

PROFILES OF MEDICAID'S HIGH COST POPULATIONS



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PROFILES OF MEDICAID'S HIGH COST POPULATIONS

Prepared by

Jeffrey S. Crowley

Health Policy Institute, Georgetown University

and

Molly O'Malley

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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.

INTRODUCTION

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. Medicaid plays several unique roles in bolstering our nation's health care system. This includes providing coverage to certain categories of low-income Americans, including people with disabilities and chronic conditions across the age span, and providing essential financial support for safety net providers, including rural and community health clinics, public hospitals, and other entities.

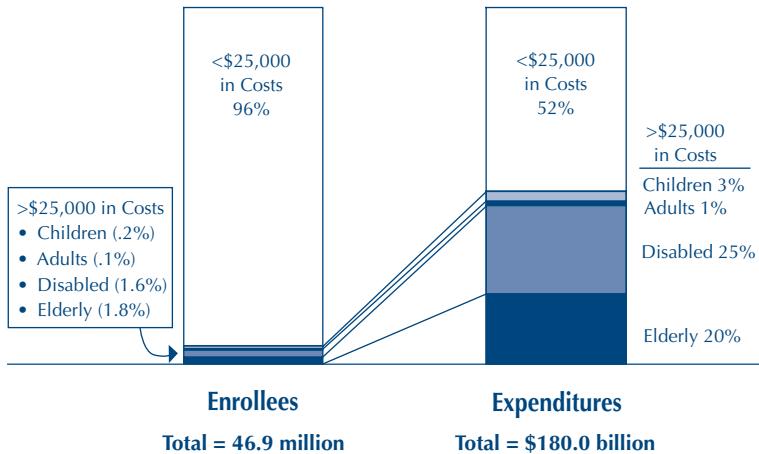
Another critical role of Medicaid is to finance both acute and long-term services for a significant proportion of the population with very high health care costs. Acute care encompasses medical care services such as physician and hospital care, prescription drugs, and laboratory and diagnostic testing. 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. Medicaid provides long-term services to seniors (persons age 65 and older) and non-elderly people with disabilities in both institutional settings (such as nursing homes) and community settings (which permit individuals to live in their own homes).

In 2004, Medicaid spent \$272.6 billion on personal health care services, comprising 17.5% of national spending on personal health care.¹³ This included \$207.8 billion on acute care (14.8% of national spending on acute care) and \$64.8 billion on long-term services (41% of national spending on long-term services and supports). Medicaid covers both acute care and long-term services and supports, making it the only major public or private program designed to meet the diverse needs of people with complex and costly conditions.

Within Medicaid, spending is highly concentrated on a small percentage of beneficiaries. A recent analysis found that 4% of the Medicaid population was responsible for 48% of program spending in 2001 (**Figure 1**).¹⁴ Another way to identify high cost and high need Medicaid beneficiaries is to consider their use of long-term services and supports. Seven percent of all Medicaid beneficiaries used long-term services in 2002 and these beneficiaries accounted for 52% of total Medicaid spending.¹⁵

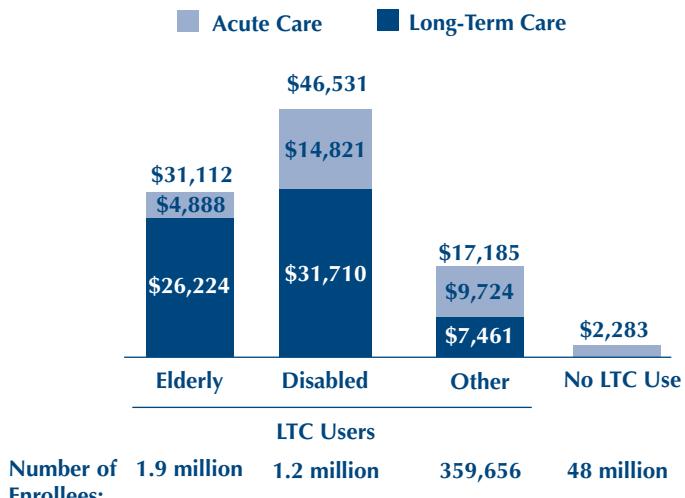
The receipt of long-term services is a good predictor that individuals have high costs (**Figure 2**). When per person spending on Medicaid long-term services users was compared to persons who do not use long-term services, non-elderly people with disabilities who use long-term services cost more than twenty times more than beneficiaries who do not

Figure 1
4 Percent of Medicaid Population Accounted for 48% of Expenditures in 2001



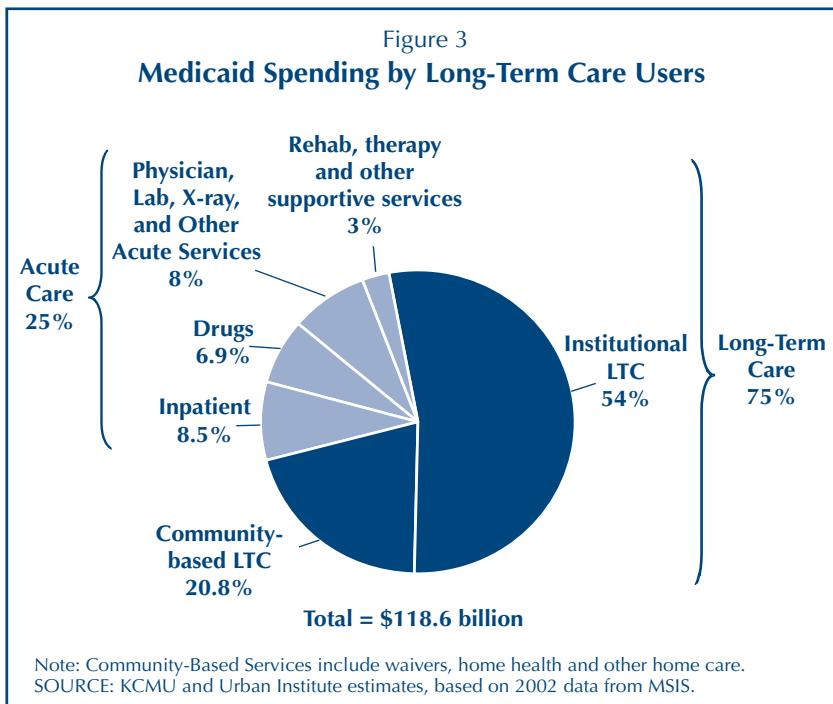
SOURCE: Urban Institute estimates based on MSIS 2001 data.

Figure 2
Medicaid Spending Per Enrollee



SOURCE: KCMU and Urban Institute estimates based on MSIS 2002 data.

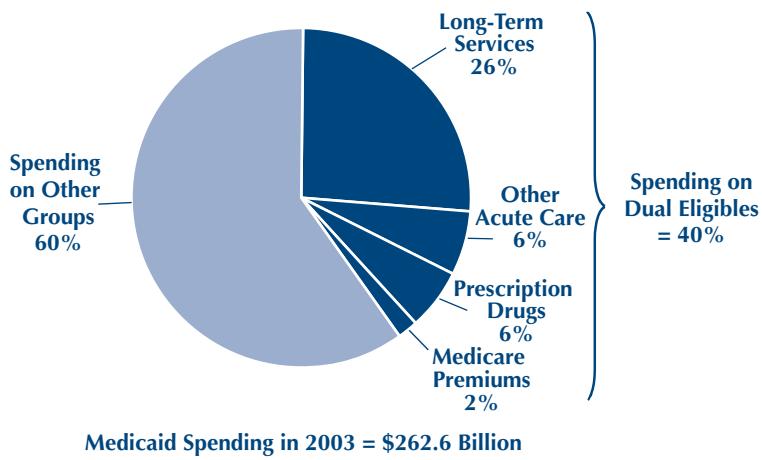
use long-term services, elderly long-term services users cost more than thirteen times more than persons with no long-term services use, and long-term services users who qualify for Medicaid through a category other than disabled, such as parents and children, cost more than seven times more than beneficiaries with no long-term services use. Not all spending on long-term services users is for long-term services, twenty-five percent of Medicaid spending on these beneficiaries is for acute care (**Figure 3**).



Medicaid takes pressure off of the private insurance system and Medicare by providing comprehensive coverage of acute care and long-term services needed by high cost beneficiaries. Private health insurance was designed to provide coverage for healthy workers and their families. It was not designed to cover people who need long-term services and, as a general rule, private insurance does not cover long-term services. Further, private insurers place limits on coverage through annual and lifetime caps that may be adequate for most people, but are insufficient for people with extensive needs. By providing a safety net for people who cannot obtain private coverage or for whom private coverage is inadequate, Medicaid provides an indirect subsidy to the private insurance system, which keeps private insurance premiums and costs lower than they otherwise would be and which limits pressure to expand private insurance benefits to adequately serve high-need individuals.

Medicaid also shoulders a very significant share of costs for low-income seniors and people with disabilities who also receive Medicare. Seniors with low incomes can qualify for Medicaid and receive help with Medicare cost-sharing and coverage for services not covered by Medicare, including long-term services and supports. In 2003, dual eligibles (low-income Medicare beneficiaries who also receive Medicaid) comprised 14% of Medicaid enrollment, but were responsible for 40% of Medicaid spending.¹⁶ The majority of this spending was for long-term services and supports (**Figure 4**).

Figure 4
**Medicaid Spending for Medicare Beneficiaries
(Dual Eligibles)**



Note: Reflects spending for services only.
SOURCE: KCMU estimates based on CMS data and Urban Institute analysis of data from MSIS.

The main route through which non-elderly adults with disabilities qualify for Medicaid, however, is through the disability category. This requires the Social Security Administration (SSA) to make a determination that they have a disability and a low-income. While states can opt to cover people with disabilities and seniors with income up to \$1,815 per month (300% of SSI in 2006), mandatory Medicaid eligibility generally requires individuals to have income less than \$605 per month in 2006 (74% of the federal poverty level), the income limit for beneficiaries of the Supplemental Security Income (SSI) program.¹⁷ In most states, eligibility is limited to individuals with less than \$2,000 in resources (such as personal savings). Individuals who qualify for Medicaid coverage can receive coverage as soon as they are found to be eligible. By contrast, for non-elderly people to qualify for Medicare, they must receive the same Social Security determination of disability as for Medicaid, and then they must wait more than two years until they can receive Medicare coverage. Medicare coverage for non-elderly people is available to persons who worked and have a sufficient work history to qualify for Social Security Disability Insurance (SSDI) payments. Once they have been determined to have a disability they must wait 5 months before receiving their first SSDI payment. SSDI qualifies individuals for Medicare, but non-elderly SSDI beneficiaries must wait an additional 24 months from receiving their first SSDI check until they start receiving Medicare. Persons who have been disabled since childhood can receive Social Security benefits and Medicare based on the work history of a parent, but they are still subject to the 24 month waiting period starting at age 18. Medicaid is a critical source of assistance to low-income SSDI recipients during this time.

Recently, Medicaid has been at the center of the nation’s health care policy debate. Due to its large size and the very significant public investment in services for low-income Americans, it is appropriate that policy makers consider ways to make the program more efficient, deliver services better, and adapt to changes in the standard of care for the diverse populations served by Medicaid. Through this report, we seek to inform the Medicaid policy debate by examining specific high cost populations. As these populations will show, it is important to think about the type of health care system our nation needs—and Medicaid’s role in anchoring the broader health system—not just in terms of the level of services that is appropriate for so-called “average” individuals, but for individuals with exceptional needs as well.

