

House Committee on Energy and Commerce

Subcommittee on Health

Subcommittee Hearing – February 14, 2024 at 10 am – Rayburn 2123

Hearing title: Legislative Proposals to Support Patients and Caregivers

Testimony of Dr. Andy Shih – Chief Science Officer, Autism Speaks

Thank you, Chairman Guthrie, Ranking Member Eshoo, and all members of the Committee for holding this hearing and for inviting me to testify on the Autism CARES Act of 2024. I would also like to thank Rep. Chris Smith and Rep. Henry Cuellar for their leadership in introducing this important bill.

I am Dr. Andy Shih, Chief Science Officer for Autism Speaks, a national, non-profit organization dedicated to creating an inclusive world for people with autism throughout their lifespan. We do this through advocacy, services, supports, research, and advances in care.

This Committee has long recognized the urgent need to invest in autism research and training programs to ensure better care and wellbeing for autistic people. The Autism CARES Act is a remarkable example of how bipartisan collaboration can propel progress.

The most recent data from the National Center on Birth Defects and Developmental Disabilities indicates that 1 in 36 children and 1 in 45 adults are on the autism spectrum.¹² Like everyone else, each autistic person has unique strengths and challenges. Over the past two decades, we have seen a fundamental change in our understanding of autism and, most important, acceptance of autistic people.

At the same time, in large part due to the research that the Autism CARES Act has funded, we also have a much clearer picture of the significant disparities that autistic people experience in terms of access to quality health care, daily life supports and services, and employment opportunities. We know that autistic people struggle with a myriad of co-occurring health conditions at much higher rates. For example, about three-quarters of autistic children have one or more mental health

¹ Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-2):1–14.
DOI: <http://dx.doi.org/10.15585/mmwr.ss7202a1>.

² Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. *J Autism Dev Disord*. 2020;50(12):4258-4266. doi:10.1007/s10803-020-04494-4

conditions.³ Inextricably linked to these challenges is that many of the inequities that exist within our society are exacerbated for people with autism, which can often lead to poorer outcomes.⁴⁵

To be sure – we have come a long way. Around thirty years ago, the National Institutes of Health was spending less than \$10 million a year on autism research and autism was thought to be extraordinarily rare. Since the first version of the Autism CARES Act was signed into law, we have seen tremendous progress. For example, we have begun to learn about the molecular mechanisms that account for individual differences in autistic people, helping to lay the groundwork for personalized healthcare.⁶ We also have a better understanding of how environment, including social determinants, can influence wellbeing and outcome, and importantly, how to intervene at individual, family and community levels to enhance health equity.⁷

The Autism CARES Act has been the single greatest driver of autism research investment and training programs for future health professionals who serve autistic people. It has led to countless advancements in our understanding of autism, from the biology of the condition to the medical complexities that affect autistic individuals at much higher rates. Through support of clinical and community-focused programs, the Autism CARES Act ensures this knowledge reaches all families through improved services, personalized interventions, and toolkits for autism-specific challenges.

This work has formed a critical foundation for moving forward. With reauthorization of the Autism CARES Act, we will build on the progress made to close the significant gaps that remain for too many autistic people and ensure that every autistic person is able to reach their full potential. This includes investing more in research focused on the daily life challenges of autistic adults and improving our understanding of autism and aging, such as elevated risks for dementia and heart disease. It includes furthering research on how to reduce disparities in autism diagnoses and access to services. It includes ensuring that we are researching how to best support autistic people who are non-speaking or may need additional communication supports. It includes investing in more research to how we can best meet the health care and safety needs for autistic people who require 24-hour care and may struggle with harmful behaviors. And so much more.

I will just close with this thought. With the increased autism prevalence rate, coupled with a much greater acceptance of autism in our nation, it's likely each of you knows someone – a loved one,

³ Rast, Jessica E., Garfield, Tamara, Roux, Anne M., Koffer Miller, Kaitlin H., Hund, Lisa M., Tao, Sha, Kerns, Connor M., Rosenau, Kashia A., Hotez, Emily, Anderson, Kristy A., Shattuck, Paul T., and Shea, Lindsay L. National Autism Indicators Report: Mental Health. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, August 2021.

⁴ Anderson, Kristy, A.; Roux, Anne M.; Steinberg, Hillary; Garfield, Tamara; Rast, Jessica E.; Shattuck, Paul T.; and Shea, Lindsay L. National Autism Indicators Report: The Intersection of Autism, Health, Poverty and Racial Inequity. Philadelphia: Policy and Analytics Center and Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, April 2022.

⁵ Karpur A, Lello A, Frazier T, Dixon PJ, Shih AJ. Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016. *J Autism Dev Disord.* 2019;49(4):1652-1664. doi:10.1007/s10803-018-3862-9

⁶ Buch AM, Vértes PE, Seidlitz J, Kim SH, Grosenick L, Liston C. Molecular and network-level mechanisms explaining individual differences in autism spectrum disorder. *Nat Neurosci.* 2023 Apr;26(4):650-663.

⁷ Constantino JN, Abbacchi AM, May BK, Klaiman C, Zhang Y, Lowe JK, Marrus N, Klin A, Geschwind DH. Prospects for Leveling the Playing Field for Black Children With Autism. *J Am Acad Child Adolesc Psychiatry.* 2023 Sep;62(9):949-952.

friend, neighbor, or constituent – who is on the autism spectrum. I would also guess that if each of you turned to speak with the colleague next to you, that the individual experiences, the strengths and challenges of the autistic person you are thinking of, would be very different. As you move towards reauthorizing and enhancing the Autism CARES Act, I urge you to keep those individuals in mind. Let's work to ensure that they, along with millions of others on the spectrum live the best life possible. Thank you again for the opportunity to testify and I look forward to your questions.