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Chief Science Officer, Autism Speaks

Response to Question for the Record from House Committee on Energy and Commerce Subcommittee on Health hearing on February 14, 2024, entitled, “Legislative Proposals to Support Patients and Caregivers.”

Question From Rep. Neal Dunn

Genetic counselors play an essential role when there are genetic aspects to disease and conditions. They ensure patients and family members who would benefit from genetic testing gain access to appropriate testing and ensure physicians and their patients understand test results well. Genetic counselors also help navigate follow-up care and identify clinical trials that may be of benefit. Today, Medicare does not reimburse genetic counselor services. Should this policy change?

Response from Dr. Andy Shih – Chief Science Officer, Autism Speaks

We believe both Medicare and Medicaid coverage of genetic testing as well as genetic counseling, which go hand in hand, could be beneficial for many autistic people and their families. To be clear, we support this because we believe the knowledge gained from genetic testing and counseling can be critical to identifying risks and early intervention for co-occurring health conditions that autistic people experience at higher rates and thus help to close the significant gaps in appropriate health care access and outcomes that exist for autistic individuals.¹²

We know from research findings that autistic people are more likely to experience a myriad of co-occurring health conditions, including seizure disorders, gastrointestinal issues, sleep disorders, and mental health conditions.³ Genetic testing, particularly at a young age, coupled with genetic counseling, can help prepare individuals and families for navigating their future health care needs based on any risks identified in genetic testing. This could potentially lead to important preventive care interventions that could significantly improve the quality of life for many autistic people. Unfortunately, genetic testing and counseling is often costly, and particularly for families that rely on Medicaid as their primary health coverage — this could be out of reach. We hope that the Committee will consider taking additional steps to ensure Medicaid coverage of both genetic testing and genetic counseling moving forward.

Similarly, we also believe that Medicare coverage of genetic testing and genetic counseling could be beneficial for many autistic people. CMS data indicates that 1.6% of fee-for-service Medicare

¹ Karpur, Arun et al. “Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children’s Health 2016.” *Journal of autism and developmental disorders* vol. 49,4 (2019): 1652-1664. doi:10.1007/s10803-018-3862-9

² Rast, Jessica E., Roux, Anne M., Anderson, Kristy A., Croen, Lisa A., Kuo, Alice A., Shea, Lindsay L., and Shattuck, Paul T. *National Autism Indicators Report: Health and Health Care*. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, November 2020.

³ Prevalence of co-occurring conditions in children and adults with autism spectrum disorder: A systematic review and meta-analysis. Micai M, et al. *Neurosci Biobehav Rev*. 2023. PMID: 37913872

beneficiaries under the age of 65 had claims with an autism diagnosis in 2018 (latest data available).⁴ With the increased public awareness and diagnosis of autism in recent years, we imagine that number is even higher today. As CMS has pointed out in reporting the aforementioned data, adults with autism are at higher risk of developing other chronic conditions such as diabetes, coronary heart disease, and cancer.⁵⁶ Other recent research has shown that autistic people may be at a higher risk for neurodegenerative conditions, like Alzheimer's disease.⁷ Thus, for those autistic individuals who did not access genetic testing and counseling at a young age, they could still significantly benefit from accessing these services as an adult Medicare beneficiary. Knowing the potential risks and available beneficial treatments for co-occurring serious conditions like seizure disorders, cancer, or heart disease could change the trajectory of the care received by many autistic adults. Again, as with Medicaid, we believe Medicare coverage of genetic testing and genetic counseling could benefit many autistic people.

Thank you for the thoughtful question and we would be happy to further engage with you or your staff if you would like further information.

⁴ Centers for Medicare and Medicaid Services. "Autism Spectrum Disorder (ASD) Disparities in Medicare Fee-For-Service Beneficiaries." Data Snapshot, February 2021. https://www.cms.gov/about-cms/agency-information/omh/downloads/omh_dwnld-datasnapshot-autism.pdf

⁵ Ibid

⁶ Association Between Autism Spectrum Disorders and Cardiometabolic Diseases: A Systematic Review and Meta-analysis. Chaturika S, et al. JAMA Pediatr. 2023 Mar 1;177(3):248-257. PMID: 36716018

⁷ The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder. Vivanti G, et al. Autism Res. 2021 Oct;14(10):2189-2199. PMID: 34378867