PROFILES OF SELECTED MEDICAID HIGH-COST POPULATIONS

STUDY APPROACH

This paper examines six high-cost Medicaid beneficiary populations. The specific populations were selected either because they have needs for which Medicaid is especially well equipped to respond or because they are overwhelmingly dependent on Medicaid as the only available program for meeting their needs. These populations are illustrative examples only and are not intended to suggest that they are the only—or even the majority of high-cost groups. There are numerous other groups such as organ transplant recipients, persons with hemophilia, and persons with neurodegenerative diseases such as multiple sclerosis or Parkinson's disease that also could have been profiled.

In exploring these groups, we provide information on how many people have the conditions identified, we describe their needs for services and supports, and we describe the role that Medicaid plays in meeting the acute care and long-term services needs of these populations. We also include short profiles of individuals with each of these conditions and describe model programs or cutting edge practices used to meet their needs. To collect this information, we reviewed information from the Centers for Medicare and Medicaid Services (CMS), states, and various academic, research, and advocacy organizations.

PRETERM BIRTHS OCCUR WITH INCREASING FREQUENCY AND PEOPLE WHO ARE BORN PREMATURELY OFTEN HAVE LIFELONG ACUTE CARE AND LONG-TERM SERVICES NEEDS

WHO IS AT RISK?

Every year, 12.5% of the four million births in the United States are preterm and 100,000 children develop health problems because of their early births.¹⁸ Preterm birth is defined as a birth that occurs after fewer than 37 weeks of gestation.¹⁹ The preterm delivery rate has increased thirty percent since 1981.²⁰ A characteristic associated with prematurity is low birth weight. The minimal normal birth weight is considered to be 2,500 g/5.5 lbs, and newborns weighing less than this are considered to have a low birth weight. Very low birth weight is defined as newborns weighing less than 1,500 g/3.31 lbs. A study of very low birth weight babies found that twenty years after birth, they had significantly higher rates of chronic conditions than control subjects.²¹ The use of sophisticated technology has increased the survivability of low birth weight and prematurely delivered babies, but this has been accompanied by increased rates of subsequent health problems, such as cerebral palsy, blindness, reactive airway disease (a condition related to asthma), recurrent infections, poor growth, and cognitive and behavioral deficits.²²

WHAT SERVICES AND SUPPORTS ARE NEEDED?

In July 2006, the Institute of Medicine (IOM) released a new comprehensive report on the causes and consequences of preterm births. New estimates indicate that the societal economic burden associated with preterm birth in the United States was at least \$26.2 billion in 2005. Two-thirds of this cost is accounted for by acute medical care. The IOM found that the spectrum of neurodevelopmental disabilities includes cerebral palsy, intellectual impairments, visual and hearing impairments, and more subtle disorders of central nervous system function. These dysfunctions include language disorders, learning disabilities, attention deficit-hyperactivity disorder, minor neuromotor dysfunction or developmental coordination disorders, behavioral problems, and social-emotional difficulties. Preterm infants have an increased risk of hospitalization during the first few years of life and increased use of outpatient care. Children who were born prematurely are also more likely to have lower academic achievement scores and require significantly more educational assistance than other children.²³

WHY IS MEDICAID IMPORTANT?

Prematurity takes a toll on families and strains the overall health care system. For children who are born prematurely, Medicaid coverage provides comprehensive access to acute

care and long-term services that may not be available to children who are privately insured. By assuring that the full-range of a child's needs are met from birth or early in childhood, it is possible to mitigate or minimize lifelong disability. While data are not available to document the health insurance status of these children, some will certainly qualify for Medicaid on the basis of disability. Others, however, will become eligible for Medicaid on the basis of low family income.

Families Turn to Medicaid when Private Coverage is Not Enough for Children with Disabilities

Medicaid plays an important role for children with disabilities, including children who were born prematurely, for whom private coverage has proven to be inadequate.

- Private insurance is generally ill-equipped to meet the therapy and long-term services needs of children with disabilities who have extensive needs
- In some cases, parents have had to give up custody of their children so that they could receive Medicaid

Sources: Swigonski, N., Kinney, E.D., Freund, D., and Kniesner, T.J. "Unfinished Business: Inadequate Health coverage for Privately Insured Seriously Ill Children," *Children's Health Care*, 30(3), 219-236 (2001) and see, for example, *Castaway Children: Must Parents Relinquish Custody in Order to Secure Mental Health Services for Their Children*, National Council on Disability, September 2002.

States have various opportunities for providing Medicaid coverage to children with disabilities or special health care needs. Since 1982, the TEFRA (or Katie Beckett) option has permitted states to waive the requirement to consider parental income when assessing eligibility for Medicaid for children with disabilities who otherwise would qualify for an institutional level of services.²⁴ This option has been used by many states to provide community services to children with disabilities. States have also used Home and Community-Based Services (HCBS) waiver programs (special Medicaid programs operated by states to provide community long-term services to targeted groups of beneficiaries such as children with disabilities) to provide community-based services to these children. In the Deficit Reduction Act of 2005, Congress enacted the Family Opportunity Act that permits states, starting in 2007, to offer Medicaid buy-in coverage to children with disabilities (even if they do not require an institutional level of care) in families with income up to 300% of the federal poverty level. The Family Opportunity Act will permit states to cover children with disabilities who do not require an institutional level of care, but whose extensive needs have often forced families to take extreme measures to ensure that their children with disabilities maintain Medicaid eligibility including relinquishing custody or artificially maintaining family income below poverty.

REAL PEOPLE | REAL NEEDS

Alejandro (Alex) Paz, age 4, a resident of Springfield, Virginia, was born extremely prematurely, and this has led to ongoing health and developmental challenges. During a critical period of his early development, Medicaid coverage was an essential lifeline that ensured that his health and developmental needs were met.

Alex's story begins with his mother, Kathy Mingledorff. Thirteen weeks into her pregnancy she started experiencing problems with excessive bleeding and this led her to the emergency room. This problem continued for weeks, and by nineteen weeks she was admitted to the hospital and transferred to a special unit for high-risk pregnancies. Alex was born after 25 weeks of gestation—an extremely premature birth considering that normal gestation is 40 weeks—weighing only one pound and 15 ounces.

Due to his early birth, Alex had several health challenges including severe jaundice, apnea (where there is a pause in breathing), and bradycardia (which is a slowed heart rate). During his initial hospitalization, he required seven blood transfusions. He was eventually discharged after 76 days weighing three pounds and 15 ounces. While Kathy had insurance coverage for herself during her pregnancy, it did not cover Alex. Within about a month of his discharge, however, Alex became eligible for Medicaid, which provided retroactive coverage for his stay in the neonatal intensive care unit.

During his first year of life, he developed normally for a time, but between the ages of one and two, he slowly stopped eating and drinking. He was diagnosed with gastro-esophageal reflux disease, reactive airway disease, and failure to thrive. It turned out that his airway was so inflamed from reflux that it closed up. He was hospitalized for a month with a gastric feeding tube and his mother worked with a nutritionist as they struggled to maintain his weight. Over the next year, he twice developed respiratory syncytial virus (RSV), a serious respiratory infection, and was hospitalized three times. Every time he developed any viral infection, he had to be hospitalized and placed on intravenous fluids and nutrition to keep him alive. In January 2005, Alex had surgery to help create a stronger esophageal sphincter to help control his reflux.

Nearly two years later, Alex is doing much better. He is also no longer on Medicaid. About a year ago, Kathy returned to work and the increased family income made him ineligible for Medicaid coverage.

Speaking of Alex's health coverage, Kathy says, "I haven't been happy since he left Medicaid. My insurer doesn't want to pay for anything."

He still takes several prescription medications, he receives occupational therapy, and he attends a feeding clinic. Kathy says that sensory integration dysfunction is his biggest current challenge—the way he experiences the space around him, pressure, heat and cold is different than other people. This has led to problems with self-injury and other behavioral issues, which makes ongoing occupational therapy all the more important.



Alejandro (Alex) Paz, Springfield, Virginia

CUTTING EDGE MODEL PRACTICES

The Early and Periodic, Screening, Diagnostic and Treatment Services Benefit (EPSDT)

There are no model programs for meeting the long-term needs of Medicaid beneficiaries who were born prematurely. Depending on the nature of their disability or health condition, however, model programs may exist for providing optimal services to individuals with a specific condition or cluster of conditions.

There is a provision of the Medicaid law enacted in 1989, however, that ensures that all children (including children who were born prematurely or who have special health care needs) get their needs met. This is the mandatory Early and Periodic, Screening, Diagnostic and Treatment (EPSDT) benefit. EPSDT requires states to inform children under age 21 that EPSDT services are available, to provide a comprehensive array of screening and prevention services (including a health and developmental history, a comprehensive physician examination, appropriate immunizations, lab tests, and lead toxicity screening), and to provide treatment for all medically necessary services.

The EPSDT benefit reflects an important investment in children. It guarantees all children on Medicaid a benefits package that is more comprehensive than adults are guaranteed, and requires states to cover all medically necessary mandatory and optional services for children,

including optional services that a state does not cover for adults. This includes health education services, vision, dental and hearing services, as well as various therapies and other long-term services and supports.

In addition to ensuring coverage of services that may not be available to adult Medicaid beneficiaries, EPSDT also ensures an adequate level of benefits, requiring states to cover a level of services that are medically necessary, even if benefit limits such as therapy caps exist for adults. This benefit has been described as a preventive benefit rather than a treatment benefit because it is designed not just to cure or treat an illness or injury, but to cover acute care and long-term services that will prevent or ameliorate the long-term effects of chronic illness and disability to help a child attain or maintain an optimal level of health.

EPSDT is a critical protection that is intended to protect children, including children who were born prematurely. Nonetheless, state efforts to comply with the EPSDT mandate have been criticized. A 2001 report from the Government Accountability Office, citing research by the National Health Law Program, reported that from 1995 to 2001, 28 states were sued for failing to provide access to EPSDT services.

CHILDREN RECEIVING FOSTER CARE OFTEN HAVE EXTENSIVE NEEDS AND THE STATE HAS TAKEN RESPONSIBILITY FOR PROTECTING THEIR WELFARE

WHO IS AT RISK?

