



November 30, 2021

Susan A. Daniels
Director, Office of Autism Research Coordination
National Institute of Mental Health
6001 Executive Boulevard
Bethesda, MD 20892-9663

Dear Director Daniels:

ANCOR is a national, nonprofit trade association representing more than 1,600 private community providers of Medicaid Home and Community Based (HCBS) services to over one million people with intellectual and developmental disabilities (I/DD). ANCOR writes these comments in response to Question 5 and Supplemental Question 1.

Question 5. What Kinds of Services and Supports Are Needed to Maximize Quality of Life for People on the Autism Spectrum? (Topic: Services)

We appreciate the IACC's commitment to supporting services to maximize the quality of life for individuals with autism. The IACC must ensure its strategic plan includes support for systems of care that incorporate a full spectrum of individualized and specialized supports and services. Specifically, the strategic plan must provide support for strengthening and expanding the Medicaid Home and Community Based Services (HCBS) program.

As the IACC has previously recognized, the Medicaid HCBS program is integral in improving the lives of people with autism and decreasing unmet needs. The HCBS program supports community integration and addresses the specific needs of each individual with person-centered planning. HCBS providers ensure individuals receive the services and supports that are important for each person, such as career-readiness programs and transition programs to bridge the gap from child to adult services.

The HCBS program furthers self-determination, independence, and empowerment of people with autism in their homes and in the community. However, waitlists for community-based service programs for individuals with I/DD currently stand at approximately 800,000 across the country. The IACC must recommend and support access to HCBS for all eligible individuals.

Supplemental Question 1. What are important issues for the IACC to consider with regard to the impact of the COVID-19 pandemic on the autism community?

Direct Support Professionals (DSPs) are the backbone of the HCBS program. However, the DSP workforce faces a long-running recruitment and retention crisis. Decades of stagnant reimbursement rates and an inability of providers to offer competitive wages has led to a significant shortage of DSPs nationwide. The COVID-19 pandemic has exacerbated this existing workforce crisis.

The lack of DSPs and high turnover rates have led to tangible negative effects for people with disabilities. A lack of consistency among caregivers leaves individuals they serve without familiar faces and severs bonds that have been created over time. Providers report higher rates of program closures and delayed introduction of services due to insufficient staffing. Without stable support in the community, individuals relying on those services are at higher risk of hospitalization and institutionalization.

The DSP workforce crisis has worsened due to the COVID-19 pandemic, and there is no end in sight. The IACC must support greater investments in stabilizing, recruiting, and training DSPs, including supporting efforts for career advancement and professionalization of the DSP workforce. If the crisis is not addressed, individuals with autism will lose access to the options and resources necessary to remaining in their homes and in the community.

Thank you for this opportunity to provide comment. Please reach out to me at eaguilar@ancor.org if we can provide further clarification or information regarding these comments.

Sincerely,

Elise Aguilar

A handwritten signature in cursive script that reads "Elise Aguilar".

Director of Advocacy
American Network of Community Options and Resources (ANCOR)