Haitian, Chinese, Somali, Ethiopian, and Asian/Pacific Islander Perspectives on Research

abstract

Researchers often approach community-based organizations as an access point to engage underserved populations in studies. In this article, 5 representatives of community organizations present their perspectives on the complexity of researcher-community partnerships and the nuances of engaging Haitian, Ethiopian, Somali, Chinese, and Asian/Pacific Islander populations in research. Each representative presents recommendations for gaining trust and understanding within their communities and challenge researchers to move beyond seeking knowledge and into social action that improves the lives of their constituents. Pediatrics 2010;126:S137–S142
The Opening Doors Project, funded by the National Institute on Disability Rehabilitation and Research, conducts 3 research studies involving youth with disabilities and special health care needs from underserved communities. In November 2008, the Opening Doors Project hosted a state-of-the-science conference that included presentations from representatives of community-based organizations (CBOs) that serve immigrant communities in the Boston, Massachusetts area. These CBOs are 5 of the 9 partner organizations of the Opening Doors Project. The conference organizers had asked the discussants to present their perspectives, on behalf of their community members, on engaging community members in research. They spoke to a diverse audience of families, youth with disabilities, researchers, and federal funding agency representatives about why working with communities and their representatives is critically important and highly nuanced.

Dr Foley collated the comments by themes and made minimal edits to statements so that the spoken word arrived grammatically correct on the page. This article presents excerpts of these comments. In several instances, Dr Foley added a word or phrase for clarity and indicated so in the text. The following were the discussants:

- **Renald Raphael, MD** is a Haitian physician who has worked with the Haitian American Public Health Initiatives since 1997 as the program supervisor of the Family Support Program. Dr Raphael has worked in the public health field for many decades promoting culturally and linguistically competent education in maternal and child health. He has extensive experience developing programs for Haitian immigrants who are dealing with disability and mental health issues.
- **Martin Adolphe** is a Haitian mother of an adult son with autism. Mrs Adolphe was a social worker and researcher in Haiti. She is currently the chairperson of the Family Governing Board of the Haitian Family Support Services, a Developmental Disability Services (DDS)-funded program for Haitian families with children with developmental disabilities.
- **Joseph Wu, MA** is the Family services director of the Boston Chinatown Neighborhood Center, the largest community services provider for the Asian American community in New England. He is a licensed mental health clinician and serves on multiple advisory committees, including a committee at Tufts Medical School and the Massachusetts Council on Compulsive Gambling.
- **Binyam Tamene** is a native Ethiopian and founder and executive director of the Ethiopian Community Mutual Assistance Association (ECMAA). The ECMAA, established in 1986, serves the needs of all individuals of Ethiopian descent. ECMAA programs include after-school youth programs, elderly services, citizenship assistance, employment assistance, and health education. Mr Tamene also leads a weekly radio program that reaches >8000 Ethiopians in Massachusetts.
- **Carolyn Leung Rubin, EdD** is a qualitative researcher and community educator. She is currently the program manager for the Aligning Researchers and Communities for Health at the Tufts Clinical and Translational Science Institute. She has been active in the Asian American community and has worked with multiple Asian American CBOs to develop and strengthen their work. She is also the education coordinator for the Asian and Pacific Islanders With Disabilities of California.
- **Abdirahman Yusuf, MPA** is the co-founder and executive director of the Somali Development Center in Jamaica Plain, Massachusetts. He is the chairperson of the Opening Doors Partnership Committee.

**THE GATEWAY ROLE**

CBOs are an important structural feature of cultural and ethnic communities, particularly for immigrants, and provide a range of social, health, legal, and financial services. Staff members are predominately bilingual and bicultural professionals with significant knowledge of their community’s diverse sociopolitical, historical, and cultural norms. Many are engaged in their own research or have significant experience in working with academic institutions and frequently act as a gateway for researchers to access community members. Panel members discussed the nuances of this gateway role with varying degrees of comfort.

