

PROFILES OF MEDICAID'S HIGH COST POPULATIONS



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EXECUTIVE SUMMARY

Medicaid is the cornerstone of our nation's diverse and complex system of financing health and long-term services. A partnership of the federal government and the states, Medicaid pays for over 40 percent of all long-term services and covers services not covered by Medicare or private insurance. A critical role of Medicaid is to finance services for a significant proportion of the population with very high costs, who often have both acute care and long-term services needs. Acute care encompasses medical care services such as physician and hospital care, prescription drugs, and laboratory and diagnostic testing. Long-term services refer to the services and supports people need when their ability to care for themselves has been reduced by a chronic illness or disability. Long-term services provide assistance with everyday activities, such as assistance with dressing, bathing, using the bathroom, preparing meals, taking medication, managing a home, and managing money. It also includes types of services such as habilitation, case management, adult day, and respite services.

This paper examines the role that Medicaid plays in addressing six populations with serious health needs resulting in high costs. For each population profiled, we describe the condition and the need for services and supports, as well as the role of Medicaid in meeting those needs. We also include profiles of real people with these conditions and descriptions of model programs or cutting edge practices designed to meet the needs of these high cost populations with exceptional needs. As these populations will show and as policy makers think about the type of health care system our nation needs, it is important to consider Medicaid's role in anchoring the broader health system.

Overview of High Cost Populations Profiled:

- 1) Preterm births occur with increasing frequency and people who are born prematurely often have lifelong acute care and long-term services needs.** Every year, 100,000 children develop health problems because of their early births.¹ A recent study of very low birth weight babies found that twenty years after birth, they continued to have significantly higher rates of chronic conditions than control subjects.² Preterm infants have an increased risk of hospitalization during the first few years of life and increased use of outpatient care. Among the conditions leading to poorer health are reactive airway disease, recurrent infections and poor growth.
- 2) Children receiving foster care often have extensive needs and the state has taken responsibility for protecting their welfare.** Each year, more than 800,000 children in the United States spend time in foster care.³ Many have experienced abuse or neglect. In other cases, however, parents have turned to the child welfare system as a last resort to gain access to mental health services that they are not able to obtain for their children elsewhere.⁴ Many of these children have extensive needs for health and long-term

services. Case management services also play a critical role in coordinating various services needs and helping to ensure that children actually receive the services that physicians and other services providers have prescribed.

- 3) People with spinal cord and traumatic brain injuries have unexpected and financially catastrophic health and long-term services needs.** Roughly 250,000 Americans have spinal cord injuries, and each year about 11,000 new injuries occur.⁵ Over half of all spinal cord injuries occur in young people between the ages of 16-30. These injuries are financially catastrophic with average first year treatment costs varying from roughly \$219,000 to \$741,000, depending on the severity of injury. Ongoing costs for each subsequent year range from roughly \$15,000 to nearly \$130,000.⁶ The service needs of people with spinal cord injuries involve two distinct phases: the initial rehabilitation, and ongoing health maintenance and assistance. Depending on the level of impairment, individuals have varying levels of need for services, yet a critical type of support is personal assistance.
- 4) People with mental illness expose the potential for increased public costs when individuals cannot access the services they need.** Roughly 20% of the U.S. population is believed to have some form of mental health disorder and five percent is believed to have a serious mental illness, with a diagnosis such as schizophrenia, major depression or bipolar disorder.^{7,8} Recognizing that many diagnoses are lifelong conditions, access to a continuum of care that includes preventive services and screenings, medical and social interventions, crisis management, and inpatient services is important.
- 5) People with intellectual disabilities have specialized needs that would not be met in the private health insurance system or a long-term services system developed to meet the needs of people with physical disabilities.** Studies have shown that between 1-3% of the U.S. population has an intellectual disability (the preferred term for people with mental retardation which is just one form of developmental disability).⁹ Intellectual disabilities are characterized by significantly low intellectual functioning combined with deficits in adaptive behavior. A common need of people with intellectual disabilities is for supervision and cueing, in which individuals are prompted to perform various activities of everyday life. For example, some people may be physically able to maintain appropriate hygiene and dress themselves, but they need cues to remind them when they should perform certain actions, such as showering. Another key service involves habilitation services that assist in the acquisition, improvement, and retention of skills necessary to maximize the ability to function.
- 6) People with Alzheimer's disease and related dementias need a safety net because increasing service needs and high costs can be overwhelming, even when individuals have saved for their needs in retirement.** An estimated 4.5 million Americans have

Alzheimer's disease and this number has more than doubled in the last twenty-five years.¹⁰ While the majority of people with Alzheimer's disease are seniors, 6-8% of people with Alzheimer's disease are diagnosed before age 65.¹¹ Alzheimer's disease is a serious medical condition characterized by declining cognitive function that creates changing medical and social support needs for individuals and families as the condition progresses. Over time, individuals need increasing levels of assistance with maintaining a home, managing finances, and then personal activities such as bathing, dressing, and feeding. As Alzheimer's disease progresses, individuals eventually require round-the-clock supervision and assistance.

