Medicaid, the Affordable Care Act and impact of repeal efforts on individuals with intellectual/developmental disabilities (I/DD)

Calls to action

- We urge you to preserve access to community living and healthcare for individuals with I/DD, some of the most vulnerable individuals in society.
- Don’t reduce funding to states that support housing, employment, training, case management and the health of individuals with disabilities, including individuals with I/DD.
- Don’t block grant these federal programs.

Medicaid is an often invisible source of government funding for many different programs that help millions of individuals with disabilities and their families. Medicaid provides government-funded health insurance for children and adults who do not have much money and who have a disability. This means that Medicaid services are critically important to the quality of life of these individuals, as well as the quality of life of the families who care for them.

Background

The various proposals to repeal the Affordable Care Act (ACA) include funding cuts that are putting Medicaid’s “optional” and “waiver” benefits at risk. Medicaid law requires that all states provide services such as doctor visits, hospitalization and nursing home care, among others. Other critical services for individuals with disabilities are not required by law (i.e., optional benefits), but are allowed if a state chooses to provide them and follows federal requirements. Once a state includes an optional service as part of its state plan, benefits must be about the same, available throughout the state, and individuals get to choose their providers and plans.

States provide many different services and supports as optional benefits. Examples of some of the optional benefits include: prescription drugs; clinic services; physical therapy; occupational therapy; speech, hearing and language disorder services; diagnostic, screening, preventive and rehabilitative services; dental services; prosthetics; eyeglasses; personal assistance services; case management; state plan home- and community-based services; and Community First Choice Option, allowing states to provide home- and community-based services and supports under the state plan as an alternative to facility-based care and receive increased federal matching funds.

Medicaid for adults with disabilities

According to the Kaiser Family Foundation, in the 32 states (including D.C.) that have adopted the ACA’s Medicaid expansion, some adults with disabilities are eligible for Medicaid based solely on their low income. The ACA expands Medicaid eligibility to nearly all adults with income up to 138% FPL ($16,643/year for an individual in 2017) without an asset limit. It provides enhanced federal matching funds for states to cover this group. Thirty-five percent of adults on Medicaid who are not working report they have a disability or illness. Some expansion efforts for adults with disabilities have been effective. A recent study found that working-age adults with disabilities are significantly more likely to be employed if their state has adopted the Medicaid expansion, compared to states that have not expanded.1
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Home and Community-Based Services Waiver.

The most important waiver for individuals with I/DD is the 1915(c) Home and Community-Based Services Waiver. This waiver helps states provide long-term supports and services in home and community settings rather than in institutions. Waiver services include providing direct-support professionals to assist with meals and other activities of daily living. Waiver services also include habilitation, communication support, assistive technology, supported employment, behavioral supports and services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and communities.

For many individuals with I/DD, Medicaid generally is the only source of funds that allows them to live and work in the community and avoid more costly and segregated nursing homes or institutions. Nationwide, state and federal Medicaid together provide more than 75% of the funding for services for individuals with I/DD.

Example of a beneficiary receiving Medicaid community-based services:

Curtis, age 20, Kansas

Curtis lives with his mother and is diagnosed with autism, intellectual disabilities and sensory integration issues. He functions on the level of a 2nd or 3rd grader and recently has started to read. While he has a very easygoing personality, he cannot be left alone and needs help with shaving, bathing and taking medication. Medicaid provides attendant care services that help him to learn basic life skills at home, such as making his bed and dusting his room, while his mother is at work. His attendant also accompanies him to the library, to get his hair cut, to community events and to the book store, where his favorite activity is looking at picture books. Source: kff.org

What’s at stake?

Optional and waiver services would be under attack if Congress deeply cuts and caps Medicaid funding. There would be real-life consequences for individuals with I/DD. They would lose services and supports. Waiting lists would quickly grow, creating a crisis for more than 730,000 individuals with I/DD living with aging caregivers. Individuals could lose critical services such as personal care, prescription drugs and rehabilitative services. States may decide to stop providing these services altogether. Individuals would lose the supports for community-based services and could be forced into more expensive, inappropriate residential settings. Returning to the days of institutionalization and of “warehousing” individuals with disabilities is unacceptable and a human rights violation.

The costs of providing healthcare and long-term services and supports will not go away. They would be shifted to individuals, parents, states and providers. States will not be able to make up the difference from the deep cuts under per-capita caps. States will be focused on keeping Medicaid spending under the cap, or face penalties.

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