**Renald Raphael, MD**

People like myself, you might think I am an expert on Haitian culture. But, in fact, I am not. I might have a view. A researcher might call me to ask what I think about Haitian beliefs. I might say something that might not be completely accurate because it does not reflect what the larger community thinks. Do not take for granted whatever the gateway provider will tell you. The gateway provider does not really represent the whole community. So, although I am a gateway provider, I do not reflect the whole community. I may have my view, my perspective on health. But I cannot really represent the community. It would be important for researchers to come to Boston and come to our organization and get a group of people [together] and talk to them. I would like to make sure that
when we are trying to reach the community, we try to reach out to the community at different levels, not just through the gateway provider.

**Martin Adolphe**

You need to live in the community life of people. If a researcher calls and asks about Haitian health, I need to check with the community to get that answer. You need to live in the community life to understand each component of the community.

**Joseph Wu, MA**

There is a lot of opportunity for our community to participate and to learn. In Chinese culture, cooperation is very much valued. We see that we have to cooperate with authority, providers, and researchers as someone that is respectable and formidable. There is a trust with researchers and research institutions. Education is very important in Chinese culture. In the Confucian perspective, it is highly valued.

Research brings in an intellectual element into the process. Funding agencies and researchers need to bear in mind how the research process can impact the relationship between the community organization and the community. There is risk involved. A lot of times, the community knows only the agency and not the researchers. They only know us. So if anything happens, then our trust with the community could be at risk. The researchers need to build in procedures and safeguards to protect those relationships. I was working with Boston University’s School of Public Health to do research on a smoking-cessation project for families with children who have asthma. When I was trying to talk to people through telephone interviews, I was greeted with a lot of skepticism. “Who are you? Where are you from? Who are you representing? Can I talk to your boss? Can I talk to your agency?” Although we speak the same language and are from the same culture, I am still greeted with the same skepticism. Every day, I have to think of innovative ways to reach out to people.

**Binyam Tamene**

I left my country a while ago, and I hope I know about the Ethiopian culture. But, every time I interact [with community members], I find I ask myself, “Do I really know them?” By living here, my attitude has somehow really changed. I assume that everyone changes. A person can come to you [and] ask you for some type of assistance, and you try to help him. Then, [he] comes the next week or the week after. Then, after maybe the fourth meeting, I start to get a sense of what he really wants. The trust issue is really important. It is really important to have the personal interaction. I understand the society we live in. You ask a direct question and you expect a direct answer. You will, unfortunately, be disappointed if you expect that interaction in the Ethiopian community.

**Abdirahman Yusuf, MPA**

We at the Somali Development Center work with researchers to help them conduct research. We explain to them the needs of the community members. To whatever ability they have, they will help us address some of those needs. Researchers do not do direct service, but they help us build our capacity to do so. You are asking people about something, but they say they have different needs. It is important that researchers work together with us to help our communities before we can even begin to participate.

**LIVED EXPERIENCE**

Researchers who seek to work with immigrant communities may find that CBO personnel have an unparalleled expertise in the political, social, and cultural perspectives of the community in question. This expertise is based on lived experience, many years of close connection with multiple sectors of the community, and many years of intensive efforts to integrate newcomers into American society. The value of this expertise should not be underestimated. Discussants suggest that partnerships that value this knowledge as expertise generate a mutual effort to address complex social problems.

**Martin Adolphe**

You need to use the people’s language as spoken by and used by the people. In Haiti, if you go to school, you are taught in French. But, the majority of the Haitian people speak Creole. People from the North and the South speak Haitian Creole, but they have idioms. You need to know to whom you are speaking. You should not translate from English to French or Creole. We have that problem so many times. We [are working with a] breast cancer researcher [who is] translating [research] materials from English to Creole. The community [voice] is lost because the researcher does not consider so many components. There are [questions] about what tests you need to do to check your breasts, but how am I going to talk to them about this? You need to educate the community, and there are so many things that you need to tell them before you ask them about it. You need to have the appropriate language to tell them. Therefore, you need to test materials culturally [and not just translate English concepts into another language].