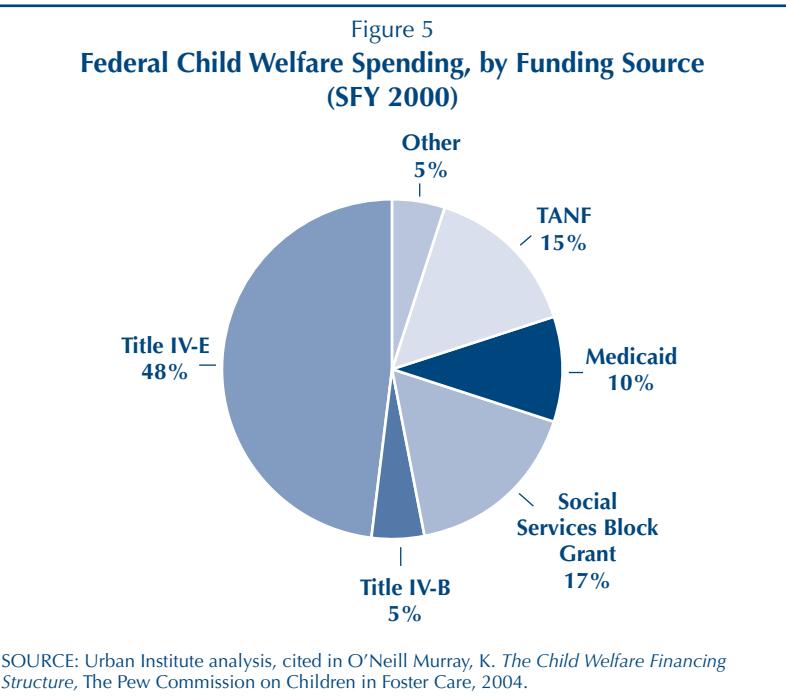
Each year, more than 800,000 children in the United States spend time in foster care.²⁵ Foster care is a form of substitute care, usually in a home licensed by a public agency, for children whose welfare requires removal from their homes. Many have experienced abuse or neglect. In other cases, however, parents have turned to the child welfare system (the array of federal, state, and local programs that are designed to protect the health and well-being of children and which fund and monitor foster care placements and adoption assistance) as a last resort to gain access to mental health services that they have not been able to obtain for their children elsewhere.²⁶ Children receiving foster care are at particularly high risk for having physical or mental health needs—whether it is from mistreatment that led to their placement in foster care or pre-existing health and long-term services needs. Half of all adults who were placed in foster care as children have serious mental health problems into adulthood and one quarter suffer from post-traumatic stress disorder.²⁷

WHAT SERVICES AND SUPPORTS ARE NEEDED?

Children receiving foster care rely on Medicaid for a broad range of acute and long-term services. This includes inpatient hospital services, clinic services, and prescription drugs. These children differ from many other children, however, in the extent to which they need mental health and other disability-related services. Case management also can be critical in coordinating various services needs and helping to ensure that children actually receive the services that physicians and other services providers prescribe.

WHY IS MEDICAID IMPORTANT?

Medicaid is the major provider of health and long-term services to children receiving foster care. The other federal programs that fund or support the child welfare system do not provide coverage for acute care and long-term services. Ten percent of federal child welfare spending comes from Medicaid (**Figure 5**). An Urban Institute analysis for fiscal year 2001 identified 869,087 children who were receiving foster care who were enrolled in Medicaid. Of these, 509,914 were enrolled in Medicaid all year. States spent approximately \$3.8 billion of federal and state Medicaid funds on children receiving foster care. Per capita spending for children receiving foster care was \$4,336 per child—more than three times the per capita spending on children without disabilities receiving Medicaid.²⁸



In 2001, thirteen percent of Medicaid spending on children receiving foster care was for rehabilitation services; eleven percent was for inpatient psychiatric services; and seven percent was for targeted care management (TCM).²⁹ Case management is particularly important for these children because it increases the likelihood that children receiving foster care will receive the health and long-term services they need. This is particularly important as these children are likely not able to effectively advocate for their own service needs, and their presence in the child welfare system likely indicates that they are unable to rely on parents or guardians to protect their interests.

TCM is a separate Medicaid option that permits states to limit case management services to certain populations including children receiving foster care. Thirty-eight states provide TCM to children receiving foster care. Children receiving foster care who receive TCM are more likely than children receiving foster care who do not receive TCM to receive several services including physician services, prescription drugs, dental services, rehabilitation services, and inpatient psychiatric services.³⁰

Medicaid Case Management Funding for Children Receiving Foster Care

Case management services help individuals gain access to needed medical, social, educational, and other services.

- Case management services can include assessment of service needs, development of a specific service plan, and referral
- Case management services cannot be used to finance the delivery of the underlying service
- With respect to foster care services, the Deficit Reduction Act of 2005 (DRA) specifically prohibits case management funds from being used for research gathering and completion of documentation required by the foster care program, assessing adoption placements, home investigations, providing transportation, administering foster care subsidies, and making placement arrangements.

SOURCE: Section 6052, Reforms of Case Management and Targeted Case Management, of the Deficit Reduction Act of 2005 (P.L. 109-171).

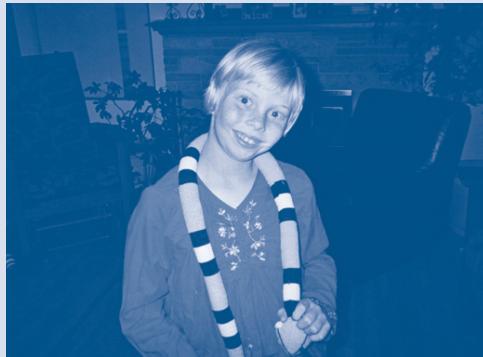
REAL PEOPLE | REAL NEEDS

Journey McGowan is 9 years old and lives with her adopted family in Minneapolis, Minnesota. She has had multiple, ongoing health problems since birth. This includes fetal alcohol syndrome, reactive attachment disorder, Asperger syndrome, and bipolar disorder (see the glossary for definitions of these conditions). While it may seem overwhelming to have so many co-occurring conditions, unfortunately, this is all too common for many children who receive foster care.

Journey was first placed in foster care at ten months and she stayed with Mary McGowan and her family for 5 months before leaving the foster care system when there was an attempt to reunite her with her biological mother. She was again placed with Mary after age two, and at three and a half, Mary adopted her. Journey now has 3 other siblings and Mary and her partner are in the process of adopting another child—as well as continuing to provide foster care to other children.

Mary says the comprehensive services provided to children in Medicaid are essential to meeting the needs of children such as Journey. In fact, when she adopted Journey, several people counseled her not to give up Medicaid for private coverage. When Journey was 7 to 8, she was hospitalized three times in an inpatient mental health facility, and her behavior was increasingly out-of-control. Mary says that if she stayed on the path she was on, her violent behavior would have hurt someone—or the family would have had to consider removing her from their home. Eventually, Mary placed Journey in an intensive residential mental health program for ten months. Mary says that this was a lifeline, and when Journey got out, she was a different child, and all of the changes have been positive.

“Because of Medicaid, Journey got the intensive psychiatric treatment that she needed. There is no way that private insurance would have covered this—and our family certainly did not have the resources to cover this,” said Journey’s mother, Mary McGowan.



Journey McGowan, Minneapolis, Minnesota

CUTTING EDGE MODEL PRACTICES

Child Health and Disability Prevention Program (CHDP), Health Care Program for Children in Foster Care, San Diego, California

Providing health and long-term services to children who transition into and out of the child welfare system can be challenging. This is complicated for children with disabilities who have long-term service needs that may require immediate attention and for whom interruptions in services pose serious threats to their health and safety. The San Diego County Child Health and Disability Prevention Program (CHDP) Health Care Program for Children in Foster Care offers some important lessons for how Medicaid and child welfare agencies can work together to respond to the needs of children receiving foster care.

San Diego is one of many California counties and programs around the country that co-locates public health nurses in child welfare offices. Public health nurses, funded by Medicaid, work with social workers to meet the health and long-term service needs of children receiving foster care. The following are key services provided by the nurses:

- Advocacy for the health care needs of individual children;
- Medical case planning and coordination that includes obtaining timely assessments of children, participating in the development of individualized health care plans for children,

and expediting referrals for services;

- On-site technical assistance and training for social workers;
- Training and consultation on health issues for foster families; and,
- Serving as a liaison with providers serving children receiving foster care.

A critical challenge for the child welfare system is to ensure that adequate numbers of qualified providers are available. CHDP operates a provider unit in which public health nurses recruit and monitor a network of specialized providers that are authorized to conduct CHDP exams and are permitted to bill Medi-Cal (Medicaid in California) for a wider array of well-child services than other providers.

Since the Health Care Program for Children in Foster Care was established in 1989, the success of the program has led the state to expand the program to other counties. **Commenting on the importance of this program to Medi-Cal, Judith Quinn, Manager, Health Care Program for Children in Foster Care said,**

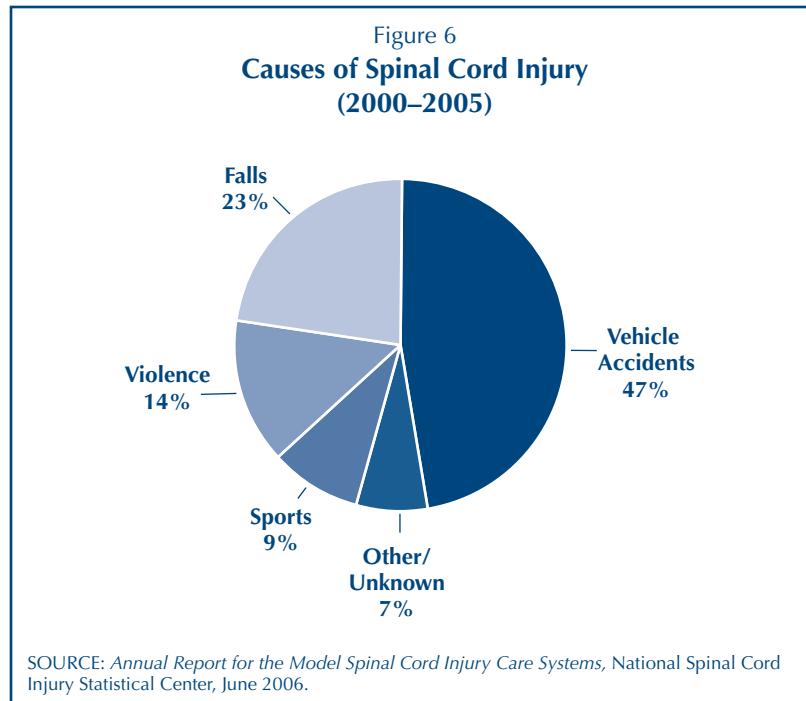
“We truly do make a difference in the lives of our children, one child at a time.”

PEOPLE WITH SPINAL CORD AND TRAUMATIC BRAIN INJURIES HAVE UNEXPECTED AND FINANCIALLY CATASTROPHIC HEALTH AND LONG-TERM SERVICES NEEDS

WHO IS AT RISK?

Roughly 250,000 Americans have spinal cord injuries, and each year, about 11,000 new injuries occur.³¹ A spinal cord injury is damage to the spinal cord that causes loss of sensation (feeling) and motor (muscular) control. A related condition is traumatic brain injury, which refers to the effects on the brain after a head injury. This possibly entails the loss of memory, vision, communication and mobility, and can also lead to personality changes. An estimated 5.3 million Americans are living with a disability caused by a traumatic brain injury. About 1.5 million Americans sustain a traumatic brain injury each year, but only 80,000 experience the onset of long-term disability following an injury.³²

The major causes of brain and spinal cord injuries are similar, with falls, motor vehicle accidents, and violence significant contributors to both types of injuries. Nearly half of all spinal cord injuries in the United States result from motor vehicle accidents (**Figure 6**), with nearly a quarter resulting from falls, and 14% resulting from violence, primarily gunshot wounds.



WHAT SERVICES AND SUPPORTS ARE NEEDED?

