Why does Medicaid matter to people with disabilities and their families?

What is Medicaid?

Medicaid is an often invisible source of government funding for many different programs that help millions of people 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. Medicaid’s services, including its prescription coverage and personal care services, are often more extensive than those provided by other insurers.

Medicaid also provides government funding for something called “long term care.” These are the services that people with disabilities often rely on throughout their lives. It used to be that long term care meant only institutional care; now it also means community-based care. For example, group homes are paid for in part with Medicaid dollars; so, too, are many of the direct support workers who help people with disabilities live and work in their communities. New Jersey’s Division of Developmental Disabilities depends on Medicaid funding to provide many of these services.

Medicaid is an “entitlement.” That means if someone is found to be eligible for Medicaid, then that person must receive Medicaid services. Eligibility for people with disabilities is based on an assessment of both disability and financial resources. For adults with disabilities age 18 and over, for eligibility purposes they are considered a “family of one,” even if they live with their families. Adults with disabilities often meet Medicaid’s financial eligibility requirements because although most want to earn enough money to be self-supporting, only a small percentage are actually employed in jobs that make this possible. For those individuals who are competitively employed, however, new Medicaid rules called “work incentives” now make it possible for people with disabilities to work and still be eligible for Medicaid coverage.

Many people with disabilities live with their families. This means that Medicaid services are critically important to not only the quality of life of these individuals, but also the quality of life of the families that care for them.

Why are Medicaid waivers important?

Medicaid waivers are programs that are designed to meet certain specific needs. They provide different benefits than the traditional Medicaid program is designed to provide, and are called
“waivers” because some of the rules that apply to Medicaid are waived, or put aside. Waivers can be good for people with disabilities, because they allow states to find creative ways to meet their needs.

Home and Community Based Services (HCBS) Waivers are designed to support people in their communities. In New Jersey, this waiver is called the "Community Care Waiver (CCW)." Some of the services provided by the Division of Developmental Disabilities through the CCW are "self-directed services." These services give individuals the choice of managing their own supports in order to create meaningful lives for themselves.

Many states have waivers that provide family support services such as respite care for those families who are caring at home for a family member with a disability. New Jersey is currently deciding how best to include these services in its waiver programs.

**How is Medicaid paid for?**

Medicaid is paid for by matching federal/state government funds. That means the state and the federal government split the cost of providing Medicaid benefits. If the amount of money a state spends on Medicaid goes up because, for example, more people become eligible for Medicaid, than the federal government must continue to meet its obligation of matching what the state spends. Currently, the match in New Jersey is about 50% federal funds and 50% state funds.

**Things to be aware of:**

Many states are experiencing severe budget shortfalls, and as a result are looking for ways to save money by reducing how much they spend on Medicaid. Some of the changes being proposed involve using more managed care for the health insurance part of Medicaid. Other proposals include things called “block grants” or “caps.” Block grants or caps mean that the federal government gives the state money for Medicaid in one lump sum, and the state decides how to spend that money. Once the federal/state partnership is changed in this way, if a state’s Medicaid expenses go up, the federal government would no longer have an obligation to match what the state spends. Additional expenses would either have to be paid for by the state alone, or the state would have to cut back on who is included in its Medicaid program and/or what benefits it provides. In other words, the entitlement of Medicaid that guarantees benefits for people with few financial resources and a disability would be gone.

While some changes to Medicaid can help states improve services to people with disabilities in cost-effective ways (for example, Home and Community Based Waivers that help states provide services in the community rather than large institutions), other changes may make it harder for people with disabilities to have their health and long term care needs met. However, with sufficient federal/state funding Medicaid can continue in its unique roles as both the provider of health insurance for the country’s most vulnerable citizens, and as a provider of essential supports in the movement towards full community inclusion of all people with disabilities.

**There is no other program that does what Medicaid does for individuals with disabilities and the families that care for them.**