**Joseph Wu, MA**

We need to look at how we can engage diverse populations to understand specific needs. For example, in pharmacology, there are new fields, like ethnopharmacology, that target developing medicines for particular ethnic groups. I represent a Chinese community, and we serve over 4000 individuals throughout the year across different age groups. They are all dif-
different, from different countries and backgrounds. They brought in a lot of different experiences and expectations when they came to this country as immigrants. One thing we try to do is look at them as individuals rather than as a large ethnic group. We have some who come from mainland China, Hong Kong, [and] Vietnam [and] some who come from other Southeast Asian countries or other places, like Europe. They [have] brought in different socio-political backgrounds in understanding their environment. Immigrants coming from mainland China come through political and cultural upheaval. They have not really experienced what it means to have freedom of speech. When they speak, they have to be concerned about whether they are giving their private information to others. They are afraid that people next door may be eavesdropping on them. I think that it is important to understand their concerns and fears when they come to the new country and what experience they [have] brought with them. A lot respond with a lot of skepticism.

Binyam Tamene

The community members who we provide services to have come from Ethiopia, but most of them [came] from refugee camps [where they had] very traumatic experiences. Because of political instability, people have gone through imprisonment, torture, and all kinds of traumatic experiences. They left their country to protect themselves from hardship they faced in their own country. And, in the refugee camps, they had a hard experience. The people whom we serve had a very traumatic experience from their own government. Any kind of institution is to be seen with suspicion. [The people whom we serve] come from a society where family is very important in the life of every member of society. They totally depend [on], interact [with], and get things done in interaction with their extended family. But, when they left, they happened to find themselves alone and lonely. They settled in America as just a wife and husband and maybe 1 or 2 children. [They had] no big family, no extended support. And that extended family back in Ethiopia has a very important meaning for them, because every problem gets addressed within the nucleus of the extended family. Any problem has to be addressed and resolved within the family and by the family. Things do not go outside of the family. When they come here, that support is not there. They get into loneliness, depression, and all kinds of problems that you can imagine.

Carolyn Leung Rubin, EdD

I want to also emphasize that when you talk about the API [Asian/Pacific Islander] community, it is an extremely diverse community by language, generation, ethnicity, and class. So people often ask me, “Why do you talk about APIs?” You have to remember that 40 years ago, people were calling us “Orientals.” We were called the same thing that people called rugs. It was a very empowering move for the Asian American community to say, “We want to be called ‘Asian American.’ ” And now in the last decade, we want to be called “Asian and Pacific Islanders” or “APIs.” We face the delicate task of being heard by policy makers. We cannot just say, “I am Hmong” or “I am Lao.” We have to say, “I am Southeast Asian” or “[I am] API.” We know, in the policy world, [that] numbers matter. If we do not have the numbers behind us, we do not get heard at the national level. At MAP for Health [Massachusetts Asian and Pacific Islanders for Health], we work with people who are HIV-positive, who are gay, lesbian, bisexual, and transgendered. We sometimes find that, within our own communities, we do not get acceptance. So we reach across to other API communities to find others for solidarity. It is another reason why “API” is a political term.

I think it is important to conduct research that looks at smaller communities; this is really important for the API community. When you look at us at the aggregate, national level, it looks like we are doing okay. Education rates are not so bad. But, if you start to disaggregate the data by ethnic group [and] by region, then you see a lot of disparities. The disparities are not just by ethnicity. What you often hear is that people will say, “Okay, let’s look at Southeast Asians.” Then you see some different poverty rates. It is not just that all the Chinese are doing okay either. If you look at Boston’s Chinatown or New York’s Chinatown, then you see some very high poverty rates too. I think it is really important to do small, localized studies.

