

CROSS TALK

What defines ‘success’ for autism treatments?

BY CLAIRE CAMERON

12 FEBRUARY 2019

What makes a successful autism treatment depends on whom you ask. A researcher may judge a treatment based on the results of a clinical trial or on the outcome measure chosen. For an autistic person, the best measure of success might be an improvement in quality of life. To others, no ‘treatment’ makes sense for autism’s core features.

To get a glimpse of such disparate perspectives, we asked three researchers and two autistic people to tell us what a successful autism therapy looks like to them.

Deborah Fein

Professor, University of Connecticut

Treatment is more likely to be successful if a child had mild traits at the time of diagnosis and received therapy between the ages of 2 and 3.

A therapy’s success depends on the child

Obviously, there is no one way to define a therapy’s success. The simplest answer is that success is defined by the context of a specific child and treatment strategy. For example, a therapist defines a goal that the child is likely to be able to achieve, and that will make a difference to the child’s life. This goal may be accurately copying a circle, requesting a juice box by pointing to it or starting a conversation with a peer. The clinician defines a time frame for achieving that goal — say, three months. If the goal is met as specified, the intervention was successful.

But on a broader scale and a longer time horizon, success might be measured in terms of the difference between a child’s functioning in important domains — communication, daily-living skills, academics and so on — and her likely potential in those areas. For some children a brain

malformation or known genetic etiology sets limits on that potential.

For most children with autism, however, their cognitive and emotional potential is not known. The best way to estimate it is to get them the best therapy as early as possible and see how quickly and in what domains they progress over two years. One might know at that point, for example, that motor and self-help skills can improve quickly but expressive language is extremely difficult.

This pattern of growth is likely to persist and can help clinicians and parents set optimistic — but realistic — goals. Only then will they have any idea about the bigger questions: whether a child will be able to finish high school or go to college, marry or support herself.

In our long-term outcome studies, we found that a minority of children lose their autism traits and attain typical levels of social, cognitive and linguistic functioning. We dubbed this an ‘**optimal outcome**.’ It was hard to predict who would reach this outcome, but it was more likely if a child had mild traits at the time of diagnosis, especially in the motor domain, and received a therapy called **applied behavioral analysis** (ABA) between the ages of 2 and 3. Two other teams of researchers identified similar groups of children.

Carol Greenburg

Editor, Thinking Person’s Guide to Autism

Many conditions that co-occur with autism require treatment, but autism in and of itself does not.

Autism needs no treatment, just support

What I don’t know about my distant cousin J. outweighs what I do know. I’ve never met J., but whispers about her were an ominous presence throughout my childhood. I know she is almost exactly my age. Like me, J. is autistic, though she was diagnosed as a child, whereas I was diagnosed at age 44.

Both of us grew up at home instead of in an institution. It never occurred to my parents to raise me anywhere else, because I spoke and therefore seemed ‘normal.’ But my mom thought that J. should have been institutionalized to spare her family the lifelong burden of caring for her. My mom said that having an autistic child was the worst thing that could happen to a parent, not knowing she herself had an autistic daughter whose views she was shaping with those words.

I’m not out to demonize my family. In the 1960s and even into the ’70s, it was unthinkable that education or anything that looked like community-based work and life applied to someone like J. Autism put J. into the category of ‘untreatably ill’ as a child. Like J., my son, who is also autistic, spoke few words when he was young. He, too, has high-support needs. But from there, J.’s experience and my child’s diverge dramatically.

Like others in the neurodiversity movement, I regard autism as a disability, not an illness. In both

my personal and professional opinion as a special-education advocate, autism in and of itself requires no treatment. Many illnesses and other medical conditions that tend to co-occur with autism do require treatment, however.

Although the distinction may seem inconsequential to many family members and autism professionals, it is important to me. Another important distinction: Treatment and intervention are not the same as support. Although J., my son and I may or may not need treatment for co-occurring conditions, we all need support. Of the three of us, I'm pretty sure my son is the only one who is getting even close to the type and level of support he needs.

For my son, support begins, but does not end, with acceptance from family and friends. My son needs and gets a one-on-one education. Under the Individuals with Disabilities Education Act, he is legally entitled to this. We are working on high support to continue into at least part or all of his adulthood for his living and employment choices. Please note, I wrote it and I meant it: These choices are his. Lack of spoken or written language does not erase his ability to communicate; we have to make a serious effort to fully understand what he works hard to tell us.

Most autistic adults are not as lucky as I am to get plenty of personal support from loved ones. However, like most verbal autistic adults, I get absolutely no institutional support. Just because I speak doesn't mean I don't need specialized healthcare or help as a disabled parent getting services for my disabled son. As my son ages out of school, and as I age, everyone in my family needs more and better-quality scientific research that focuses on our quality of life. We need research on issues such as the astronomical rate of **suicidality in autism** and **co-occurring physical and mental illnesses**, more than we need research focused on the causes of autism.

Connie Kasari

Professor, University of California, Los Angeles

Measuring the success of an early intervention should involve metrics that are meaningful for the lives of autistic children.

Well-designed studies identify effective autism therapies

What defines 'success' for an autism intervention is a critical question for both researchers conducting early-intervention studies and families searching for ways to help their children. Randomized controlled trials provide the most trustworthy evidence of a therapy's effectiveness. However, trials are often not replicated. They also often compare treatment with no treatment or with poorly defined services instead of another viable intervention. Add to this the fact that there are probably more 'reviews' than there are studies to review, and you can see how we get stuck in our understanding of what constitutes success.