The service needs of people with spinal cord injuries involve two distinct phases: the initial rehabilitation, and ongoing health maintenance and assistance. The initial rehabilitation period often involves extensive medical management to ensure that individuals recover and heal from their injuries. It also involves teaching individuals to adapt to their new impairment. This can include teaching individuals how to function and perform core activities, such as how to dress oneself, how to use the bathroom, and how to transfer into and out of a bed. It also involves training on community re-integration, so that individuals are given the supports they need to do more than stay in a bed or sit idle in their residence all day. This can include helping people to seek out employment, education, or other forms of social engagement. Spinal cord injuries create several health challenges and stress the body in ways that require close monitoring on a lifelong basis. This includes a special emphasis on maintaining the health of the skin, the bowels, and the bladder. When individuals are re-hospitalized after the initial rehabilitation, it is often because of problems with these critical organs. Depending on the level of impairment, individuals have varying levels of need for a variety of long-term services. A critical type of support, however, is personal assistance.

Spinal cord injuries are classified by severity, and this generally corresponds to where—or how high on the spinal cord—an injury is sustained. The least severe injury can cause incomplete motor function. A more severe condition is paraplegia, which causes paralysis of the legs and often portions of the trunk. Tetraplegia (also called quadriplegia) causes paralysis of the arms and legs and leads to impairments of other body functions. Low tetraplegia commonly causes paralysis of the limbs, but individuals often maintain fine motor control of the hands and fingers. High tetraplegia is caused by an injury even higher on the spinal cord than low tetraplegia and generally leaves individuals unable to control their hands or fingers. Some persons with high tetraplegia also use a ventilator to assist with breathing, for at least some part of the day.

Brain injuries also span a broad spectrum of severity. Some individuals with traumatic brain injuries may recover to the point where they do not experience recurring symptoms. Other persons with severe injuries, however, may have long-term problems with cognition and memory, behavioral issues, as well as functional limitations. All individuals with a traumatic brain injury require rehabilitation, but the severest cases involve extensive cognitive therapy, which promotes the development of new neural networks in the brain and requires individuals to re-learn how to control their muscles and perform physical and mental activities.

Average first year treatment costs for people with spinal cord injuries vary from roughly \$219,000 for a person with an incomplete motor functional impairment to more than \$741,000 for a person with high tetraplegia. Average costs for each subsequent year also

range from roughly \$15,000 to more than \$130,000, respectively. It has been estimated that the lifetime cost for a 25 year old who sustains an injury that causes high tetraplegia is nearly \$3 million. Similar cost estimates for providing services to people with traumatic brain injuries are not available, but it has been estimated that direct medical care and indirect costs associated with traumatic brain injuries cost the national economy more than \$60 billion in 2000.^{33,34}

The Demographics of Brain and Spinal Cord Injuries

Spinal cord and brain injuries are characterized by notable gender, age, and racial/ethnic characteristics:

Mostly Men

- Men are 1.5 times more likely than women to experience a traumatic brain injury
- Since 2000, seventy-eight percent of spinal cord injuries have occurred in men

Common in Young People

- The two age groups at highest risk for traumatic brain injuries are children age 0–4 and 15–19
- Fifty-three percent of all spinal cord injuries occur in young adults between the ages of 16 and 30

Over-Representation of African Americans

- African Americans have the highest death rate from traumatic brain injuries
- Twenty-three percent of spinal cord injuries since 2000 have occurred in African Americans, nearly double their share of the overall population

SOURCE: *Facts about Traumatic Brain Injury*, Centers for Disease Control and Prevention, August 2005 and *Annual Report for the Model Spinal Cord Injury Care Systems*, National Spinal Cord Injury Statistical Center, University of Alabama at Birmingham, June 2006.

WHY IS MEDICAID IMPORTANT?

These conditions are so costly that virtually no individuals have the capacity to finance the cost of their own services unless they have insurance; even then, the level of impairment could lead to individuals becoming unemployed—and losing access to private coverage. Therefore, Medicaid quickly becomes the only source of assistance for many individuals whose acute care and long-term support needs arise from spinal cord or brain injuries.

Brain and spinal cord injuries tend to occur in young adults who are often uninsured or underinsured, with limited savings. These injuries have the potential to be financially catastrophic, thus increasing the role of public financing. Medicaid is generally the only program available to assist uninsured individuals with these injuries. As discussed previously, Medicare, the other public health insurance program, is largely sheltered from responsibility for covering non-elderly individuals with brain and spinal cord injuries, especially during the critical—and highest cost—first year following an injury, due to the Medicare waiting period.

REAL PEOPLE | REAL NEEDS

Henry Claypool, now 43 and a resident of Arlington, Virginia, has been living with a spinal cord injury since he was 19. A student at the University of Colorado at Boulder, Henry was injured in a snow skiing accident in 1982 when his ski came off causing him to crash into a tree. His accident caused several serious injuries including a collapsed lung, as well as the injury to his spinal cord, which caused paraplegia, and a peripheral nerve injury that limits his ability to control his right arm and hand.

Henry was evacuated by an air ambulance to a level 1 trauma center in Denver. As with many people with his level of injury, tending to his other physical injuries, including repairing his lungs, was the priority immediately following his injury. He remained at the trauma center for two weeks before being transferred for rehabilitation to Craig Hospital, also in Denver and one of the 16 model spinal cord injury centers in the United States. Due to complications from his other injuries, Henry spent 4 months at Craig Hospital. At the time, most people with paraplegia or quadriplegia were initially hospitalized for about six weeks of intensive rehabilitation. Under current standards, the average rehabilitation is about 4 weeks. Although he was a college student, Henry was also working full-time and insured when he had his accident. Nonetheless, whether it was related to coverage limits or the fact that his injuries meant he would not be returning to the workforce anytime soon, his private coverage was insufficient. He became eligible for Medicaid while he was at the trauma center. Despite starting out with private insurance, he needed Medicaid to cover his extensive rehabilitation costs.

He emphasizes the importance of the initial rehabilitation for people with spinal cord injuries:

"It is difficult to experience, learn, experiment and refine just how one will function after a life changing experience like spinal cord injury in just 4 to 6 weeks. One must continue to learn and adapt as their understanding of the experience of their 'new body' progresses."

He states, however, that the structured regimen is an opportunity for individuals to learn as much as possible—a starting point for a longer-term adjustment. During the initial rehabilitation, goals are set with respect to maintaining an individual's health, addressing psychosocial issues, education (including family education), mobility training (such as how to transfer from bed to a wheelchair and ambulation), learning how to move a wheelchair outside of the hospital, learning to operate a motor vehicle, and performing various activities of daily living (such as feeding, grooming, bladder and bowel care, and bathing, etc.).

Over the past two decades, Henry's injury has not prevented him from living an independent and meaningful life. He graduated from college, and has had a long career helping other people with disabilities both through working to deliver services and in the policy arena. For nearly the last ten years, he has worked at the national level on public policy issues, including serving as the Senior Advisor for Disability Policy to the Administrator of the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services), the federal agency responsible for Medicare and Medicaid. He has also worked on disability policy issues for the Social Security Administration and as an independent consultant. Due to Medicaid's initial investment in his rehabilitation, and armed with the skills acquired through his education, Henry has been working and privately insured for most of the time since his accident. Henry is enjoying his personal and work lives, but he has some trepidation for the future and, due to long-term effects of his injury, doubts that he will be physically able to work to a normal retirement age. No matter what the future holds, Medicaid has already played an essential role in his life.



Henry Claypool, Arlington, Virginia

CUTTING EDGE MODEL PRACTICES

The Shepherd Center, Atlanta, Georgia

The Shepherd Center is a catastrophic care hospital in Atlanta, Georgia that specializes in providing medical care and rehabilitation to people with spinal cord injury and disease, acquired brain injury, multiple sclerosis, and other neuromuscular problems. It was founded in 1975 by an Atlanta family that became aware of the dearth of services for people with spinal cord injury—after their son, James Shepherd, experienced a body surfing accident as a young adult. Since that time, the Shepherd Center has grown into the largest catastrophic care hospital in the United States, with 100 beds, including an 8-bed intensive care unit. It has been a member of the Spinal Cord Injury Model System, a federal research and demonstration program, since 1982.

Relevance to Medicaid policy. The Shepherd Center and other model system hospitals accept Medicaid patients, but gaining Medicaid approval for a rehabilitation stay can be challenging, especially for persons who do not reside in Georgia. The Shepherd Center and other model system hospitals, however, do more than other facilities to achieve functional gains, achieve a return to home, assist people in being re-employed, and avoid preventable health conditions. The Shepherd Center and other model system hospitals have a lower rehospitalization rate, their patients have fewer secondary complications, they have a lower skin sore rate, as well as having a higher percentage of their patients who are discharged to home instead of a nursing facility when compared to other hospitals. Therefore, an initial investment in this type of quality care may lower overall public costs and will likely have tangible impacts in the life of the individual.

Many hospitals across the country operate rehabilitation programs. When an individual sustains a brain or spinal cord injury, they are likely to receive services as close to home as possible. Because health outcomes are not the same at all institutions, however, this initial geographic determination could result

in diminished lifetime success for the affected individual. This diminished success invariably results in increased medical costs, increased secondary complications, and a series of negative impacts on the affected individual, his or her family, and the community at large. If cost were not an issue, families faced with a spinal cord injury should ensure that their loved ones get to one of the spinal cord injury model system hospitals—and the sooner they get there in terms of hours and days, the better. Medicaid programs may need to re-evaluate their policies—and adopt a longer-term view of cost-effectiveness—that make it difficult for individuals with spinal cord and brain injuries to go to the Shepherd Center and other model system hospitals for rehabilitation.

What makes the Shepherd Center noteworthy?

The Shepherd Center is unique in several ways: 1) it offers an extensive continuum of rehabilitation services; and 2) it takes a holistic approach to rehabilitation that enhances the effectiveness of its patient care programs. Whereas a typical rehabilitation hospital may teach a person how to dress and transfer into and out of a wheelchair, the Shepherd Center sees that not as the goal, but as the starting point that will result in maximal community re-integration. The Shepherd Center has an extensive therapeutic recreation program that teaches people to adapt to their injuries and return to doing the activities that they enjoy, whether this is gardening, basketball, water skiing or hunting.

Two other notable features of the Shepherd Center are its vocational rehabilitation program and its Marcus Community Bridge program. These initiatives ensure that the skills individuals gain during their rehabilitation are applied at home and in the community. The Shepherd Center also has an extensive outpatient program that may limit the need for rehospitalization. Many of these services and programs are made possible due to the extensive philanthropic support provided by the local community.

PEOPLE WITH MENTAL ILLNESS EXPOSE THE POTENTIAL FOR INCREASED PUBLIC COSTS WHEN INDIVIDUALS CANNOT ACCESS THE SERVICES THEY NEED

WHO IS AT RISK?

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.^{35,36} Mental illness is a category of health conditions that is characterized by alterations in thinking, mood or behavior that is associated with distress or impaired functioning. Some commonly occurring forms of serious mental illness (mental illness that is so severe that it, in and of itself, is potentially disabling) include schizophrenia, major depression, and bipolar disorder. Schizophrenia is characterized by profound disruption in cognition and emotion, affecting the most fundamental human attributes: language, thought, perception, affect, and sense of self. Major depression is a condition in which individuals become despondent and dejected and this interferes with the ability to work, sleep, eat, and function. Bipolar disorder is a serious condition characterized by repeated episodes of mania and depression. Many other types of mental illness or mental disorders exist that vary dramatically in their symptoms and severity.

