Autism Speaks



Walk Donate Q

Autism and 'optimal outcomes' – Is it time to refine our thinking?

Two of the world's leading experts on autism intervention urge researchers and clinicians to reconsider the goal of autism services

By <u>Stelios Georgiades</u>, co-director of the McMaster [University] Autism Research Team, in Hamilton, Ontario, and psychologist <u>Connie</u> <u>Kasari</u>, of the Center for Autism Research & Treatment, at the University of California, Los Angeles. Drs. Georgiades and Kasari both serve on the <u>Autism Speaks Medical and Science Advisory Committee</u>.



For decades, we've heard autism described as a disorder of brain development. More recently, we're seeing it embraced in the context of neurodiversity. Neurodiversity frames autism as an example of the differences in human brain development – with no one standard labeled as "normal."

At first glance, the two views – disorder versus neurodiversity – may seem at odds. In "**Reframing Optimal Outcomes in Autism**," in this month's *JAMA Pediatrics*, we find common ground by rethinking the goals and scope of interventions such as behavioral therapies, medicines and related services. (*Follow the title link to read the full opinion paper*.)

In particular, we urge autism researchers, clinicians and therapists to rethink what we mean by "optimal outcomes."

For years, we've been using this term to describe a relatively small group of people with autism who, with therapy and support, experience such a marked decrease in autism symptoms that they no longer meet the criteria we use to diagnose the condition.

In other words, their social communication skills improve and their repetitive behaviors and/or restricted interests decrease to a degree that's within the range of what we might consider "normal."

Should we focus exclusively on verbal and cognitive abilities?

But this approach focuses almost exclusively on highly verbal, cognitively able individuals as representing optimal outcomes. It overlooks the many people with autism who can communicate despite their inability to speak verbally. It likewise looks past the many people with autism who have fulfilling lives and an embracing community regardless of having aspects of intellectual disability.

Conversely, someone who has strong verbal abilities and few outward symptoms might strongly disagree with the label "optimal

outcome" if he or she is unhappy, anxious or depressed.

In short, we believe that **the old concept of optimal outcomes fails to appreciate the complex and variable ways that children – and adults – with autism grow and develop.** It's certainly incompatible with the idea of embracing neurodiversity.

Developing a more-inclusive optimum

Recently, mental health researchers Elizabeth Costello and Barbara Maughan <u>proposed</u> **re-defining "optimal outcome" as the best possible outcome based on each child's personal characteristics and available supports**.

We find this as a much more suitable concept for developing autism services and setting goals for each child, teen or adult. The focus is not on reaching certain milestones related to their "typical" peers. Rather it's social and community engagement and any emotional, cognitive, moral or physical Complete your \$90 gift

Nost importantly, we need to include the person with autism and his or her fa apportant and meaningful outcomes.



Autism and 'optimal outcomes' - Is it time to refine our thinking? | Autism Speaks

Changing our notion of optimal outcomes is a big step toward an inclusive spectrum approach. The next step is to consider how services and supports must change and adapt based on how a child, teen or adult develops and benefits from interventions.

In autism intervention research, knowing *when* to change something and *to what* are vital questions that we're just beginning to address.

There is considerable agreement in the autism community that whatever "view" of autism we embrace – disorder or diversity – the immediate challenge for researchers is to deliver the evidence that people require to effectively select, personalize and adapt interventions to meet each person's variable and changing needs.

We hope you'll join us in this conversation by emailing us via <u>research@autismspeaks.org</u>.



<u>Subscribe</u> to *Autism Speaks' Science Digest* to receive autism research news and expert advice posts delivered quarterly to your inbox.

4.7k Shares



BLOG

The Hatching Hope Foundation brings advocacy and support to Dallas-Fort Worth families



BLOG

Expert Q&A: Genderaffirming care for transgender autistic youth



BLOG

Self-advocacy tips for LGBTQIA+ autistic adults seeking medical care

adulting on the spectrum

PODCAST

Adulting on the Spectrum: On autism advocacy and TikTok

adulting on the spectrum

PODCAST Adulting on the

BLOG Meet Molly and



Expert Q&A: Tips for



How to make the

<u>Spectrum:</u> <u>Synesthesia and</u> <u>experiencing the</u> <u>world through senses</u> <u>Brendan, a young</u> <u>couple from</u> <u>Whitehorse, Canada</u>

<u>an active and healthy</u> <u>lifestyle</u> holidays more meaningful for yourself and your autistic loved ones

Need Personalized Support?

Our Autism Response Team (ART) is specially trained to connect people with autism, their families, and caretakers to information, tools, and resources.

Get in Touch with ART 🕨

https://www.autismspeaks.org/science-blog/autism-and-optimal-outcomes-it-time-refine-our-thinking

Donate 🕨

News, Updates & More

Sign Up Now!

Follow Us

f 🖸 in 🗗



Contact Us Privacy Policy Terms of Service RSS Grants

© 2023 Autism Speaks Inc. 501(c)(3) organization, EIN: 20-2329938.

https://www.autismspeaks.org/science-blog/autism-and-optimal-outcomes-it-time-refine-our-thinking