

The Autism Society of America Comments on the Access Rule

On behalf of the Autism Society of America, we write to comment on CMS–2442–P, or the Ensuring Access to Medicaid Services proposed rule. We believe this rule will have a significant positive impact on home and community-based services. Following are our comments for your consideration.

I. Workforce Compensation

The Autism Society agrees that one of the biggest challenges people face when trying to get HCBS is the shortage of direct care workers. A stable and reliable workforce is necessary to support people to live and fully participate in their communities. Without a robust direct-care workforce, many people cannot access the services they need. ANCOR found in a recent report that 83 percent of providers are turning away new referrals due to insufficient staffing. Insufficient staffing is mostly due to low wages. Therefore, we are so pleased that this rule will help strengthen the direct care workforce by establishing that 80 percent of Medicaid payments be spent on compensation for direct support professionals.

II. Access to HCBS

The federal government does not currently collect information about states' waitlists, making it difficult to determine how accessible HCBS is in different states. In addition, many states are not transparent in their waiting list numbers and how long it will take for applicants to be reviewed and receive services. As of 2021, approximately 650,000 individuals were on waitlists across the country, but it is likely that this number is higher since states are not mandated to report. The Autism Society appreciates that this proposed rule will ensure transparency. The proposed rule would require each state to describe, every year, how they maintain the waitlist; including whether people on the waitlist are screened for eligibility and whether (and how frequently) they are rescreened for eligibility. States would also be required to report how many people are on the waitlist and how long people stay on the waitlist, on average. We strongly agree with this provision. States vary in the criteria and screening process they use to deem individuals eligible. This then affects their different levels of waitlists, creating confusion among individuals waiting for services. We recommend that CMS requires states to also publicly report the criteria they use to determine placement and movement within the waitlist.

The Autism Society strongly agrees with the proposed rule requiring states to annually report the average length of time people have to wait for services to start after they are

initially approved to receive homemaker services, home health aide services, or personal care services; as well as the percentage of authorized hours provided to individuals for those same services. This reporting will identify the disconnect between the services for which people are approved and what they receive. We believe this requirement should be applied to other HCBS programs as well.

III. Person-centered planning

The Autism Society strongly agrees that services people receive through Medicaid HCBS programs must be planned using a person-centered process. People with disabilities should have a say in what services they receive based on their individual desires and needs. It is very important that these plans are reviewed and updated often to meet changing needs. We believe individuals should be able to revise the plan with their team as needed, but at least annually. More state monitoring and reporting of this issue is necessary because too many do not have person-centered plans that are reviewed so their service plans can be adjusted as their HCBS needs change.

IV. Reporting and addressing critical incidents to improve health, safety, and service quality

The Autism Society of America unequivocally believes every person should live free from abuse and neglect. People with disabilities, especially those with Autism and other intellectual and developmental disabilities, are vulnerable to verbal, physical, sexual, psychological, or emotional abuse; neglect; and exploitation, including financial exploitation. Too often, these violations of human rights are unreported or underreported. We agree with the proposed rule that requires states to operate and maintain an electronic incident management system that identifies, reports, triages, investigates, resolves, tracks, and trends critical incidents, such as accidents or incidents of abuse and neglect. We recommend that the critical incidents must also be reported to the designated Protection & Advocacy (P&A) system for the state as Federal law establishes that P&As “have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.”

Providers of services should not be the entities to provide information on incidents of abuse and neglect. The Autism Society agrees with the requirement that states use information from sources other than provider reports to identify critical incidents.

It is also important that the rule sets timeframes for investigation, resolution, and corrective actions related to critical incidents. States should have to report the results of all incidents at least every two years, if not every year.

V. Grievance procedures

The Autism Society strongly encourages a patient's bill of rights that promotes and provides an independent process for reporting issues individuals with disabilities are facing associated with receiving their services. The Autism Society appreciates that the rule will establish a grievance process. Many individuals have issues with their providers and state agencies but do not have anywhere to turn. Some people report that their agency is not following the HCBS Settings Rule, including not following the requirement for person-centered planning. Others face high turnover issues with their direct support professionals, leading to lower quality of services. This rule would create a grievance system that will ensure that states track, investigate and respond to resolve these issues. It is important to make sure the procedures are easy to follow and accessible to all.

VI. Quality measures

Other Medicaid services have to report on quality measures. The Autism Society appreciates that this rule will require HCBS to do the same. Quality measures should include issues that matter most to the individual, such as ensuring their person-centered plan is being followed and that they are the key stakeholder (along with their parents, when appropriate), ensuring they have independence in their choices and who they see and engage with. It is also critical to stratify the data by race, gender, disability, age, etc. This will ensure that services are being provided in an equitable fashion and are free of discrimination. Mandating a set of quality measures that states have to collect and track will ensure that providers and the state Medicaid agency are working toward offering the best services so that individuals with disabilities can fully engage in their communities and live self-determined lives. This data needs to be updated as often as possible and be easily accessible to anyone who wishes to review it.

Thank you for considering these comments on the Access Rule. For any questions about these comments, please contact Kim Musheno, Vice President of Public Policy at kmusheno@autism-society.org.