Autistic Perspectives Needed

Community Participation Services and Research Are at a Critical Juncture

July 18, 2019

This post was first first published on the Health Affairs blog on July 17, 2019, and is shared here with permission.

The US spends more than $80 billion per year on Medicaid-funded home and community-based services (HCBS). This investment provides vital support to adults with disabilities, who typically do not have access to these resources through private insurance. Over the next several years, states will be mandated to implement new federal requirements that will, for the first time, establish a federal minimum standard for HCBS and modernize and shape delivery of these services for years to come. As part of this process, the Centers for Medicare and Medicaid Services (CMS) called for states to offer meaningful and repeated opportunities for stakeholders to provide input into their transition plan and processes. Autistic adults make up a growing portion of these stakeholders, as a result of an increase in autism spectrum disorder (ASD) diagnoses and an aging population of autistic people diagnosed in childhood who will need services through adolescence and adulthood. Autistic voices and perspectives will be critical to shape a service system that can effectively meet their needs, but it remains unclear whether states' public comment periods and feedback processes have included effective mechanisms for this group to be heard.

Transition Plans For Medicaid HCBS Settings

A 2014 CMS regulation known as the HCBS Settings Rule established basic HCBS standards for the first time. These new federal requirements focused on ensuring that HCBS are provided in genuinely community-based settings; implement more robust person-centered planning; and provide basic rights protections for beneficiaries, including guarantees for individual choice in daily decisions about privacy, food, and schedules. Following an original date of compliance of March 2019, the deadline has now been extended to March 2022. Tennessee—a leader in the organization and provision of HCBS—became the first state to receive approval in 2016. To date, 14 states have received approval for their plans, and 37 states have secured initial approvals.

These plans are critical, as the services they guide are likely to be among the few service options available to autistic adults in the decades to come. Current low rates of employment suggest that autistic adults will need both employment services (to find and maintain work) and the daily living supports that fall under Medicaid HCBS. Even for adults who gain private health coverage through an employer, these types of services are rarely covered.

Identifying Key Targets For Improvement

To date, almost no research has examined rates of community participation or inclusion among autistic adults, so we lack the baseline information necessary to evaluate states' success in creating more accessible and person-centered services. Most research published on individuals with autism and community participation has relied on parent or caregiver reports and has focused on children, school settings, and using transportation to navigate communities. While these studies offer valuable building blocks, we lack robust evidence concerning the needs of autistic adults. Assessing their needs is especially important because autism is diagnosed, in part, on the basis of nuances, "deficits," or preferences in social communication and interaction. Researchers and policy makers need to identify which types of community participation autistic adults prefer, which supports are needed for optimal participation, and how best to support people with social communication differences. Gathering this information is integral to helping autistic adults build meaningful relationships, valued social roles, and natural support systems across family relationships, friendships, and romantic relationships.

To be most effective, states will need to build capacity for HCBS to detect the needs of individuals, incorporate those needs into service planning, and deliver support to individuals with a continuum of social interaction and communication skills. It remains unclear if the direct support workforce is prepared for this task. The diverse communication needs of autistic adults will have direct impacts upon other services as well. Direct support staff will need to be able to support the development of

communication skills among service participants with a range of abilities as well as assist in application of communication skills across different settings, from public transportation to work environments to family and peer interactions. The training and tools needed for direct support staff to support a variety of social relationships have yet to be developed.

Prioritizing Stakeholder Voices

Autistic adults have not had substantial opportunities to offer perspectives on how community participation would work best for them. Engaging autistic adults directly in rigorous research to capture their preferences for community participation is the linchpin for creating a service system to reach them and meet their needs. This process will also help identify policy goals and benchmarks. Admittedly, capturing these critical perspectives will be complicated. Yet, the payoff is likely to be substantial. A strong evidence base supports the benefits of integration and community participation, which has been shown to be an important predictor of outcomesamong individuals with mental health diagnoses. Furthermore, social isolation and social connectedness are key social determinants of health. Identifying the forms of community participation that autistic adults most value and accommodating their unique preferences and accessibility needs are crucial steps in shaping the future of HCBS.

The Interagency Autism Coordinating Committee, which provides guidance to the Department of Health and Human Services on issues related to ASD, has called for a prioritization of research that is both based in the community and directly engages community members. To be successful, this research effort must include autistic adults from an array of backgrounds. Spanning rural, suburban, and urban areas will be critical given the different strata of community participation opportunities and transportation options available across these settings. Autistic adults from different racial and ethnic groups, genders, and sexual orientations should be represented to ensure that the community participation preferences captured reflect a multitude of backgrounds and experiences. Care must be taken to ensure that the voices of autistic adults who have intellectual disabilities or who are alternative and augmentative communication users are incorporated. Outreach to those who are not currently receiving services is also needed, to determine barriers to participation.

If CMS acts quickly, there is an opportunity to require that states demonstrate that they have incorporated the voices of individuals impacted by HCBS revisions in their policy plans in measurable, meaningful ways. Without this input, CMS requirements risk leaving out a group that has invaluable insight to offer on the effective support of community participation.

Authors' Note: We use identity-first language in this blog post, consistent with the preferences of many adults in the autism community.

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