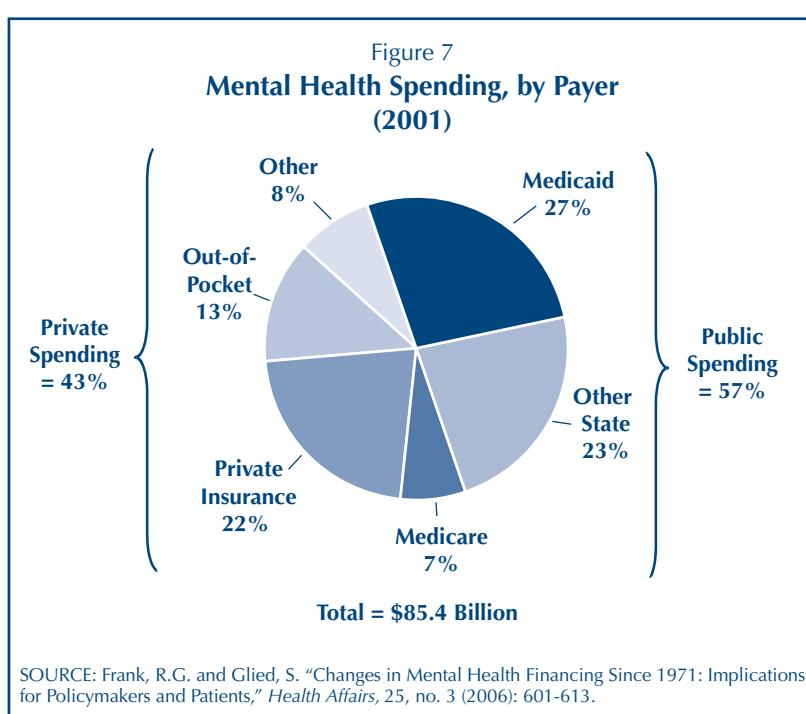
WHAT SERVICES AND SUPPORTS ARE NEEDED?

People with mental illness have a variety of needs including care from psychiatrists, individual and group counseling, and various therapy services. Over the past couple of decades, pharmaceuticals have gained a greater prominence in the medical management of mental illness. While not effective, tolerated, or desired by all people with mental health needs, the development of latest generation prescription drugs have enabled individuals with even very serious forms of mental illness to live in and remain engaged with their own communities.

In conceptualizing mental illness, mental health professionals and advocates counsel that there must be a recognition that many diagnoses are lifelong conditions, and this fact has implications for an individual's housing situation, employment, and social relationships. Lack of treatment or inadequate access to medical and social supports can mean the difference between effectively living in the community and entering a cycle of last resort care in high-cost settings such as institutions or jails. A long-term view of mental health services for individuals with mental health disorders includes access to a continuum of care that includes preventive services and screenings, medical and social interventions, and crisis and inpatient services.

WHY IS MEDICAID IMPORTANT?

In 2001, Medicaid accounted for 27% of total national spending on mental health services, the single largest source of mental health financing (**Figure 7**). Medicaid plays an important role in meeting the needs of a subset of people with mental illness. This includes persons whose mental illness is severe enough for them to qualify for assistance on the basis of disability, as well as Medicaid beneficiaries who qualify on the basis of another disability or through a different eligibility category, who also have mental health service needs. While only four percent of program beneficiaries qualify for Medicaid because of a mental disorder that qualifies them as disabled, a much larger share of enrollees (13 percent) rely on Medicaid for mental health benefits.³⁷



The lack of adequate coverage for comprehensive mental health services by other public and private payers remains a policy challenge and this increases the need for comprehensive mental health services provided by Medicaid. In recent years, Medicaid's share of total mental health spending has grown considerably.³⁸ While Medicare pays for inpatient mental health services, there is a lifetime limit of 190 days of coverage. Further, unlike the twenty percent cost-sharing that beneficiaries must pay for most other services, Medicare cost-sharing for outpatient mental health services is typically fifty percent. Moreover, in the private insurance market, plans typically set discriminatory limits on inpatient and outpatient mental health care and impose higher co-payments and deductibles

for these services. Although a minimal requirement exists in current law directing plans not to apply stricter lifetime or annual spending limits on mental health care, most plans have made this a meaningless protection in light of the stricter limits and higher co-payments on mental health services that are allowed.³⁹

Medicaid is often the only avenue through which people with a severe mental illness can get their needs met. But when Medicaid is not available to them and they have no other access to needed care, their conditions worsen. Under these circumstances, such individuals may be brought to costly hospital emergency rooms or find themselves among the ranks of the homeless. Many, in deteriorating mental health, come into contact with law enforcement and end up in the criminal justice system. Indeed, public resources could be conserved if there were more options for states to intervene earlier to establish Medicaid eligibility than the current situation where repeated periods of hospitalization or incarceration frequently occur before individuals have a sufficient history of mental illness to meet the Social Security standard for disability.

Many state Medicaid programs have experimented with various models for providing services that include interventions that provide a continuum of care for those who need the support of a structured therapeutic environment—and which can be used to minimize the need for inpatient services. For example, partial hospitalization programs allow individuals to live in their own homes, but during the day, individuals go to a hospital or clinic to receive services. Another model for delivering services is the concept of assertive community treatment. These programs involve multidisciplinary teams that provide intensive services to persons with severe mental illnesses. The majority of services are delivered where consumers live and work. These programs also provide immediate crisis response, and can often prevent the need for inpatient hospitalization.

Rehabilitation and Targeted Care Management (TCM) are Essential Mental Health Services

Medicaid beneficiaries with mental illness use the full range of acute and long-term services to meet their various needs. Rehabilitation services and targeted case management (TCM), however, have become particularly important to state efforts to meet the needs of people with mental illness.

- Forty-six states plus the District of Columbia use the rehabilitation services option to provide a range of services including crisis services, medication education and management, skills training, and other services to enable individuals to live in the community.
- All states and the District of Columbia, except Delaware use the targeted case management (TCM) option to provide services to some populations. In the states that provide TCM to persons with mental illness, TCM is commonly used in conjunction with rehabilitation services to link persons with mental illness to medical services, as well as educational, housing, supported employment, and other social services.

SOURCE: *Medicaid Benefits: Online Database*, Kaiser Commission on Medicaid and the Uninsured, accessed on November 28, 2006.

REAL PEOPLE | REAL NEEDS

Jamie Armstrong, age 45, has been living with schizo-affective disorder since age 17. He also has other mental health problems, including post-traumatic stress disorder, which resulted from difficult circumstances in his childhood, as well as chronic physical health problems, including high blood pressure and fibromyalgia, a condition that causes chronic pain in muscles, ligaments, and tendons. A resident of Cassopolis, Michigan, Jamie has received Medicaid and Social Security disability benefits for nearly 20 years.

As with many people with mental health problems, Jamie is able to successfully manage his condition largely through reliance on a pharmaceutical regimen that works for him. He currently takes four different drugs used to treat mental illness. Some of these drugs may have created or exacerbated some of his other chronic conditions. In the past, he was on a different mental health drug for a long time, and he found that this initially caused him to lose weight, but then it was followed by substantial weight gain. The added weight caused him to develop Type 2 diabetes, a phenomenon that has been reported with other people taking psychotropic medications. Jamie eventually switched to another drug, and he was able to lose weight—and the diabetes went away. At the present time, Jamie uses fairly limited mental health services in addition to his prescription drug regimen. He sees a psychiatrist every 3 months, he has a case manager, and access to a psychiatric nurse. He is also able to access therapy and counseling, as needed, on a walk-in basis.

Jamie credits his current treatment success to several factors that seem to be common features of many people who are recovering from mental illness: he has a strong support system and he is in a long-term relationship. As with many people with disabilities, a big part of his life involves helping others. For many years, he has been engaged in helping to operate Schizophrenics Anonymous groups, he has been involved in a prison project to help meet the mental health needs of people who are incarcerated, and he serves as a consumer representative on various state policy making boards and advisory panels.

Jamie is very satisfied with Medicaid, but he is concerned about new co-payments he must pay—and he is worried that this will increase further. Previously, he did not have co-payments for his drugs, but now he must pay \$3.00 for each prescription and starting in January 2007, his co-payments are increasing again to \$2.15 for generics and \$5.15 for brand name drugs.

"Every dollar makes a difference, and three dollars for each of my medications really adds up. This is the cost of a loaf of bread and a gallon of milk," Jamie says.



Jamie Armstrong, Cassopolis, Michigan

CUTTING EDGE MODEL PRACTICES

MHA Village, Los Angeles, California

As the largest funder of mental health services, Medicaid programs have a huge stake in the development of new models for meeting the needs of people with mental illness in ways that improve health and lower public costs. The *MHA Village* is an example of a model program both because it is effective and is responsive to the needs of people with mental illness—and because the program has demonstrated that it is cost effective.

The *MHA Village* is a program of the National Mental Health Association of Greater Los Angeles. It was first established by California's mental health department in 1990 as a state demonstration project—without receiving Medicaid funding—to test an "integrated services" approach to providing community mental health services. It builds on many of the principles of assertive community treatment, but goes beyond assertive community treatment chiefly in its emphasis on self-direction, promotion of well-being, and a focus on individual goals. In 1996, the program was converted to a county program and it started to partially rely on Medicaid funding. In 1999, the program became the model for providing comprehensive care for people with mental illness who are homeless, leaving jail, or at risk of homelessness or incarceration.

The *MHA Village* incorporates many aspects of mental health care including treatment, rehabilitation, self-help, employment, and family/community involvement. The program is focused on recovery—a motivating concept for people with mental illness that includes four stages: **Hope**, where individuals gain a positive

vision for their future, and this can include setting goals such as getting a job, earning a diploma, or having an apartment; **Empowerment** is the stage where individuals gain a sense of their capabilities, an innovation of the model includes offering individuals a menu of options and they are given a choice of the type of services they would like to use; **Self-responsibility** is the third stage of recovery where individuals recognize that they need to take responsibility for their own lives, and individuals are encouraged to take risks such as by applying for a job, enrolling in school, or asking someone out on a date; and **A meaningful role in life** is the last stage of recovery where individuals use the skills gained to find a purpose in their lives that is separate from their illness.

One of the notable aspects of the *MHA Village* approach is a "whatever it takes" approach and a long-term commitment to individuals. Services are available whenever needed, and individuals cannot fail out of the program based on their behavior—once they enter the *MHA Village*, participants can count on stable, long-term support from the Village. This approach challenges longstanding Medicaid approaches to funding services, that normally require services providers to bill for the delivery of specific, clearly defined medically-oriented services.

"Medicaid was originally based on an illness-based model and not a recovery-based model. Until Medicaid adapts, it challenges efforts to deliver cost-effective community-based services," says Richard Van Horn, President and CEO of the National Mental Health Association of Greater Los Angeles.

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

WHO IS AT RISK?

There are approximately 4.5 million individuals with developmental disabilities in the United States.⁴⁰ Developmental disabilities are severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities such as the capacity for independent living, learning, mobility, receptive and expressive language and self-care. There are numerous types of developmental disabilities including autism, cerebral palsy, and epilepsy.

Intellectual disabilities are the most common type of developmental disability. Studies have shown that between 1–3% of the U.S. population has an intellectual disability.⁴¹ People with intellectual disabilities are the same as people with mental retardation. Due to the high level of stigma associated with this term, however, individuals are encouraged to avoid using it. An intellectual disability (sometimes called a cognitive impairment) is characterized by significantly low intellectual functioning combined with deficits in adaptive behavior.

WHAT SERVICES AND SUPPORTS ARE NEEDED?