Key Findings:

Medicaid assists people with financially catastrophic needs at all stages of life. While Medicaid is a program for low-income people, virtually any American (except the exceptionally wealthy) could be just one accident or illness away from needing assistance from Medicaid. For some, purchasing private insurance coverage in advance of the onset of disability could provide important protections. Nonetheless, some conditions are so costly, that even private insurance may not be able to effectively finance all of these costs. People with spinal cord and traumatic brain injuries may face health and long-term services costs exceeding several million dollars over their lifetimes. As Alzheimer's disease progresses, most families determine that nursing home care is necessary—and this is quite costly averaging over \$70,000 per year.¹² Therefore, even individuals that planned for increased long-term services needs as they age may find that after several months or years, they need to rely on the critical assistance provided by Medicaid.

People who rely on Medicaid are diverse and have complex health needs. The individuals profiled in this report have very complex, extensive, and specialized needs. They have a broad range of needs for acute medical care, as well as long-term services and supports. For example, people with intellectual disabilities may have co-occurring physical health problems. In this case, specialized services may be needed to assist individuals both in performing activities of everyday life, as well as adapting to physical limitations. Needs may vary considerably and can change quickly.

Medicaid shoulders uniquely public responsibilities. The Medicaid program is responsible for ensuring that children receiving foster care receive the acute care and long-term services they need; providing life-saving coverage for young adults who experience serious injuries while uninsured, such as young adults who experience traumatic brain injuries; and providing a safety net for individuals and families who planned for their long-term services needs, but whose resources have been exhausted by the high costs of services, such as some people with Alzheimer's disease who eventually require 24-hour supervision or assistance.

Medicaid provides the coordination of many services not available elsewhere. Disability and chronic conditions produce overlapping needs that involve both acute care and long-term services. The availability of both types of services through Medicaid makes it especially well suited to serving people with high costs and complex needs. Medicaid has adapted to the diversity of needs of the Medicaid population by providing cutting edge services—services that are often not provided by other payers. For people with mental illness, the integrated services delivery models developed by Medicaid programs provide a way for people who have mental health service needs to remain in the community and continue to have their needs met. While Medicaid programs need to continue adapting and improving, similar models in the private sector are rare to non-existent. Additionally, the Early and Periodic, Screening, Diagnostic and Treatment (EPSDT) benefit conveys a strong public commitment to the low-income children served by Medicaid, including children who may have been born prematurely and who continue to have ongoing health and long-term services needs. This benefit screens children for health conditions and provides for timely interventions that may limit the development of long-term disability.

Medicaid covers people who otherwise would be uninsurable. A critical role of Medicaid is to serve as a safety net for people who need assistance with acute and long-term services needs. The private long-term care insurance market is not available to those who already have long-term services needs. All of the populations described in this paper would be unable to purchase long-term care insurance after the onset of disability. Further, many of these individuals have extensive needs for ongoing acute medical care services; private long-term care insurance, if it were available, would only meet some of the service needs of many individuals.

No system exists, other than Medicaid, to serve these populations. For the populations described in this report, there are often no other major public or private sector programs for comprehensively meeting their acute care and long-term services needs. For example, children who were born prematurely and have ongoing needs often turn to Medicaid only after running into gaps in private health insurance coverage; and people with Alzheimer’s disease may start out using savings or private long-term care insurance to finance services, but turn to Medicaid after other resources have been exhausted. For people with intellectual disabilities and other co-occurring developmental disabilities, such as epilepsy or cerebral palsy, Medicaid provides a comprehensive set of services including day habilitation, occupational therapy, skilled nursing, speech therapy, and case management services that may enable them to live in the community instead of an institution.

In order to more efficiently and fairly finance acute care and long-term services for all Americans, as the population ages and disability rates increase, policy changes may be needed to expand the financing base for long-term services and strengthen financing for Medicaid programs. This may include reforming Medicare so that its benefits package

more appropriately matches the needs of its beneficiaries. It could also include private sector initiatives or other efforts to promote planning for or insuring against future needs for long-term services. At the same time, by understanding more about the populations described here, it becomes clear that Medicaid plays a unique and critical role in meeting the acute care and long-term services needs of millions of seniors and people with disabilities with high costs, offering protection when no other system exists to serve them.



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