One Size Fits All Does Not Fit Medicaid's Most Vulnerable

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Over the past two decades, community inclusion and ensuring that people with intellectual and developmental disabilities (I/DD) have access to care and services within their homes and in the community has been at the forefront of the disability community and their advocacy efforts. One of the overarching themes of the Americans with Disabilities Act (ADA) is, “Community Integration for Everyone.” The concept of “integration for everyone” incorporates the idea that people with disabilities would access services in the community as people without disabilities, including healthcare services spanning primary and preventive care to specialized healthcare. In a perfect world, people with I/DD would have a primary care provider who includes them into a practice that serves the varying needs and conditions of all individuals and that they would have access to specialists when appropriate. Because most individuals who have I/DD have relatively mild variations of the condition, relying upon the existing healthcare system is logical and reasonable.

Complex Health Needs of People with

Intellectual and Developmental Disabilities

In the face of logic and reason comes reality. While most people with I/DD have mild variants, those who experience moderate to severe I/DD face a number of significant challenges in the current healthcare system. There is a portion of the population with I/DD who, in addition to the intellectual and/or developmental disability, suffer from a variety of genetic anomalies and have complex medical and behavioral issues. These individuals are the most medically frail and behaviorally challenged; thus, a one-size-fits-all model of healthcare does not work. This is evidenced by the overuse of emergency room visits and high healthcare utilization cost by this group.

The I/DD medically frail and behaviorally challenged population described above requires multiple levels of care. This care must be tailored to the individual and their needs and must accommodate the individual's changing needs throughout his or her lifetime; the complexities of their condition grow and evolve with them. Moreover, caring for this special group encompasses more than the general population. The physicians and nurse practitioners that provide healthcare services to people with I/DD and medical frailties and behavioral challenges need expertise not just in primary care, but also in the various disabling conditions that affect some individuals with I/DD.

Medical schools have expanded their curricula and residency programs to include education about and experiences in working with people with I/DD, so the number of providers with the required expertise is growing. However, the medical needs of persons with I/DD are greater than those of the general population, according to evidence-based studies, and are more costly. Healthcare providers need to spend more time in a primary care visit for a person with I/DD—about an hour versus the typical five- to ten-minute primary care visit—which limits the number of patients a provider can see in one day.

In addition to the extended time requirement, there's a financial component that deters healthcare providers from serving people with I/DD. Most people with I/DD have medical insurance through Medicaid and the fee schedule is so low that many healthcare providers cannot afford to treat people with I/DD. In order for primary care providers to treat people with significant disabilities, they must be compensated appropriately for the additional time that is needed to meet the many health needs of this frail population.

New Healthcare Changes Will Add Additional Barriers

The proposed American Health Care Act (Act) will add additional barriers for those with I/DD seeking healthcare and other support services. According to the Kaiser Family Foundation, approximately 40% of Medicaid spending is on care for people with disabilities. The American Health Care Act imposes per capita caps on Medicaid spending. Not only will such caps not provide the additional reimbursement needed for primary care providers to treat people with I/DD as discussed above, they are predicted to cut existing Medicaid funding for healthcare and support services that are critical to the health and well-being of those with disabilities. The Act is projected to cut Medicaid by about $116 billion over the next 10 years. These cuts will force states to make up the difference with cuts to medical services, provider reimbursement, or both.

Patients who suffer from I/DD and medical frailties and/or behavioral challenges are dependent upon Medicaid in order to receive lifesaving medical care and supports for activities for daily living, including nursing care, physical and occupational therapy, speech-language pathology services, medical social services, medications, medical supplies, transportation and dietary counseling and services. Cuts to Medicaid funding and the imposition of per capita caps would significantly limit the ability of people to obtain these services, or deny them the services altogether. Without these services, millions vulnerable individuals with I/DD will be at risk and there will be a damaging collateral effect upon their family and caregivers.

Solution to Protecting Access to Care

The solution for protecting access to care for people with I/DD with medical frailties and/or behavioral challenges is two-fold. Medicaid should develop an adequate reimbursement rate for providers who treat individuals with I/DD and other specialized populations that takes into account both the experience and time required. Further as the American Health Care Act moves forward, disability advocates, including individuals, families, caregivers, and providers, should encourage Congress to prevent the proposed dramatic cuts to Medicaid.

People with intellectual and developmental disabilities are among our most vulnerable patients, and their healthcare and support needs should be fully met.

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