Beyond the obvious shortcomings of our research base, outcome measures used in research may

be idiosyncratic or have only limited applicability to a particular child. Take the use of intelligence quotient (IQ) as an outcome. Low IQ is not a core feature of autism, and many children with autism have an IQ in the typical range, so the goal should not be to increase IQ. By contrast, social-communication problems are a core feature, and improving social communication can have far-reaching effects on later development.

We now know that early interventions can lead to meaningful social-communication outcomes, such as improved engagement with others, joint attention and play skills. Using an intervention called **JASPER** we developed at the University of California, Los Angeles, we consistently find significant effects on social-communication skills, which are linked to later improvements in language and cognition.

However, children's needs change over time, and no single intervention works for all children. Most children benefit from a combination or sequence of interventions. For some time now, my colleagues and I have advocated for **studies of personalized interventions**. To this end, we are exploring designs that modify treatment based on the child's progress. This approach can help uncover the unique, effective elements of an intervention. Knowing these elements, as well as details such as how long to wait for response and when to change course, is critical for refining and assessing autism treatments.

Benjamin Alexander

Writer, Freelance

Therapies that keep the child focused and communicating — whether verbally or nonverbally — have the most promise.

Therapy brings my nonverbal words into the world

I was diagnosed with autism 21 years ago. At the time, no one gave any suggestions to my parents as to how to help me. Many a late night, my parents surfed the web to find anything that might bring me out of the funk of autism. When I was 3, my parents made an appointment with a doctor named Stanley Greenspan. Unfortunately, we had to wait several months to see him in Bethesda, Maryland — a long way from our home in New Orleans, Louisiana. So in the meantime, my long run from autism began with a therapy called applied behavioral analysis (ABA).

My parents hired a consultant group from Portland, Oregon, to come to New Orleans and teach college students how to perform ABA. How can I describe it? The therapy was very Pavlovian because I was asked to respond to requests. If I responded correctly, I would be given a treat, usually Goldfish crackers. There were never bolts of electricity given to me if I gave a wrong answer, but I sure felt like an animal in a Skinner box. It was mindless and involved no thinking at all.

“Show me the ball, Ben.”

“To hell with you!” I would say in return, in only the silent speech that I had.

“Identify the book and you will get a Goldfish, Ben.”

“I hate Goldfish,” I replied through my hand-flapping.

After about six months of these mindless exercises, my parents decided to call it quits because they saw that I was miserable. So, can I say that ABA was successful for me? I could speak a few words as a result of the many hours of identifying objects by recall. Did ABA cure me of autism? Absolutely not. I could not function like your everyday neurotypical kid, so it was off to the next intervention.

My next trial of therapy was the ‘Floortime’ technique Greenspan espoused. This method was different from what I was used to because it made me think, and not just respond for food. There were no external rewards, only the satisfaction of doing whatever I wanted. Greenspan told my parents to get down on the floor with me and follow my lead. He said that if we did what I wanted to, instead of what they wanted me to do, it would help develop my mind.

Would I consider Floortime a ‘success’? Once again, no, as I am still nonverbal, although I can express my creative ideas by typing. However, I firmly believe that Floortime made a difference by developing my thought processes and creativity.

To me, it seems that therapies that keep the child focused and communicating — whether verbally or nonverbally — have the most promise. In my case, I spent hour after hour typing with a speech therapist so that I could express my thoughts and ideas. Was this method successful? I am still very much autistic, but the therapy has helped me bring my nonverbal words to the world.

Matthew Siegel

Director, Spring Harbor Hospital

Success for some autistic children is stripping away the anxiety, the pain, the aggression — leaving just autism and its challenges.

Success means helping autistic people get back to just having autism

Much of my clinical work occurs at an inpatient center that primarily serves school-aged children with severe forms of autism.

These children are typically minimally verbal and have intellectual disability. Many also have significant psychiatric or behavioral challenges, such as aggression (toward others and themselves); severe, prolonged episodes of emotional dysregulation (tantrums); anxiety; attention deficit hyperactivity disorder; depression and, occasionally, psychosis. Typically, they have had multiple drug and behavioral treatments that haven’t worked. Our center is often the last stop of a

long journey.

So, for me and my team, 'success' means, perhaps strangely, helping a person get back to just having autism. Our goal is not to make a person 'normal' or 'perfect' or 'great,' but to ease the anxiety, reduce or eliminate the self-injury, quell or stop the aggression. If what is left is simply autism and its challenges, that is a success.

People stay with us for about a month, on average. Over that time, they receive multiple assessments, ABA and an individualized behavioral plan. Most also receive targeted medication, speech and occupational therapy. Sometimes, we need to work with families on the child-parent relationship. We also look for medical issues and sources of physical pain — which can be a major factor in behavioral problems — and we treat any such problems. If at the end of a month significant problems remain, we keep going. In a minority of cases we have to explore other options, such as longer-term residential treatment facilities.

Ultimately, we want individuals to re-engage in the life they had before things worsened. For a lot of the children, their world has shrunk significantly. As a result, their quality of life is extremely low. Autism researchers tend to focus on addressing the condition's core features instead of on quality of life. Thinking about an intervention's outcomes in terms of quality of life requires a shift in perspective, but it's a necessary shift when treating these individuals.