Intellectual disabilities occur in a wide range of severities, and individuals have a broad range of need for services. When many people think about long-term services, they often think of people with physical impairments who need assistance with everyday activities such as bathing and dressing, and using the toilet. Some, but certainly not all people with intellectual disabilities have these needs due to physical impairments. For example, some people with intellectual disabilities may have another developmental disability such as epilepsy or cerebral palsy—or they may develop physical impairments as adults.

People with intellectual disabilities, however, have different types of long-term services needs. A common need 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 (and in some cases, instruction) to remind them when they should perform certain actions, such as showering.

Another key service category for people with developmental disabilities involves habilitation. Habilitation services assist in the acquisition, improvement, and retention of skills necessary

to maximize the ability to function. Unlike rehabilitation, which is focused on restoration of functioning, habilitation services are focused on maintenance of functioning and the acquisition of new skills, even if individuals will not attain an increased capacity to function. For persons with developmental disabilities, habilitation services can include a range of services on topics such as self-care, life skills, behavior, and vocational preparation.

IQ Testing Forms Part of a Diagnosis of an Intellectual Disability

IQ testing is used as a basis for a diagnosis of an intellectual disability, but a low IQ alone, is not sufficient for a diagnosis.

- The IQ scale is normalized so that average intelligence (adjusted for a person's age) produces an IQ score of 100.
- Scores above 100 indicate above average intelligence and scores below 100, indicate below average intelligence.
- Persons with an IQ score of 70 or below are considered to have an intellectual disability (due to variation in testing, an IQ score of 75 is considered the upper limit for an intellectual disability classification).

SOURCE: *Mental Retardation: Determining Eligibility for Social Security Benefits*, Committee on Disability Determination for Mental Retardation, National Research Council, 2002

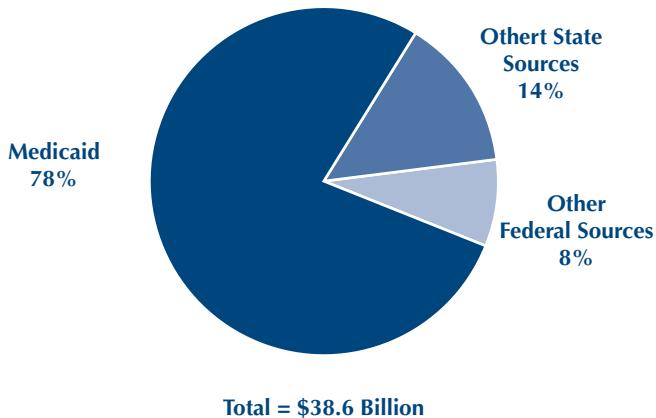
WHY IS MEDICAID IMPORTANT?

Individuals with cognitive impairments severe enough to qualify for Medicaid on the basis of disability must generally have an IQ score of 59 or below, with IQ scores in the range of 60–75 only qualifying if individuals have another co-occurring severe disability such as autism, epilepsy, or cerebral palsy.

A striking feature of the service delivery system for persons with intellectual and other developmental disabilities is the extent of Medicaid's involvement (**Figure 8**). Medicaid comprises seventy-eight percent of spending on developmental disability services. Of the remainder, 14% is from other state sources and 8% is from other federal sources, such as SSI payments and the Social Services Block Grant.⁴² Medicaid spending for persons with developmental disabilities is substantial, accounting for 10% of total Medicaid spending in 2004.⁴³

When Medicaid was established, many people with intellectual and other developmental disabilities were placed in large state-run facilities as their only option for receiving public assistance. These institutions often housed individuals in deplorable conditions. Following public education and litigation in the 1960s and 1970s, states took steps to close or radically downsize many of these institutions. There was an increased recognition that the institutional focus on providing medically-oriented, nursing care was not meeting the needs of most people with intellectual disabilities. In 1971, Congress added an optional Medicaid service category for persons residing in Intermediate Care Facilities for persons with Mental Retardation (ICF/MR). These are institutions (or distinct parts of an institution) that are primarily for the diagnosis,

Figure 8
Spending on Developmental Disability Services, 2005



Notes: Spending includes programs for persons with mental retardation and other developmental disabilities. Other federal sources includes Supplemental Security Income (SSI) payments and Social Services Block Grant funding.

SOURCE: *The State of the States in Developmental Disabilities, 2005*, Coleman Institute, University of Colorado, 2005.

treatment, or habilitation for people with intellectual disabilities. They provide, in a residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration for health or rehabilitative services to help individuals function at their greatest ability. Since the 1980s, Medicaid financing has made possible another transition toward a greater reliance on serving people in community settings. ICF/MRs retain, however, a significant role in providing long-term services to persons with intellectual disabilities. There are 7,400 ICF/MRs in the U.S. serving roughly 129,000 people.⁴⁴ As a general rule, ICF/MRs tend to serve a population with greater needs than community settings, as they are operated to provide 24 hour services. In many cases, persons in ICF/MRs have higher medical needs than others or exceptional behavioral needs that make it harder to serve in less costly community settings. Over the past couple of decades, the average size of ICF/MRs has declined significantly. Nonetheless, most advocates believe that the majority of persons in ICF/MRs could benefit from receiving services in community settings.

HCBS waiver programs have become a primary tool that states use to provide community services to persons with intellectual disabilities. In 2002, more than 367,000 people with intellectual and other developmental disabilities received HCBS services. HCBS services for this population average approximately \$35,000 per year per person—a significant investment, but significantly lower than the average cost in large state institutions (\$146,325) and other settings.⁴⁵ This cost differential is explained, in part, by the fact that institutional costs include room and board expenses in facilities that provide round the clock care and monitoring, whereas HCBS programs do not cover housing costs. Nonetheless, for persons with community housing who do not require intensive medical management, HCBS waiver programs provide important options for persons with developmental disabilities to receive services in community settings that maximize their independence.

REAL PEOPLE | REAL NEEDS

Isabella Raines is a 53-year-old resident of Birmingham, Alabama. She has cerebral palsy and a communication and mobility disability. Isabella started receiving Medicaid when she turned 18. She is a dual eligible—meaning that she receives both Medicaid and Medicare. In addition to counting on Medicaid to supplement any gaps in Medicare coverage and help her pay Medicare cost-sharing, she participates in a Medicaid home- and community-based services waiver program that provides her with day habilitation services, occupational therapy, skilled nursing, speech therapy, and case management services.

Unlike some people with developmental disabilities who have been placed in state institutions, she has always lived in the community with her family. Over the years, family support and family sacrifices have enabled Isabella to lead a full life. Isabella and her family are now facing challenges common to many individuals with developmental disabilities—ensuring that she receives adequate services as her mother and other family members become less able to provide caregiving and other supports due to their own aging.

Isabella is mostly happy with the services she receives, but says, “I need more in-home personal care, because my Mom is getting old and it is difficult for her.”

In the past, when people with developmental disabilities were more routinely placed in state institutions, many families around the country, including Isabella’s, were determined to keep their children at home. This involved real sacrifices often without sufficient social support. Families have generally taken responsibility for providing informal caregiving and fighting the system to ensure that their children received the medical, educational and other services they need to maximize their potential and help them build lives that maximize their independence. Many of the parents who brought about such a fundamental transformation in how we provide services to people with developmental disabilities and integrate them into society are becoming elderly and are increasingly less able to provide the unpaid supports that have contributed so much to the lives of their adult children. Ensuring that Medicaid and other programs are available to provide enhanced services to enable these individuals to continue to lead lives in the community is a policy challenge.



Isabella Raines, Birmingham, Alabama

CUTTING EDGE MODEL PRACTICES

Soreo In Home Support Services, LLC, Tucson, Arizona

Virtually everyone agrees that most people with disabilities who need long-term services and supports would prefer to remain in the community living in their own home, as opposed to living in an institution. While policy decisions and resources can limit the availability of community services, another barrier can be a shortage of community services providers or other community resources to actually provide needed long-term services and supports in people's homes. Soreo is a Tucson, Arizona-based company with over 200 employees that provides in-home supports to more than 600 Medicaid beneficiaries.

As with many other states, the Medicaid agency in Arizona funds services for people with developmental disabilities through a separate system than it uses for people with physical disabilities and seniors. Soreo has contracted with the state to provide in-home supports through both systems. The state funds case managers to conduct a functional assessment and refer to entities such as Soreo for a level of services up to the institutional cost. Wendy Sokol, Soreo CEO, says the most common scenario is for an individual, who does not attend a day program, school, or work, to receive up to 40 hours of services per week, with the individual's family expected to supplement this by providing informal (*i.e. unpaid*) services in the evening and on weekends.

"One of the things that the state does right is they say upfront that we cannot do everything on our own. They recognize that for this to work we need a real partnership between the state, providers, and the individual and their family," Sokol says.

Soreo has had a role in a cutting edge area of long-term services policy—supporting family members to be personal care attendants. Recently, policy makers have focused much attention on promoting consumer direction initiatives so that individuals can hire, supervise and fire personal attendants, including in some cases spouses, parents or other family members. Soreo helps to facilitate this type of family involvement by actively encouraging family members to become personal attendants. In such cases, Soreo provides training to the family member, and hires them. They receive the same pay scale and benefits as other employees. This approach helps address dual policy goals of increasing beneficiary satisfaction with the services they receive and it helps address workforce shortages that are common in many parts of the country for in-home services providers.

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

WHO IS AT RISK?

Dementia is a symptom of several medical conditions that involves a loss of mental function in two or more areas such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Several conditions can produce dementia, such as multi-infarct dementia (which results from multiple strokes), Parkinson's disease, and Huntington's disease. Alzheimer's disease, however, is by far the most common cause of dementia. Alzheimer's disease is a form of degenerative brain disease resulting in progressive mental deterioration with disorientation, memory disturbance and confusion. An estimated 4.5 million Americans have Alzheimer's disease and this number has more than doubled in the last twenty-five years.⁴⁶ Alzheimer's disease is not just a condition of the elderly. While the majority of people with Alzheimer's disease are seniors, 6–8% of people with Alzheimer's disease are diagnosed before age 65.⁴⁷

WHAT SERVICES AND SUPPORTS ARE NEEDED?

Alzheimer's disease is a serious medical condition that creates changing medical and social support needs for individuals and families as the condition progresses. In the early stages of Alzheimer's disease, an individual may have limited medical needs, although depression and other mental health conditions are common. As the disease progresses, however, there is an increased need for supervision, behavioral interventions, and habilitation services to help individuals maintain, as long as possible, the ability to perform activities of everyday life. In the early stages of the disease, individuals can remain relatively independent. Over time, however, individuals need increasing levels of assistance with maintaining a home, managing finances, and then personal activities such as bathing, dressing, and feeding.

In addition to memory loss and behavioral changes, Alzheimer's disease has serious implications for other co-occurring medical conditions, and can increase the challenge of providing appropriate services for other conditions. A researcher with the Alzheimer's Association found that coexisting conditions can exacerbate cognitive and other symptoms in people with dementia and coexisting medical conditions are more difficult to treat effectively in people with dementia as persons lose the ability to communicate effectively and report symptoms that individuals experience over time.⁴⁸ As Alzheimer's disease progresses, individuals eventually require round the clock supervision and assistance. Eventually, most families determine that nursing home care is necessary.

Community and Institutional Alzheimer's Disease Services are Quite Costly

As with other populations, there is a strong preference for individuals with Alzheimer's disease to remain at home, for as long as possible. While cost-effective compared to institutional care, community services are also expensive.

