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CHAPTER



Medicaid and Persons with Disabilities

Recommendations

Medicaid and Persons with Disabilities

- 1.1** The Secretary and the states should accelerate the development of program innovations that support high-quality, cost-effective care for persons with disabilities, particularly those with Medicaid-only coverage. Priority should be given to innovations that promote coordination of physical, behavioral, and community support services and the development of payment approaches that foster cost-effective service delivery. Best practices regarding these programs should be actively disseminated.

- 1.2** The Secretary, in partnership with the states, should update and improve quality assessment for Medicaid enrollees with disabilities. Quality measures should be specific, robust, and relevant for this population. Priority should be given to quality measures that assess the impact of current programs and new service delivery innovations on Medicaid enrollees with disabilities.

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CHAPTER

Medicaid and Persons with Disabilities

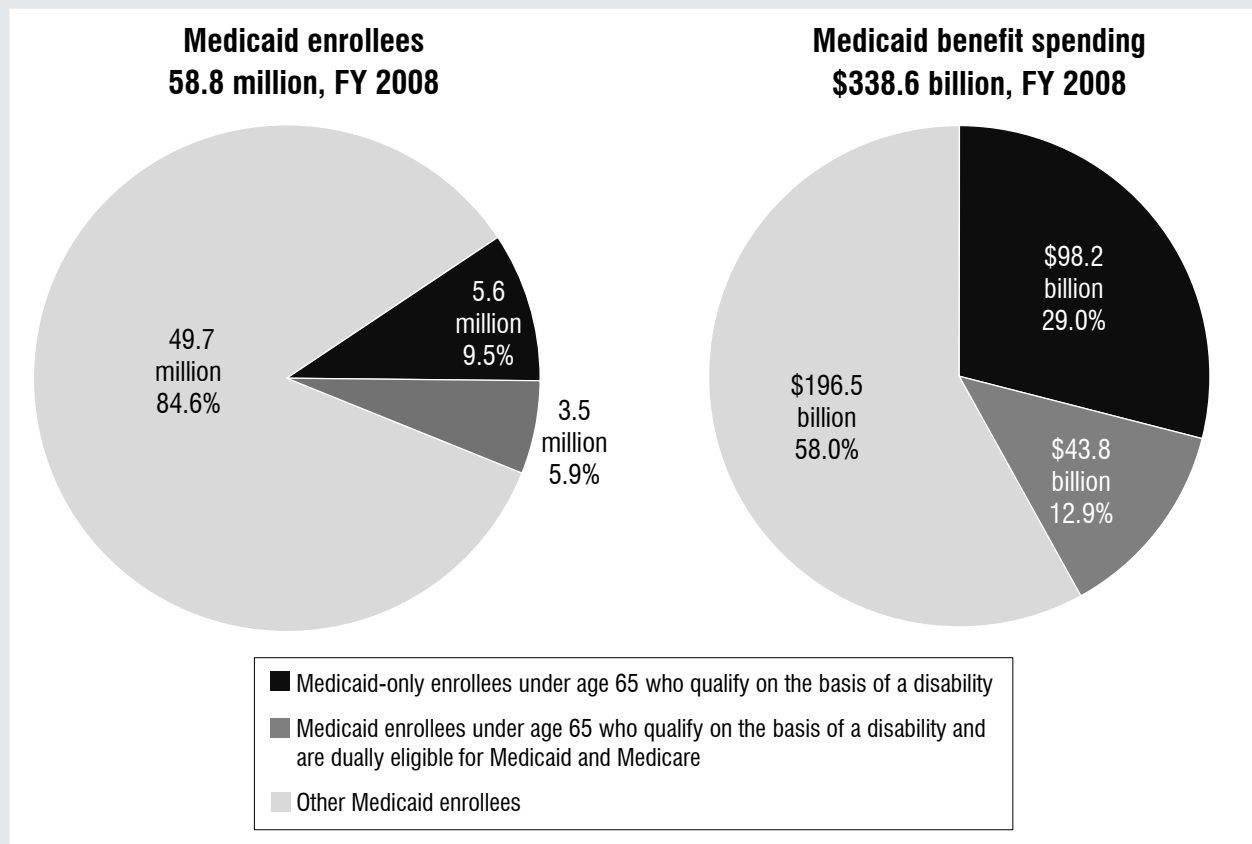
Medicaid financed health care and related services for 58.8 million individuals in fiscal year (FY) 2008, including over 9 million low-income persons under age 65 who qualified for the program on the basis of a disability.¹ Most of these Medicaid enrollees—62 percent or 5.6 million people—relied on Medicaid as their only source of coverage,² while 38 percent or 3.5 million people were dually enrolled in both Medicaid and Medicare. These figures do not include the many individuals with disabilities who qualify for Medicaid through an eligibility pathway other than based on a disability (e.g., as a low-income child, parent, or individual age 65 and older).

