

CROSS TALK

How to successfully recruit participants for autism studies

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12 MAY 2016

A critical segment of autism research requires the recruitment of participants from across the spectrum, but also from a variety of ethnic and socioeconomic backgrounds.

In reality, however, many families don't have the time to participate in research, and are unlikely to make the time if they don't eagerly embrace the study's goals.

So how do scientists successfully recruit research participants? *Spectrum* asked experts to reveal the best practices and suggest tips for balancing the needs of the research with those of the families.



Thomas Frazier

Director of research, Cleveland Clinic Foundation

Researchers should be clear about the study's goals when recruiting families to participate, and should address their individual needs.

When recruiting families, transparency is key

As both a clinician and director of the **Cleveland Clinic Children's Center for Autism**, I straddle the line between treating people with autism and encouraging them and their families to join our research projects.

Overall, I would say that 80 percent of families who come through our clinic are interested in research and 50 percent are highly motivated. But when we recruit families for studies, we make

sure that we're transparent about whether the research will have immediate benefits for their child. We're also clear about how much commitment a study is likely to take.

For example, for our eye-tracking study we explain that we're trying to develop an objective tool to track treatment outcomes in children sometime in the future — meaning it is unlikely to help their child. Because that study takes only 10 minutes, most families say yes anyway.

If we're testing a behavioral therapy, we make sure to counsel families about other available treatment options that might be a better fit for their child. For example, we are testing the effectiveness of a 10-week, low-intensity intervention. But if we feel a child would benefit from more intensive treatment, we advise families to work with our outreach coordinator to investigate other options.

Taking time:

We try not to exclude people from studies unless we feel that there's an unsurmountable barrier to their participation. We had one family that wanted to travel roughly two hours each way to participate in a pharmacological study. There was a chance this family might drop out of the study because of the commitment, but we allowed them to join and they made it through.

We had another family with a child who had very challenging behaviors. In the first half hour of the study, he bit me, bit my research coordinator, and kicked and punched us many, many times. Most researchers in this situation would have determined that the child is not testable. Luckily, our research coordinator is a board-certified behavioral analyst, and I'm a behavioral psychologist, and we took the time to work with him.

In two hours, we finished all our cognitive testing. Not only was this good for research, but the scores on his cognitive tests were 20 points higher than those obtained by his school. We were able to use these scores to help the boy's family access therapies that were more appropriate for his abilities. This experience was a cool example of how, as a clinical researcher, if you go beyond the first hurdle, you can improve your research and make life better for families.



Themba Carr

Postdoctoral research fellow, UCLA Center for Autism Research and Treatment

Researchers should encourage economically disadvantaged families to join research projects by removing barriers to access and partnering with communities.

Creative collaboration can attract diverse participants

Traditionally, families from communities with fewer economic resources are underrepresented in

autism research. In the United States, these tend to be minority families. This is concerning, given that the results from these studies directly affect how families access services. Researchers are beginning to pay more attention to this issue in autism, which is encouraging, but I think we have a long way to go.

One way to promote participation of underrepresented communities in autism research is to address barriers that may be inadvertently built into the design of some studies. As a graduate student at the University of Michigan, I had the opportunity to work on a large, multisite randomized controlled trial of an autism treatment. We quickly realized that some aspects of the project, such as transportation costs and the length of the intervention, might be making it difficult for some families to participate.

Based on this observation, we started a small study to find ways to **promote these families' participation**. We lowered the time requirement from more than a year to just a few months, eliminated travel requirements by offering in-home visits, maintained a liberal cancellation policy and helped caregivers access other sources of support in their communities. By taking the time and effort to make a few practical modifications, we were able to include a more diverse group of families than those that usually participate in autism studies.

Community building:

Some families may hesitate to participate in research because of a perception that the findings will not benefit them, and might even harm them. In the African-American community in particular, there is a history of research that put participants at great risk. There is also a sense that researchers come into a particular community, get their data and then leave. As a result, some families are unlikely to see participating in a study as a way to help a loved one on the spectrum. One way to encourage these families to participate in research is to involve them in the planning process. That way, we can ensure that the interventions we're investigating are sustainable in the community and will continue to benefit families long after the study is over.

Families from under-resourced communities may be more likely to participate in research if they feel they are contributing beyond just being a research 'subject.' Participation can range from the formation of a community advisory board tasked to approve and give feedback, to having community members directly involved in the research itself by developing research questions, co-writing grants, implementing procedures, and analyzing and disseminating results.

That sort of collaboration isn't easy to do. It requires a level of transparency, communication and trust that is rare. But collaboration will result in higher-quality research that can more readily be translated into services that benefit families from diverse backgrounds.