- Seven in ten people with Alzheimer's disease live at home where 75% of care is unpaid care provided by family and friends. The remainder is paid care which averages \$19,000 per person per year.
- The average cost of care at adult day centers is \$56 per day, but can be significantly higher for specialized dementia care.
- The average cost of a year of nursing home care is \$74,095.

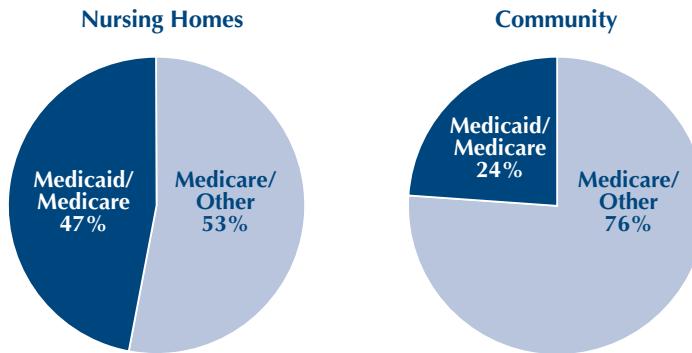
SOURCES: *Alzheimer's disease statistics*, Alzheimer's Association, 2006; *Adult Day Services: Fact Sheet*, AARP, February 2004; and Metlife Market Survey, 2005.

WHY IS MEDICAID IMPORTANT?

Medicare is the primary source of health coverage for seniors. As has been stated, however, Medicare does not provide coverage for long-term services and supports. This coverage gap creates burdens on individuals and families to provide or finance increasing levels of long-term services as Alzheimer's disease progresses. The majority of community long-term services are provided by unpaid caregivers (family and friends) that is not financed by public or private insurance. Because the unpaid care burden can be so intense—or because paid care is so costly, many individuals and families find that, despite saving for their needs in retirement, dementia-related long-term services needs exceed their lifelong savings, often quite quickly. Medicaid provides a critical safety net for individuals and families who exhaust their savings and financial resources paying for progressively more extensive long-term services.

Overall, 39% of seniors on Medicare with Alzheimer's disease were dual eligibles in 2000. Largely due to the high cost of nursing home care, Medicaid assists a larger proportion of seniors with Alzheimer's disease living in nursing homes (47%) than those living in a community (24%) (**Figure 9**).

Figure 9
Medicaid's Coverage of Seniors with Alzheimer's Disease



Notes: Includes only Medicare beneficiaries age 65 and older with Alzheimer's disease.
Medicare/Other group includes persons who only have Medicare coverage and persons who have Medicare with supplemental private coverage. Nursing home group includes beneficiaries who were in both a nursing home and the community during the year.
SOURCE: Urban Institute tabulations from the 2000 Medicare Current Beneficiary Survey.

Additionally, it appears increasingly common for Alzheimer's disease to be diagnosed in people in their fifties, a period when disability can take people out of the workforce in their most productive earning years—when people often are able to make the largest contributions to their financial nest eggs and also a period when spouses may still be working and unable to serve as full-time unpaid caregivers. Thus, younger people with Alzheimer's disease may be significantly less able to provide for their own service needs both because they have not accumulated enough financial assets and a working spouse means there is nobody available to provide unpaid supports. Medicaid is generally the only source of assistance available to these individuals.

In the Deficit Reduction Act of 2005 (DRA), Congress made some significant changes to limit access to long-term services in Medicaid by increasing the look-back period for asset transfers from three to five years. This will potentially make it more difficult for some individuals with Alzheimer's disease and other seniors to qualify for Medicaid coverage. The DRA also created a new prohibition on Medicaid eligibility for persons with substantial home equity and made changes that could limit the financial resources available to community spouses of persons who require institutional services.

REAL PEOPLE | REAL NEEDS

Mary Woods, age 87, lives with her daughter, Melva Jasper and son-in-law, Cleotis Jasper, in Milwaukee, Wisconsin. She was diagnosed with Alzheimer's disease about eleven years ago. It was only two months ago, however, that she started receiving Medicaid coverage.

Mary raised her family and worked throughout her life, working well past retirement age until she was 76. For many years, she worked as an educational assistant in a middle school for Milwaukee Public Schools. Melva says that she and Mary's other children urged her to retire, but she wanted to keep working. Finally, during a summer break, Mary came to the conclusion that she should retire. Melva attributes this to the confusion and forgetfulness that is associated with early-stage Alzheimer's disease. After her retirement, she started exhibiting increasing signs of dementia. For example, a couple of times she got lost while driving. It was around this time that Mary was diagnosed with Alzheimer's disease. She continued living alone, but eventually she became socially isolated and pretty inactive. Melva reports that she became bed-ridden not because of physical ailments, but because she did not have structure in her life or motivation to get out of bed and out of the house. Family members tried to get her involved in activities at the local seniors center, but Mary resisted these efforts. As her condition progressed, she became less able to live alone. Melva says that Mary would put food on the stove and then go to bed, so that eventually Melva's husband had to disconnect the stove so that she was not a danger to herself. About four years ago, Mary moved in with Melva and Cleotis and Melva got her into an adult day program.

"The program is almost like having a child in school ... they go on field trips and I have to sign permission slips, and I need to remember to give my Mom pocket money if they take them shopping. But the program is a lifesaver for us because my husband and I still work and it makes sure that my Mom gets out and has a socially stimulating day," says Mary's daughter, Melva Jasper.

Melva also took her mother to a geriatric clinic and worked with a social worker to try to get her other services. Because Mary worked, she has some retirement income and Social Security. Initially, Melva thought that her Mom was ineligible for public services, but her income was not enough to cover her living expenses, plus the cost of the adult day program (which is about \$1,000 per month), as well as her prescription drug costs (which cost about \$500 per month with Medicare Part D drug coverage). Melva found a local foundation that awarded a grant to Mary that paid for her adult day program for a year. Melva says that this was great, but when the grant ran out, the financial pressure was back. Eventually, assistance from the Alzheimer's Association helped Mary get enrolled in Wisconsin's Family Care program, a Medicaid pilot program that helps seniors and people with physical and developmental disabilities receive services and stay in the community. The program covers Mary's participation in her adult day program, provides Melva with one weekend per month of respite services, and covers two opportunities a year for Mary to receive assisted living when Melva can take a vacation or get a break from her caregiving responsibilities. The program has also provided some home modification services that make the home environment safer and more accessible for Mary. Mary's family is pleased with Family Care and relieved that she is able to get this essential assistance.



Mary Woods, Milwaukee, Wisconsin

CUTTING EDGE MODEL PRACTICES

Alzheimer's Family Day Center, Fairfax, Virginia

Expanding the opportunities for seniors and people with disabilities to receive community support services that delay or prevent the need for placement in an institution is a critical goal of Medicaid programs. In some cases, model initiatives can be rare and in others, Medicaid reimbursement issues can mean that states do not take advantage of cost-effective community alternatives to nursing homes.

The Alzheimer's Family Day Center (Family Day Center) is an adult day program in Fairfax, Virginia that provides specialized services for people with Alzheimer's disease and related conditions. The Family Day Center operates programs with two levels of care: one for persons with early-to-mid-stage Alzheimer's disease and another for persons with late-stage Alzheimer's disease.

According to advocates for people with Alzheimer's disease, the type of specialized services that they provide are what make the program so attractive. Participants follow a consistent routine from day to day that mixes socialization, physical activity, art therapy, and a range of intellectually stimulating activities. Another aspect of the Family Day Center that makes them unique is that, unlike many other programs, they accept persons with advanced dementia and persons who are incontinent. The staff at the Family Day Center is proud of their program, and attributes their staffing ratios as a key to their success. Depending on the level of care, there is one staff member for either three or four program participants, and they have three nurses on staff that monitor the participants,

administer medications, and provide basic care, such as blood pressure monitoring. Participants also receive physical therapy-type exercises twice per week from a licensed physical therapist.

"Part of our success comes from keeping participants engaged in activities throughout the day which helps individuals to sleep better at night and minimizes behavioral challenges for family caregivers," says Blair Blunda, Executive Director of the Alzheimer's Family Day Center.

Although there is policy consensus on keeping people in the community as long as possible—in order to minimize Medicaid expenditures on costly institutional services—the Family Day Center staff report that low Medicaid payment rates and administrative barriers prevent them from accepting many Medicaid beneficiaries. The Family Day Center averages around 30 people in its programs at one time, yet they average only 2 to 4 Medicaid beneficiaries. They report that the Medicaid eligibility process is often not smooth, saying that it often takes 90 days for Medicaid to approve coverage at the Family Day Center. There are few financial incentives for the Family Day Center to try to expand its Medicaid participation. Private pay participants pay either \$73 or \$83 per day, depending on the level of care. Medicaid, however, only pays \$47.25 per day. If Medicaid programs around the country are unable to maximize community options that can be effective at preventing the need for nursing home care, then they could be missing opportunities to minimize program costs.

FINDINGS

Our examination of six high cost populations with significant needs for acute care and long-term services demonstrates:

Medicaid assists people with financially catastrophic needs at all stages of life. With all of the planning in the world, some individuals will find that they have acute care and long-term services needs that are greater than their capacity to finance. 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. For example, roughly 250,000 Americans have spinal cord injuries, and about 11,000 new injuries occur every year, mostly in young adults. 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. People with spinal cord and traumatic brain injuries may face acute care and long-term services costs exceeding several million dollars over an individual's lifetime.

People with Alzheimer's disease illustrate the need for a safety net even for people who had planned for long-term services 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. The majority of people with Alzheimer's disease are seniors; however, 6-8 percent of people with the disease are diagnosed before age 65. As Alzheimer's disease progresses, individuals eventually require round the clock supervision and assistance. Eventually, most families determine that nursing home care is necessary—and this is quite costly. The average cost of nursing home care is \$74,095 per year.⁴⁹ Seven in ten people with Alzheimer's disease live at home where 75% of care is unpaid care provided by family and friends. The remainder is paid care, which averages \$19,000 per person per year. The average cost of care at adult day centers is \$56 per day, but can be significantly higher for specialized dementia care. 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.

These populations demonstrate that 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.

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 include conditions that arise across the age span: people who are born prematurely, children receiving foster care, individuals with spinal cord and traumatic brain injuries, people with mental illness, people with intellectual and other developmental disabilities, and people with Alzheimer's disease and related dementias. Individuals with these conditions have a range of needs for acute care, as well as long-term services and supports. For example,

people with intellectual disabilities have specialized needs that would not be met in a long-term services system developed to meet the needs of people with physical disabilities. The need for services ranges considerably and can change quickly.

Medicaid shoulders uniquely public responsibilities. This includes ensuring that children receiving foster care who have entered the child welfare system receive the acute care and long-term services they need; stepping in to provide life-saving coverage for young adults who may have recently entered the workforce and are less likely to have private coverage or personal savings, such as young adults who experience a traumatic brain injury or spinal cord injury; 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 people with Alzheimer's disease who require twenty-four hour supervision and assistance.

A foster care child, Journey McGowan (9), has had multiple, ongoing health needs since birth, including fetal alcohol syndrome, reactive attachment disorder, Asperger syndrome and bipolar disorder. Her adopted mother says, "Because of Medicaid, Journey got the intensive psychiatric treatment that she needed. There was no way that private insurance would have covered this—and our family certainly did not have the resources to cover this." The comprehensive services provided to children in Medicaid are essential to meeting the needs of children such as Journey.

