depending on the child’s age.

• Electrode application and impedances adjustment are often time-consuming and thus wearing for children. It is important to note that the more quickly the electrodes can be placed and impedances checked, the more time is left for the actual recording and the more alert the participant will be during the experiment. We have found that engaging children with books, toys, or child-friendly movies during electrode placement is helpful. Some
children may choose to bring along their favorite stuffed animal or toy into the recording booth. As long as the toy does not distract them from the task, this can be quite helpful.

- Although this is standard practice in developmental laboratories, it is worth repeating that small rewards such as sticker charts can help motivate children during the breaks to complete the multiple runs of the EEG session. We also provide children with parent-approved light snacks and a drink between the runs. Inquiring about sensitivity to food allergies beforehand is critical when asking parents about appropriate snacks. During breaks and throughout the data collection, we found it helpful to remind children not to move excessively.

Magnetic Resonance Imaging
MRI is a noninvasive imaging technique that is increasingly being used as a research tool with children. Unlike conventional xrays, MRI does not involve exposure to radiation and therefore is considered safe for children and infants (Byars et al., 2006; Nelson, 2008). However, participation of young children from underserved communities in MRI studies remains quite low. In our experience, parents expressed several major concerns in relation to MR imaging for their children, including:

1. Fear that MRI is a clinical diagnostic tool designed to detect tumors or other neurological diseases and therefore not suitable for healthy children. We have dealt with these concerns by providing an information sheet that describes in accessible language (with translated versions available) what structural and functional MR images are, how the machine works, and what the associated risks are—for example, the magnet strongly pulls on ferromagnetic objects. In addition, giving examples and references to other major pediatric neuroimaging research projects has been useful to familiarize prospective participants with neuroimaging developmental research and ease their concerns. Last, as stressed above, we verbally review protocols and procedures with participants and their family members to ensure understanding, address questions, and encourage comfort.

2. Safety screening is a necessary step to avoid dangerous physical injuries related to presence of ferromagnetic material in the strong magnetic field of MRI. However comprehensive screening questionnaires may be tiring or confusing for participants and their families, particularly, if they are presented on the same day as that of data collection. To circumvent these problems, we have adopted the following approaches:

* We provide the safety screening forms to participants prior to their visit and follow up with phone calls to clarify and address questions. The screening forms are then signed in person during the visit to the research center.
* We ensure that the translated forms are both linguistically and culturally appropriate and are written in language that is easy to understand.
* Where appropriate, we establish communication directly with participants’ primary care providers (physicians and/or dentists) to ensure safety of any medical or dental implants present.

3. General problems inherent in the use of MR imaging with children include anxiety, claustrophobia, restlessness, and difficulty in following instructions (Hallowell, Stewart, de Amorim, Silva, & Ditchfield, 2008). The following strategies have been designed to address these issues, and we too found that they worked well:

* The noise generated by the vibration of the gradient coils is quite loud and unfamiliar to the participating children. This noisy environment, together with the physical confinement of the scanner, can create anxiety. We have used a preparation session in a mock scanner (the actual empty shell of a real scanner), where the noise produced by the different acquisition sequences is generated by a computer. This has proven to be an effective way to familiarize the child with the overall environment of the scanning session. It also has helped reduce the “fear” of the big machine, or “brain camera” (Hunt & Thomas, 2008).
* We take breaks, and assure repeatedly that participation is voluntary and can be terminated at any time. This process has been very helpful in alleviating anxiety and hesitation in children who may have shown initial apprehensions (Raschle et al., 2009).
* A member of the research team or a parent can accompany the child to the MRI room and stay inside the room during the scanning period to help alleviate the child’s anxiety, providing that this is not overly distracting to the child. In cases where parents are too distracting or nervous, we recommend designating a member of the research team who has been previously introduced to both the parents and the child prior to the scan in case their company in the scan room becomes necessary.
* We keep each scanning sequence as short as possible or divide the experiment into multiple runs. In our experience, using run durations of 5–7 min with the total length of the imaging session not exceeding 60 min has generally been successful. In addition, beginning the MRI session with anatomical/structural runs during which children can watch popular, child-friendly and child-selected movies can...
significantly help reduce their anxiety and help with staying still during subsequent runs.

The difficulties inherent in the use of neuroimaging techniques, such as participants’ anxiety, claustrophobia, and restlessness, can be more pronounced when working with pediatric populations compared with adults; and even up to 20% of adult patients are estimated to refuse undergoing MRI sessions or to request to end the session before completion (Garcia-Palacios, Hoffman, Richards, Seibel, & Sharar, 2007; Meléndez & McCrank, 1993). However, we have found that careful preparation and use of methods that promote comfort can go a long way toward easing the scanning process in young children. Using the above protocol, we have successfully obtained brain imaging data from 92% of the children in our study (average age between 6 and 7 years old). Of 85 participants, only three children were too anxious to complete the imaging session, one family chose not to take part in the neuroimaging portion of the study, and two children did not meet the MRI safety criteria for scanning.

