

Q&A

Questions for Laura Anthony: Teaming up to improve research

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12 MAY 2016

Volunteering to participate in a scientific study is no small commitment. It can mean long interviews, detailed record-keeping, brain scans and blood tests. For working parents of young children with autism, finding time for such tasks can be extremely taxing.

How can researchers give back to the families who work with them? By asking for their input every step of the way, says **Laura Anthony**, associate director of the Children's Research Institute's Center for Autism Spectrum Disorders in Washington, D.C.

Anthony receives funding from the **Patient-Centered Outcomes Research Institute** (PCORI) to study autism interventions in low-income schools. To get a PCORI grant, researchers must consult people with the conditions they're studying — sometimes children as young as 7 — **throughout the scientific process**, from the design of the study to the dissemination of the results.

This requirement validates a belief Anthony says she has long held: Collaborating with families only makes the science stronger. We asked her how listening to people on the spectrum and their relatives has improved her research.

Spectrum: What can scientists gain from partnering with people who have autism and their families?

Laura Anthony: We researchers often get referred to as experts, but I feel more like an anthropologist. People with autism, and their families and teachers — they are really the experts. We're just trying to figure out what works for them. You can't develop an interview or an intervention in the clinic and expect it to work in the community without their input. In most areas of my life, I really hate to be told I'm wrong about something. But in this particular area, it's so great to hear because you learn about problems before the research makes a mistake.

In fact, partnering with people with autism makes research a lot more fun. You get to be a creative investigator and a really good listener. The experimental process is more fulfilling because you know that the feedback you're getting is making your study or intervention better.

S: How do people with autism shape your research?

LA: Sometimes we ask adults with autism to look back at what they needed or wanted from interventions when they were younger and incorporate that feedback into the design of the trial. But often we're talking to children the same age as those participating in the trial.

We get intensive feedback from children with autism as young as 7 years. If they say they really hate part of an intervention or they don't like the language of a question during an interview, then we'll change it. It's better to know ahead of time if something's not going to work, and I think that's a big part of our success so far.

S: How do families benefit from participating in this process?

LA: Researchers have this reputation of swooping in, getting the data we need and then disappearing forever. I've heard some families talk about themselves or their children being used as lab rats. There's a really negative feeling about participating in research when families don't see a clear, direct benefit, either for them or for others.

When the families get involved in our projects, I think they feel valued and empowered as more than just 'subjects' in a study. They feel like they're contributing to research that will benefit the autism community at large. They want their kids to benefit, for sure, but they're also okay with answering questions about what works and what doesn't so that others can benefit.

S: What are some of the challenges of working with families?

LA: In the beginning, we had a bit of difficulty getting to a cohesive, supportive, everybody-on-the-same-page, child-centered kind of stance. Sometimes parent advocates and school administrators are used to fighting each other. So we had to work through that just a little bit when we had them on the same board. But by the second meeting, it was already better. And now, a couple of years into it, arguments are never an issue. People are really enthusiastic.

I also think it really helps that we pay all of the consultants on the board the same amount. Whether you're a pediatrician or a parent member, you make \$125 per hour. Some people worried that paying parents these higher rates would be a challenge to the budget, but I think it sends the right kind of message — that everybody is on equal footing in this process. Children get gift cards instead of money.

S: How do you connect with families?

LA: All of my colleagues, we all like being out in the real world. We often get really good ideas from people in the community and sometimes those ideas end up being fed back into the intervention we are testing or research we are doing.

Also, it's really our responsibility as investigators in academia to communicate with the public. Most parents are not reading journal articles, so we have to find creative ways to meet families. Sometimes this means doing things we're not used to doing, such as holding Twitter chats or updating our Facebook pages.

S: What is your advice for other researchers?

LA: If you're open to listening to families and self-advocates, it will make your project better. It will make your recruitment easier, it will make your intervention more successful and you'll have more fun along the way.