

VIEWPOINT

Testing school-based autism treatments takes teamwork

BY DAVID MANDELL

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The first randomized trial I ever conducted happened by accident. In 2007, my colleagues and I began writing a proposal to study what was — and wasn't — working for students with autism in Philadelphia schools. But as we were preparing our proposal, the director of autism services for the school district said he was just not interested in such a study.

"I know what services look like in this district, and I don't need a study to tell me that," I recall him saying to me. "I found two programs I want to try, and if you help me implement them in schools, I'll let you study them."

We quickly submitted proposals to the National Institute of Mental Health and the Institute of Education Sciences, the research funding arm of the U.S. Department of Education. Officials at both institutes liked the vision we had developed with the help of our community partners, including the school district and several parent advocacy groups, and offered to fund the study.

In July 2008, we started hiring staff, recruiting families and making a plan to train teachers. To our knowledge, this was the largest **community-based trial** of an autism intervention to date. What could go wrong?

Getting schooled:

The families of children with autism in Philadelphia's public schools are unlike the families that participate in most autism studies. Philadelphia has the highest poverty rate of any large city in the United States: 28.4 percent. More than 75 percent of public school students qualify for a free or reduced-price lunch.

We are also a majority minority city: 44 percent of our residents are black, 14 percent are Hispanic or Latino, and 15 percent of families in the metropolitan area speak English as a second language.

A review published 7 March in the *Journal of Special Education* found that only 18 percent of autism intervention studies **detail the race and ethnicity of their participants**, and the overwhelming majority of participants in those that do are white¹. Although some researchers are trying to change this trend, **it's still very much the norm**.

For many reasons, including a general distrust of researchers and concerns about immigration status, minority families are **much less likely to participate in research** than are white, middle-class families.

We had proposed to recruit 168 families by October. We attended every event for families of children entering kindergarten, spoke with every autism parent advocacy group, sent out thousands of flyers and visited dozens of early-intervention programs across the city. But by the beginning of September, we had only 41 families. I woke up in the middle of most nights in a cold sweat, racking my brain for solutions.

In September 2008, the pace of enrollment accelerated dramatically, however. If I'm honest, I'd have to say that I don't know exactly why. But the events that unfolded suggest the reason has a lot to do with teachers.

Finding families:

We **trained our first group of teachers** that September. Most of them were thrilled about the additional support and training they were going to get. They were even more enthusiastic about the program materials we promised to provide free of charge and the coaches who would visit their classrooms regularly to help them put their training into practice.

The teachers started talking with families directly and sending home consent forms with notes describing the study and its benefits. As you might imagine, the families trusted the teachers and were a lot more responsive to them than they were to us. Thanks to the enthusiasm and commitment of these teachers, within just a few weeks, we met our recruitment quota.

By September 2010, we had enrolled 492 families that mirrored the demographic profile of Philadelphia.

We've tried more direct approaches such as parent nights where we serve dinner and provide childcare, and courses on toilet training or dealing with aggressive behavior. But turnout is consistently low, regardless of when and where we go. If a parent has to get on a bus or subway to attend a course after a hard day of work — especially if they're among the 50 percent of our parents in a single-parent household — they're just not going to do it.

Equal treatment:

Parents and teachers also liked the fact that every child would receive an evidence-based intervention. Most studies compare an experimental treatment to ‘treatment as usual’ — that is, whatever people would get anyway. Even in studies in which the control group gets the therapy after the study ends, parents have to wait a year for their child to get it, despite knowing that earlier treatment is better. Many families say, “No, thank you,” to this option.

If we want to recruit families that don’t usually participate in research, we must make sure that everyone gets something meaningful right away. And clinical reports don’t count toward this requirement.

We try to make the process of participating in research painless for our participants. Autism studies are infamous for their long and grueling assessments. Researchers typically confirm a child’s diagnosis, measure all sorts of symptoms and functioning, ask parents to complete hours’ worth of questionnaires and then repeat the process again a few months later.

In our studies, we instead ask parents to complete only two or three surveys that take a total of about 30 minutes. We rely primarily on reports from teachers and our staff’s direct observations in the classroom. We often end up conducting assessments under **less-than-ideal circumstances**, such as chaotic classrooms or spaces so small they could qualify as broom closets. But bringing the study to the school and alleviating the burden on teachers and families increases our confidence that we’re including children from families that would otherwise not participate.

Toting Velcro:

We also provide all the materials that teachers and parents need to make an intervention work. For some of our programs, it means that our staff sometimes travel with a portable printer to print out program materials, laminators to protect them, and giant rolls of Velcro to hang the posters on the walls. Often the biggest challenge to implementing an intervention is having the right materials on hand.

Constant change is yet another challenge when it comes to working in schools. Administrations change, teachers’ requirements change, the culture and climate of school districts change. Schools may even close due to lack of funding, especially in cash-strapped urban districts.

We’ve been through more changes in the administration of Philadelphia’s school district than I care to count. So each year, we invest significant energy in building and maintaining relationships among new administrators, principals and teachers. If we neglect these relationships, we pay for it.

I work with a brilliant team of scientists, clinicians and research support staff who see the work we do as a kind of social justice. They are sensitive to parents’ and teachers’ needs because many of them are parents and were teachers. They understand that parents and teachers are experts in the children they care for, have those children’s best interest at heart, and also have many important

priorities that compete with what we are asking them to do.

Now that we are in the middle of our second randomized trial and fifth community-based study, we have figured out ways to successfully engage under-resourced families in research. It is our mission to find more and better methods for reaching these families, and we welcome opportunities to collaborate with others who see it as their mission, too.

David Mandell is associate professor of psychiatry and pediatrics at the University of Pennsylvania.

REFERENCES:

1. West E.A. *et al. J. Spec. Educ.* Epub ahead of print (2016) **Abstract**