Abdirahman Yusef, MPA

The Somali language only [became] a written language in 1972. People spoke through proverbs, poetry, and songs. It is not just a question of interpreting language but interpreting concepts. It is framing. I am bilingual and bicultural. Sometimes, I have to create words in Somali to get across the concept. Some concepts do not exist in Somali language or culture. So I have to use metaphors and other things to get across the concept. I am not only an interpreter. I am forced to think highly creatively to get things done. For people to recognize that knowledge base is very important and beneficial to everybody.

BUILDING RAPPORT

Working with and within the community requires forethought and specific attention to how people will perceive
researchers and the research activity. Each community may have unique characteristics or norms that should be understood and considered, not only for the implications for research at hand but also for building relationships that establish rapport, understanding, mutual education, and sustainable partnerships.

**Joseph Wu, MA**

Language is the number one issue that researchers have to think about for building connection, rapport, and trust. Language is the way to bring in rapport. Researchers bring materials that are so esoteric, and people do not understand [them]. What does “randomization” or “placebo” mean? It is very new to them and hard to understand. Use interpreters, patient navigators, and preresearch outreach and provide educational workshops so [that] people will understand what you are doing and your values. Avoid research jargon, and do not intimidate people. It is building walls rather than breaking them down.

In our culture, people do not just make decisions about themselves but about how their family would be affected, whether time would be taken away from their family and taking care of children. Many people that I work with work in restaurants. They work very hard. They work in places where they are not receiving equitable benefits and they are facing a lot of competing needs. Build research around people’s daily communities. It is “going in” and not “taking them out.”

**Binyam Tamene**

Talking about developmental disabilities is something foreign in Ethiopian culture. It does not mean [that] there is not disability back home, but as I mentioned before, those things stay in the family. If there is a family member with a developmental disability, it is something of a shame for the family, something [caused by] their “sin.” So they do not talk about it. If one wants to help them, if indeed you have an intention of helping them, then it takes them a lot of time to really understand your intention. Some of the things I hear from my friends [are] also said about the Chinese, also said about the Haitians, also said about other people; with [the] exception of the language, it seems almost similar. It is very difficult to get the trust of an Ethiopian. It does not mean that they do not want to trust you, but because of past experience [it may be difficult for them]. In their past experiences, the ones who trusted [others] had very hard times.

In Ethiopia, any kind of research comes from the government. Take the case of the Ethiopian census. Who trusts them? So when [people] come for the first time, even to the ECMAA, they think that you are an extension of the government. It takes a while for them to understand us. For some reason, Ethiopians take a longer time to trust you.

**Abdirahman Yusuf, MPA**

Community members ask, “What is this going to do for us, and why do they want to know these things?” Remember, the folks that we work with are newcomers. Most do not speak English. We have to explain concepts and ideas and why. It is not something they are familiar with. We have to do the education before the education. You have to answer [questions like] “What is research?” and “Why do these people want to know these things?” before you can get to the research. You have to address what this research is going to do for them. Many of our clients are former refugees who have gone through civil wars, lost loved ones, were maimed and raped. There are all kinds of problems.

The Somali Development Center and the Congolese Women’s Association are working together with Boston Medical Center to develop a curriculum for staff, mostly female staff, to work with women. We were able to host focus groups of women and help Boston Medical Center gather Congolese and Somali women to talk about very difficult life issues. We hosted it in the same room as the [English-as-a-second-language] class with our bilingual/bicultural staff. The women felt very comfortable, and we were able to get good information that will eventually help [the community].

**VALUE OF RESEARCH TO THE COMMUNITY**

Researchers are highly trained in the technical and ethical aspects of research. Each researcher tends to have specific in-depth content knowledge in their discipline and hopes to acquire new knowledge that leads to progress. Researchers working with human subjects must follow ethical guidelines that protect the dignity and welfare of individuals. Yet, little guidance has been given to the potential for community-level benefits and harms. Discussants raised important reasons why CBOs and communities would engage in research.