Paul Lipkin

Director, Center for Development and Learning at the Kennedy Krieger Institute

Online databases can build on people's interest in their own



health to build a true partnership between researchers and families.

Online partnerships can empower real-world research

A decade ago, our team at the **Kennedy Krieger Institute** in Baltimore developed the **Interactive Autism Network (IAN)**, an online registry of families willing to participate in research studies. We capitalized on what was then a growing Internet world, and people's interest in researching their own health, by linking families of children with autism to autism researchers.

Parents, and now adults with autism, can register on the IAN website at any time, and consent to be contacted by researchers. The method allows researchers who may otherwise be limited to pools of participants in their immediate geographic region to enroll families from across the United States.

Families enrolled in IAN can choose to participate in as many or as few projects as they wish. In return, they feel that they are contributing and helping other families affected by autism. They also receive updates about research findings, often directly from the researchers. It is a true collaboration and shared effort between families and researchers.

Meet and greet:

The keys to successfully recruiting research participants are active engagement and trust. We achieve these by making it clear that the researchers want and need families' help to answer the many questions that exist around autism. Through our information portal, **IAN Community**, we teach families about the research process and inform them about new research developments. We also invite families to 'meet' the researchers through interviews, articles and webinars to help humanize the science.

IAN participants help to direct the network's research goals. One of our goals is to do research that focuses on the outcomes important to the participants, rather than the priorities of researchers. An important example of parents' contribution from beginning to end is our study of elopement — a phenomenon in which children with autism wander off with no notice. In 2011, parents called for research on this potentially deadly problem. Policymakers and researchers listened and asked IAN to survey its members about elopement.

Within six months, hundreds of families enrolled in the study, helping to confirm that elopement is a huge problem and revealing new information, such as **why children choose to wander off**. The work was published in the journal *Pediatrics* in 2012, and as a result, advocates, policymakers and

researchers have started working together to stem wandering. IAN is conducting a new survey on the topic to see what strategies parents are using to ensure their child's safety.



Jorge Chavarro

Associate professor of nutrition and epidemiology, Harvard T.H. Chan School of Public Health

People are more likely to participate in long-term research if they hear about it from someone they know.

The days of recruiting participants by mail are over

The **Nurses' Health Study** launched 40 years ago with recruitment of more than 120,000 nurses committed to sharing information about their health throughout their lives. Researchers recruited a second group of nearly the same number of nurses in 1989, and we are in the process of recruiting a third group.

We've learned a lot about recruitment over four decades. In the early years, investigators collected nurses' addresses from licensing boards across different states and wrote about half a million letters asking them to participate. It was a single mailing to a large number of people and roughly half the people responded. In 1989, the investigators had to send nearly twice as many letters to get roughly the same number of people.

When we tested this same strategy in 2007, we found out that the response to this type of mailing is much, much lower — on the order of 2 to 6 percent. There are a number of reasons why that might be, but I think the most important is that there is so much junk mail. People do not open letters unless they are expecting something from somebody they know.

So we completely changed our strategy. We identified everybody who was already participating and emailed them, saying, "Hi, thank you very much for participating in this study for the past 30 years or so. We're going to start recruiting another cohort, and we think that there's nobody better to tell other people about the experience of participating in this kind of research than somebody doing it for this long. So here are the enrollment criteria, and if you know of anybody who meets these criteria, forward them the email."

Rolling enrollment:

So far, we have recruited more than 40,000 people, and this number continues to grow. When we ask participants why they joined, they say it's their relationship with the person who contacted them. Instead of a random researcher at Harvard University, it's a colleague saying, "Hey, I've been doing this for 20 years and it's pretty cool. Here's an opportunity to do the same."

The advantage of our method is that we can draw on a vast number of ongoing participants. The disadvantage is that we have no control over how and when we recruit, although we do try to keep recruitment going by asking for referrals from new participants after they've been involved for a year.

We also reach out to nursing organizations and ask them to send e-mails on our behalf. It's not spam, but it's also not a personal invitation, so the success rate for this approach is lower.

It's quite common for researchers to offer financial incentives to potential study participants.

There's good evidence that these incentives work well for one-time surveys, so we launched a pilot study to see whether incentives would also boost recruitment and retention for a long-term study. Not only did it not help, but it actually decreased enrollment.

I think this speaks to the type of people you recruit when you rely on incentives. If you're willing to participate in a long-term study, you'll probably do it regardless of a financial benefit. Being offered money to participate might actually offend you. As a result, using incentives might enrich for people who are only participating because of the money, and who will not follow up. And you may be losing the people who are the best long-term participants.