

OPINION, Q&A

Questions for David Mandell: Curbing autism's costs

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hobbit/Shutterstock.com Pricey path: Having autism comes with high lifetime costs — a trajectory that current therapies do little to alter.

In 1955, the U.S. institutionalized more than 500,000 people, including many with autism. This was a failure of the system to truly care for people with the disorder, says David Mandell, associate professor of psychiatry and pediatrics at the University of Pennsylvania.

Things may not be much different now.

Last year, Mandell laid out the costs of having autism, from lost productivity to pricey hospital stays¹. He found that it is the fourth most expensive condition in the U.S., trailing behind only trauma, cancer and cardiovascular disease. What's more, data from Medicaid claims suggest that available autism therapies do little to lower these costs.

In an interview last week, Mandell talked about the biggest barriers to providing effective care for people with autism and the policy changes needed to right this course.

SFARI.org: What is the total economic cost of autism?

David Mandell: It's both a direct cost (what is spent) and indirect: (what is lost). We compared both sets of costs with those of a typically developing child and found that the incremental cost for an individual with autism and intellectual disability is \$2.4 million over his or her lifespan. For an

individual without intellectual disability it is \$1.4 million.

S: Why are these numbers so high?

DM: There are three major things that make autism so expensive. The first is that it appears very early in childhood; you have a disorder that runs the length of someone's lifespan.

The second is that autism is chronic. If you are diagnosed with depression, the depression could appear for certain chunks of time in your life but not all of it. Although the symptoms may vary and the trajectory may change, autism is really **a chronic condition**.

The third is that we **don't have good treatments** and supports that truly change the trajectory of autism.

S: How would you want to change the trajectory of the disorder?

DM: We're specifically talking about ameliorating the disability. We need to separate out disability from impairment.

Impairment is the extent to which a person is not able to function the way that a typical person functions. Disability is the extent to which there are societal constructs that make it difficult to operate with that particular set of symptoms. In the U.S., and in many other countries, we have a set of societal expectations that make it very difficult to operate as a person with autism.

S: Can available treatments help with the disability?

DM: We have a **number of early interventions** that lead to big changes in cognition and adaptive behavior. But we haven't done a good job of studying how that plays out across an individual's lifespan or continuing to **provide support as people get older**.

What's more, we are not good at translating those interventions from the laboratory to the community. Whatever these interventions are showing at a university-based research setting, they aren't showing the same effectiveness in a community setting.

S: How did you discover this gap between the lab and community settings?

DM: We came at it both from the top-down and bottom-up perspectives. From the top, we looked at large datasets and realized that the volume of so-called 'therapeutic' services that individuals were receiving seemed to make no difference in outcomes that we could measure. We looked at psychiatric hospitalization and whether an individual is on three or more psychiatric drugs at the same time. We did not observe any effect of these therapeutic services on these important outcomes — that really made us wonder.

The bottom-up approach was being in community agencies and schools and realizing that the interventions that I observed community practitioners using had little connection with what we would think of as the evidence base. The individuals who were delivering these interventions were passionate and well-intentioned. But they did not have the requisite training or support to implement evidence-based care with fidelity.

S: What would these individuals need to better implement interventions?

DM: When clinicians and teachers implemented interventions with fidelity — that is, when they implemented them the way they were designed, with the recommended level of accuracy and intensity — children showed impressive improvements in outcome. But this was rarely the case.

‘Efficacy’ is the extent to which interventions result in the desired outcome when they are delivered in an ideal setting. ‘Effectiveness’ is the extent to which an intervention shows the desired outcome when it’s delivered in the real-world setting with the resources available in the community. There’s a huge difference between the two. Few interventions that have demonstrated efficacy also demonstrate effectiveness.

Part of that is that these interventions can be difficult to implement in the way they were designed to be implemented. Part of it is that the kids in the real-world setting often differ dramatically from the kids who are in efficacy studies — for example, they may have more severe behavioral problems or co-occurring disorders. And the clinicians and teachers in the community don’t have the same resources and support that clinicians in university-based research studies have.

S: What are some barriers to closing this gap between efficacy and effectiveness?

DM: Implicit in a lot of our efforts to implement evidence-based practice is the belief that the rate-limiting step is skill. We spend a lot of time training teachers to use interventions, and when they don’t implement them the way we designed them, we train the teachers some more.

Our research has led us to conclude that skill is necessary, but it’s not sufficient. Teachers’ intentions to implement the interventions are also crucial. These intentions are informed by their attitudes about that intervention and the extent to which they think they can do it.

I went into a classroom where we were testing intervention fidelity. We walked in with the video camera and the teacher rolled her eyes and said, “Oh, you’re here, what do you want to see?” We told her we wanted to see 10 minutes of discrete trial training, a therapeutic approach that breaks down a skill into discrete steps. She pulled a kid from the classroom and did 10 minutes of beautiful discrete trial training. Then she said, “Are we done?” and put the materials away. We knew that she would not be doing any discrete trial training until we were back again.

She didn’t think it was important and she preferred more whole-classroom instruction. I think she

was resentful about having what she saw as an additional burden placed on her. Here we had someone with great skill, but lousy fidelity. Training her more in discrete trial training wasn't going to do anything.

S: What might help instead?

DM: We need to focus on helping teachers develop stronger motivation to use these interventions and a more positive environment that supports their use — creating an environment in which teachers believe the use of that intervention is expected, supported and rewarded. We also need to work with teachers to remove environmental and resource barriers. It becomes much more about conversation — trying to understand what she doesn't like about discrete trial training and why she doesn't think it fits in her classroom — and addressing those issues. It's counterproductive to go in and just say, "You should do this."

We forget what islands these autism support classrooms are in their schools. There may be one or two in a school and they have very little professional support. These teachers are floating on their own. One of the ways we've thought of addressing this issue is to create a community of teachers that transcends the classroom and creates a sense of community and shared mission and purpose.

S: You're working with certain schools as part of your research project, but how do you see this happening more broadly?

DM: I'm still working on the answer to that question. I think part of it lies with intervention developers to partner with community agencies and schools to learn what resources those places have and to think about what could be developed accordingly.

In many ways, we continue to act as if autism is a low-prevalence condition. We develop these intensive and time-consuming diagnostic measures and treatment models. They have very little hope of lasting in under-resourced, really besieged urban settings. We need to turn our attention to more of a public health approach, with less intensive interventions that have the potential to shift the entire distribution to the positive.

The second part is to really rethink our training and implementation models when it comes to training teachers and clinicians. We're trying to change their behavior, and yet we take everything we know about behavior change — and we're really good with behavior change for kids with autism — and we throw it out the window. These are people, with their own lives, their own agency and with varying knowledge, motivation and resources. We need to make sure that the support that we offer them is tailored to their specific needs.

References:

1: Buescher A.V. *et al. JAMA Pediatr.* **168**, 721-728 (2014) [PubMed](#)