AUCD Policy Priorities on Medicaid Long-Term Services and Supports

119th Congress

Background

Every person has the right to live safe, healthy, and self-determined lives in their communities. Medicaid is a critical program and the largest funding source that provides long-term services and supports (LTSS) that allow people to live in their communities and be employed in competitive integrated employment. When people with disabilities receive LTSS, family members are able to maintain their own employment. When Medicaid-funded service provider agencies are able to retain staff, unemployment is reduced, and money is retained by people who will spend it. In addition, Medicaid reduces healthcare costs by allowing people with disabilities to utilize home and community-based services (HCBS), rather than spending on costly and unnecessary institutionalization.

To achieve a high-quality direct care workforce that earns a living wage is essential to providing LTSS. Medicaid is the primary source of funding for the programs employing these workers and the current Medicaid reimbursement rate is not sufficient to ensure access to services and supports. Demand for workers from private industry and other human services sectors is high, leading to the loss of workers, which results in fewer opportunities for people with disabilities to live and work in the community. Investments in Medicaid will help to raise wages and provide affordable health insurance and prevent high turnover and staff shortages.

Research

The Residential Information Systems Project (RISP) at the University of Minnesota's Institute on Community Integration is a University Center for Excellence in Developmental Disabilities and member of AUCD's national Network. Since 1977, the RISP has described trends in LTSS for people with intellectual and developmental disabilities (IDD). An annual survey of state IDD agencies gathers information on the types and sizes of settings in which LTSS recipients live, characteristics of service recipients, recipients and expenditures by funding authority and age, and waiting lists. An annual survey of state-run IDD facilities serving 16 or more people asks about admissions, discharges, deaths, recipient characteristics, and staffing outcomes.

Recent findings include:

- The Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) program costs more to support a person in an institution than in the community. In 2019, average annual per person spending was $140,210 for people in ICF/IID settings compared with $48,458 for HCBS Waiver recipients.

- In 2013, there were about 710,000 people who used HCBS, and about 232,000 people who were on the waiting list. In 2019, there were 14 states with no waiting lists to receive HCBS, but the number of people who want HCBS continues to grow. In 2019 there were 930,000 people receiving HCBS and 195,000 people waiting to get these services. There are now more people with IDD who want HCBS than there is money to support them.

During the 119th Congress, AUCD will work to:

- Improve Medicaid and keep it fully funded by, including but not limited to:
  - Maintaining the individual entitlement and improving coverage and access to a full range of services provided in HCBS and other LTSS.
  - Removing the institutional bias in Medicaid (that makes institutional care a mandatory service and HCBS an optional service), mandating HCBS and requiring a waiver to provide services in institutions.
  - Making HCBS portable from state to state.
  - Increasing funding for HCBS through incentive payments and increased federal matching funds for HCBS.
  - Eliminating the spend-down limit.

- Increase reimbursement payments (including Federal Medical Assistance Percentage (FMAP)) for both Medicaid and CHIP for the U.S. territories towards parity with the states and provide additional technical assistance to ensure integrity in reporting measures.

- Incentivize implementation and ensure protection of Medicaid expansion as included in the ACA, including the option for families of children with disabilities to buy into Medicaid if private health insurance is not available or does not meet their needs, and options to establish affordable Medicaid buy-in programs for people with disabilities who work.

- Expand the direct support professional workforce, improving recruitment, retention, training, and supervision and ensure this workforce has a career structure, including adequate education, training, and skill development and commensurate compensation. AUCD will work to increase the pool of workers by working with federal agencies and programs in implementing appropriate waivers or statutory changes.

- Ensure that the Bureau of Labor Statistics and other federal agencies appropriately track data about direct support professionals by establishing a separate category within the Standard Occupational Classification (SOC) Code system and in other appropriate ways.

- Ensure full implementation and enforcement of the Centers for Medicare and Medicaid Services HCBS Settings Rule and the HCBS Access Rule.

- Work to prevent any cuts or restrictions to Medicaid, including:
  - Proposals to provide states with flexibility that eliminates basic protections for eligible persons with disabilities (e.g. imposing entitlement caps, per capita caps, or work requirements)
  - Medicaid block grants
  - Limiting provider taxes
  - Time-limiting Medicaid benefits
  - Other proposals that shift costs to states or other mechanisms that cause reductions in eligibility, services, or protections