**Joseph Wu, MA**

The Boston Chinatown Neighborhood Center is a multiservice, multiprogram agency. We always ask ourselves on a management level if we are a learning organization. Is the work that we do creating the right impact? Funding agencies are reading our proposals and asking how we are going to measure impact and how we quantify this in our reports. As program directors, we put on our research hat, [try to] know and understand what we are doing, and how we can measure the impact. Whether or not we are doing formal research, every day, we are experimenting by working with a lot of families and children and adults. One thing that we need to know is...
whether or not we are meeting people’s needs.

Renald Raphael, MD

We are tired of research being done on behalf of the community and data never getting translated into action. We would like to see the community not only participate but become the owner of these data. It is important to consider that it is not only about participation but also about ownership. That means that people need to be trained in how to conduct research. That means that the information that people give and the information coming from them will be able to address their needs. A recommendation to funding agencies is to not only look at research from a participatory perspective but also from an ownership perspective.

Binyam Tamene

It is important to invest in educating community members. Let us not assume that they do know or understand what we say. Learning is a process. I do not like an education that goes only from 1 side. It has to go from both sides—a 2-way street. Not only the people we seek information from need education, but also those who seek the information should understand and be aware of the people who they deal with. It takes time. It takes money. But, if we think of the long-term, it makes sense to invest. The return on investment will be greater. With any type of interaction or communication or research that we do with community members, we have to make sure that those who should benefit will benefit. It has to be straightforward. Emphasis on the benefits and on monetary rewards does not hurt.

The new immigrant can take advantage of immigrant groups that have been here for longer. For example, the ECMAA can learn from the Haitian American Public Health Initiatives about disability. The Haitian American Public Health Initiatives can mentor us and help us deal with these issues. I have radio programs on Sunday mornings, and I can reach people. Sometimes when people come with problems, they think that it is only their experience, but learning from people who have been through it is very important. We have to be helped to build our capacity. It is important. It may cost us, but the reward will be greater. Any kind of outreach, for surveys for example, should include budgeting for community organizations to help so that the right kind of information and feedback can be given.

Carolyn Leung Rubin, EdD

For CBOs, research can be used as a learning tool to help support the development of the organization. At Asian and Pacific Islanders With Disabilities of California, we are trying to use research to help us grow as an organization. We have a community intervention that we developed around improving employment outcomes, and we are trying to use research to improve that intervention.

I think about doing research from the perspective of an ally to the community. What does being an ally mean? When I think about being an ally, I think about my work with community organizing. I have worked with youth and have had to be an adult ally. I worked with GLBTs [gay, lesbian, bisexual, and transgendered] as a straight ally. I’ve worked with Southeast Asians, and although they are part of the API community and I am Chinese American, their issues are different. I’ve been an ally. What that means is you watch their back. Although I come with privilege and have a doctorate to my name, it does not mean that I speak for the community. I can support them to do their work. I look at it as “speaking with.”

I think it is time that we disrupt the notion that researchers are the experts. Real change happens in collaboration and in partnership. In doing that we can support communities to do their own research. I would like to see partnership models that blend community organizing and research. I hear a lot of themes that resonate with that community-organizing world: power, leadership, and alliances. We could have a real social movement in this country.

A MESSAGE FOR RESEARCHERS

The Opening Doors Project has benefited from the generous actions of the presenters, whose comments reflect an urgent mission to improve the well-being of the communities they serve. Each presenter views research and participation in research activities as a worthy exercise that could further their mission if:

- researchers approach communities with respect, honor, and cultural humility;
- partnerships form to align the purpose of research with an action of value to the community;
- words and language are purposefully chosen to promote understanding, create channels for communicating meaning, and demonstrate cooperation; and
- researchers value lived experience as critical expertise in partnerships.
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Pediatrics 2010;126;S137
DOI: 10.1542/peds.2010-1466G

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