(4) Neuroradiological review of the scans obtained for research purposes in healthy participants is a mandate from institutional review boards (IRBs). The purpose is to identify incidental findings that may pose potential health risks. However, such a process has to be carefully explained to the participants and their families. Families of participating young children need to be informed about the low incidence of such findings (Kim, Illes, Kaplan, Reiss, & Atlas, 2002), but also about the potential benefits of learning about a potential health concern. We have had two cases of incidental findings—only one required an urgent clinical intervention and its detection and follow up proved to be particularly important for the welfare and healthy development of the participant; the other case required a routine clinical referral.

RETENTION OF STUDY PARTICIPANTS

Intensive follow-up and contact with participants are both key factors in improving both participation and retention in longitudinal studies (Wendler et al., 2006; Yancey et al., 2006). Some key approaches that we have used with good results in retention of participants include:

1. Maintaining continuity of staff, particularly, those with ties to the target community, over the course of the study;
2. providing multiple and easy to use phone numbers and/or email addresses to participants to make communication convenient;
3. timely payment of promised incentives in the form of cash or gift certificates (see also Yancey et al., 2006); and
4. keeping in contact through quarterly newsletters, birthday cards, and holiday greetings. Of course, as is standard practice in longitudinal studies, we recommend contacting participants between visits to provide follow-up information update contact information and avoid unwanted dropouts.

Of note, the living conditions of participants from underserved communities may be of an inevitably transient nature, with frequent changes of residence, telephone number, and other contact information. For example, we have witnessed that many families’ access to mobile phones are limited to temporary lines and “pay as you go” plans, where the phone number expires if the line is not replenished frequently. Therefore, we recommend collecting detailed contact information (i.e., mailing address, phone numbers, and email address) from the immediate participants and also from alternate possible contacts such as grandparents, siblings, aunts, and uncles, close friends or neighbors (although it is important to clear this practice with the university IRB first).

Overall, recognition of the potential benefits of the research study to the community at large, satisfaction with the research procedures in general, and follow-up contact from the research staff are motivating factors for study participants to return and complete the study (Haack, Gerdes, & Lawton, 2012).

Using the above protocol, we have maintained an 85% retention rate in our longitudinal brain and behavior developmental study, suggesting that, despite difficulties in recruiting and retaining ethnic minority participants and participants from low-SES backgrounds (Gilliss et al., 2001; Haack, Gerdes, Cruz, & Schneider, 2012), using culturally sensitive strategies can facilitate participation of these communities in neuroimaging research. Factors contributing to our 15% attrition rate have included relocation to another country (n = 6), change of child’s foster family (n = 2), and other family issues such as parents’ separation, illness, and loss of housing (n = 5).

FINAL DISCUSSION AND CONCLUDING REMARKS

Despite many challenges and obstacles that cannot be fully controlled or even predicted, we believe that the incorporation of culturally appropriate and modified strategies when working with ethnic minorities and underserved communities can maximize recruitment, participation, and retention of these groups in neuroimaging research. Given that behavioral research labs have been carried out for decades, cultivating a trusting relationship with the community, building a research team that includes bicultural and bilingual staff, engaging community organizations and leaders, and developing strategies to flexibly accommodate personal circumstances and situations are standard strategies (Haack, Gerdes, & Lawton, 2012).
In conclusion, it is estimated that the Latino population will make up to 45% of U.S. population growth during 2010–2030 (Day, 2010). Furthermore, the number of languages spoken other than English in homes across the United States grew 140% between 1980 and 2007, and more growth is expected (U.S. Census, 2010). Unsurprisingly, these numbers are consistent with the changing demographics that are currently seen in schools and other institutional settings across the country. Neuroimaging researchers, however, have not kept up with the pace of these and other changes in the social landscape. Better inclusion of children from underprivileged and ethnic minority communities in research may lead to more representative, and hence generalizable, findings that can ultimately guide public policies more effectively and improve the lives of all. In the end, a central aim of research is to inform societal questions, including educational and social practice and policy. Because of this, research findings should represent society’s members broadly. This takes some work on the part of researchers, who may not be familiar with the cultural, social, economic, and practical constraints and conditions of potential research participants, but in the long run it will increase the representation of social groups that have traditionally been left out of neuroimaging studies (see Henrich, Heine, & Norenzayan, 2010a, 2010b).

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NOTE

1 Pseudonym

REFERENCES