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. A critical strength of Medicaid is that it has adapted to the diversity of needs of the Medicaid population to provide cutting edge services for many populations—in many cases, these are services that simply are not provided by other payers such as habilitation and targeted case management.

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. Similar models in the private sector are rare to non-existent. Jamie, who has been living with schizo-affective disorder for over twenty years in addition to other mental health problems including post-traumatic stress disorder, has been able to successfully manage his condition through reliance on a pharmaceutical regimen he receives through Medicaid. The lack of adequate coverage for comprehensive mental health services by other payers increases the need for comprehensive mental health services provided by Medicaid. Similarly, when Henry injured his spinal cord, he was able to access cutting edge rehabilitation services at a spinal cord model system hospital that have likely lowered lifetime costs by better equipping him to maintain his own health than if he had received rehabilitation at another hospital. Improvements can continue to be made within Medicaid by emphasizing a long-term view of cost-effectiveness.

Additionally, the Early and Periodic, Screening, Diagnostic, and Treatment Services (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. Alex, (age 4) was born prematurely and required seven blood transfusions during his first 6 months of life. He has relied on Medicaid to provide comprehensive services for repeated hospitalizations related to a serious respiratory infection and gastro-esophageal reflux disease—he continues to have ongoing health and developmental challenges that stem from his premature birth. The EPSDT 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. Some policy makers have advocated for inducements to purchase private long-term care insurance. All of the populations described in this paper, however, would be unable to purchase this insurance after the onset of disability. Further, many of these individuals have extensive needs for ongoing acute care; private long-term care insurance, if it were available, would only meet some of the service needs of many individuals. For example, Henry, who was working full-time and insured when he had his accident, needed Medicaid to cover his extensive rehabilitation following his spinal cord injury.

No system exists, other than Medicaid, to serve these populations. Some policy discussions of the role of Medicaid incorrectly presume that there are existing alternatives in the private sector. 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 they turn to Medicaid after other resources have been exhausted, such as Mary and her family who need assistance with the considerable costs of adult day services.

In some cases, as a nation, we have decided to finance certain services almost exclusively through Medicaid. For example, seventy-eight percent of spending on developmental disability services is from Medicaid. Isabella who has cerebral palsy and communication and mobility disabilities, relies on Medicaid to help pay Medicare cost sharing and participates in a Medicaid HCBS waiver program which provides her with day habilitation services, occupational therapy, skilled nursing, speech therapy, and case management services. Ensuring that Medicaid is available to provide enhanced services to enable individuals with developmental disabilities to continue to live in the community is a concern of hers for the future.

OUTLOOK AND CONCLUSION

Medicaid is the cornerstone of our national system for financing acute care and long-term services and supports. Medicaid's responsibility for financing these services for high cost populations and its unique capacity to meet the complex, extensive, and specialized needs of some populations is not always well understood by policy makers or the general public. Further, in fulfilling this role, Medicaid enables other parts of the health system to function by shouldering costs and providing services to complex cases, thereby relieving some of the pressure on the private insurance system and Medicare to serve these populations.

States and the federal government face ongoing pressure to control Medicaid spending due to the continued growth of Medicaid beneficiaries with high costs and the increasing costs for services. Legislative and administrative proposals have been offered by the Administration (not yet enacted or implemented) that attempt to reduce Medicaid spending by narrowing the definition of rehabilitation services and reducing funding for targeted case management (TCM) services. While these policies may yield Medicaid savings, they have important implications for high cost populations such as people with Alzheimer's disease, developmental disabilities, mental illness, children receiving foster care and other groups. At the same time, efforts to increase access to home and community-based services and to cover more people in need of long-term services and supports are constrained by resources.

Ensuring that the nation has the most efficient health care delivery system possible is a pressing issue as the population ages and the need for acute care and long-term services increases. As part of the policy dialogue, differing views have been offered about the appropriate balance between maintaining a public safety net—currently provided by Medicaid—and promoting individual or family responsibility and private market initiatives. Within Medicaid, there are serious equity issues that result in some populations receiving more resources to meet their needs than other populations, and some populations having far more extensive opportunities to receive long-term services while living in their own homes than other populations.

Medicaid plays a critical role in supporting low-income Americans and providing an essential safety net, but the nation needs to expand the financing base for long-term services and supports. A comprehensive solution likely requires a mix of public program expansions (including both Medicaid and Medicare), increased efforts by individuals and families to plan for future service needs, and an expanded role for private insurance to finance some services.

As the nation considers needed changes to strengthen our existing system for financing acute care and long-term services, it is important that policymakers and the public are aware of Medicaid's successes and unique strengths in delivering comprehensive and appropriate services to high cost populations with very complex needs. It is hoped that any changes will build on, rather than take away from the essential safety net provided by Medicaid programs across the country.

GLOSSARY

Alzheimer's disease: A disorder of the brain's nerve cells that impairs memory, affects behavior, and ultimately leads to death.

Asperger syndrome: A pervasive developmental disorder commonly referred to as a form of "high-functioning" autism. Individuals with Asperger's are considered to have a higher intellectual capacity while suffering from a lower social capacity.

Assertive Community Treatment (ACT): A team treatment approach designed to provide comprehensive, community-based psychiatric treatment, rehabilitation, and support to persons with serious mental illness such as schizophrenia.

Autism: A disorder of brain function that appears early in life, generally before the age of three. Children with autism have problems with social interaction, communication, imagination and behavior. Autistic traits persist into adulthood, but vary in severity.

Bipolar disorder: A serious condition characterized by repeated episodes of mania and depression.

Brain injury: Injury caused by an insult to the skull, brain, or its covering, resulting from external trauma that produces an altered state of consciousness, or motor, sensory, cognitive or behavioral deficits.

Case management services: A Medicaid option that permits states to provide services to help individuals gain access to needed medical, social, educational, and other services.

Cerebral Palsy (CP): A group of neurological disorders that normally develops in pregnancy or during birth. It is a life-long condition that affects the communication between the brain and the muscles, causing a permanent state of uncoordinated movement and posturing. CP is the result of an episode that causes a lack of oxygen to the brain.

Cognitive impairment: An alternative term for intellectual disability, it is a deficiency in ability to think, perceive, reason or remember.

Cueing: A service that can be provided as part of personal care or other service categories to signal or prompt and also supervise individuals with intellectual disabilities or cognitive impairments in performing tasks properly.

Deficit Reduction Act of 2005 (DRA): Legislation signed by President Bush in February 2006 that enacted numerous Medicaid and other changes in federal law, including significant changes in long-term services policies. Enacted as Public Law 109-171.

Developmental disabilities: A diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's lifetime.

Early and Periodic, Screening, Diagnostic and Treatment Services (EPSDT): A mandatory Medicaid benefit that requires states to screen children in Medicaid at regular intervals. When physical or mental health conditions are identified, states must provide treatment. This mandate is more comprehensive than any protection that exists for adults, as it requires states to provide all children with all medically necessary Medicaid coverable services—even if these are optional services that a state has not opted to cover for adults.

Epilepsy: A disorder of the brain that results in recurrent, unprovoked seizures.

Fetal alcohol syndrome: A pattern of mental and physical birth abnormalities found in some children of mothers who drank alcohol excessively during pregnancy.

Foster care: A form of substitute care, usually in a home licensed by a public agency, for children whose welfare requires removal from their homes.

Habilitation services: Services that assist in the acquisition, improvement, and retention of skills necessary to maximize the ability to function.

Home- and community-based services: A broad array of long-term services and supports provided in individuals' homes or community settings. These services generally assist individuals with activities of daily living such as bathing and dressing and instrumental activities of daily living such as managing finances or managing a home.

Home- and community-based services (HCBS) waiver: A Medicaid waiver program authorized under Section 1915(c) of the Social Security Act. Services can be provided under this waiver to individuals eligible for a nursing facility level of care. This type of waiver allows states to provide services in only limited parts of a state, provide services to certain beneficiaries without making them available to all, and cover medically needy individuals using different income and resource standards than for other Medicaid beneficiaries receiving services in the community.

Intellectual disability: A preferred term for mental retardation. A condition which results in significantly low intellectual functioning combined with deficits in adaptive behavior.

Intermediate care facility for persons with mental retardation (ICF/MR): Institutions (or distinct parts of an institution) that are primarily for the diagnosis, treatment, or rehabilitation for people with intellectual disabilities.

Low birth weight: Newborns weighing less than 2,500 g/5 lbs, 8 ounces. Very low birth-weight is defined as newborns weighing less than 1,500 g/3.31 lbs.

Major depression: Condition in which individuals become despondent and dejected and this interferes with the ability to work, sleep, eat, and function.

Mental retardation: See intellectual disability.

Partial hospitalization: A concept in the treatment of people with mental illness that allows individuals to live in their own homes, but during the day, they go to a hospital or clinic to receive services. This is a service delivery model that can be used intermittently by persons with mental illness as a strategy of avoiding long-term hospitalization.

Personal care services: Services that are sometimes called personal attendant or personal assistance services and that include a range of human assistance provided to people with disabilities and chronic conditions of all ages. The services enable these individuals to accomplish tasks they would normally do for themselves if they did not have a disability.

Post-traumatic stress disorder: Psychological and emotional distress which develops following a stressful, traumatic event or series of events.

Premature birth: A birth that occurs after fewer than 37 weeks of gestation.

Reactive attachment disorder: A mental disorder of infancy or early childhood, characterized by notably unusual and developmentally inappropriate social relatedness, usually associated with grossly pathological care. It may result in failure to initiate or respond to social interactions, or indiscriminate sociability or attachment.

Rehabilitation services: Medical or remedial services prescribed by a provider for the maximum reduction of physical or mental disability and restoration of a beneficiary to his best possible functional level.

Schizophrenia: Condition characterized by profound disruption in cognition and emotion, affecting the most fundamental human attributes: language, thought, perception, affect, and sense of self.

Spinal cord injury: Condition caused by damage to the spinal cord that causes loss of sensation (feeling) and motor (muscular) control.

Targeted case management (TCM) services: A Medicaid option that permits states to limit services to certain populations including children receiving foster care.

Title IV-B foster care program: Federal foster care program that provides states with flexible funds that are used by states to fund a broad array of child welfare services. There are no federal income eligibility requirements. The Title IV-B program is funded by both a capped entitlement and discretionary funding. Some children receiving foster care under the Title IV-B program can be covered by Medicaid through optional eligibility categories.

Title IV-E foster care program: Federal foster care program that is the largest source of federal funding for child welfare. Its two largest programs provide foster care and adoption assistance. They are permanently authorized, and like Medicaid, provide an open-ended entitlement. States can receive reimbursement under Title IV-E for three types of services: maintenance payments to adoptive families and for children receiving foster care; placement and administrative costs; and, training for staff, foster parents, and adoptive parents. Children receiving foster care under Title IV-E are a mandatory Medicaid eligibility category.

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THE KAISER COMMISSION ON
Medicaid and the Uninsured

The Henry J. Kaiser Family Foundation

Headquarters

2400 Sand Hill Road
Menlo Park, CA 94025
Phone 650-854-9400 Fax 650-854-4800

**Washington Offices and
Barbara Jordan Conference Center**

1330 G Street, NW
Washington, DC 20005
Phone 202-347-5270 Fax 202-347-5274

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