With budget constraints at the federal and state levels, policymakers are exploring ways to manage spending while encouraging the provision of high-quality services to high-need, high-cost enrollees. Addressing the needs of persons with disabilities presents challenges for Medicaid programs—not only because of the high spending associated with the population, but also because of their clinical diversity and resulting service delivery issues. Persons under age 65 qualifying for Medicaid on the basis of a disability include adults and children with lifelong disabilities that they have had since birth and others who have disabling conditions acquired through disease, chronic illness, or trauma. Medicaid enrollees who qualify on the basis of disability include persons with:

¹ In the Medicaid Statistical Information System (MSIS) data that are used throughout this chapter to describe FY 2008 Medicaid enrollment and spending, about 670,000 enrollees age 65 and older are identified as qualifying on the basis of a disability. Given that disability is not a Medicaid eligibility pathway for individuals age 65 and older, MACPAC recodes these 670,000 enrollees to have a basis of eligibility as “aged” throughout this report.

² Some Medicaid enrollees with disabilities also have private coverage. MACStats Tables 3A and 4A in the Commission’s June 2011 Report to the Congress indicate that 11.5 percent of Medicaid/CHIP children with disabilities who receive Supplemental Security Income (SSI) report having private coverage, as do 3.8 percent of Medicaid adults with disabilities receiving SSI who are not dually eligible for Medicaid and Medicare. However, for ease in terminology, we refer to Medicaid enrollees who are not dually enrolled in Medicare as “Medicaid-only enrollees” in this chapter.

FIGURE 1-1. Medicaid Enrollment and Benefit Spending, FY 2008



Notes: Other Medicaid enrollees include low-income children and adults under age 65 who qualify through non-disability eligibility pathways and low-income individuals age 65 and older. Enrollees qualifying on the basis of a disability are children and adults under age 65. Medicaid-only enrollees under age 65 who qualify on the basis of disability are individuals who generally rely only on Medicaid as their source of coverage (a relatively small share of Medicaid-only enrollees report having private insurance coverage in addition to Medicaid). Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chart are limited to Medicaid spending. Figures for dual eligibles include “partial” duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include “full” duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., long-term services and supports). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC’s June 2011 Report to the Congress for methodology. Excludes Medicaid-expansion CHIP enrollees and the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

- ▶ physical conditions (e.g., quadriplegia, amputation);
- ▶ intellectual or developmental disabilities (e.g., cerebral palsy, autism, Down syndrome); and
- ▶ severe behavioral or mental illnesses (e.g., schizophrenia, bipolar disorder).

This chapter examines eligibility, enrollment, population characteristics, services, spending, and the use of quality measures for persons with disabilities. It lays the groundwork for a more in-

depth exploration of the potential for managing spending while improving the quality of care for persons with disabilities. This analysis focuses on the 5.6 million Medicaid enrollees under age 65 who qualify on the basis of a disability and who generally rely only on Medicaid for their coverage. The Commission chose to focus on Medicaid-only enrollees who qualify on the basis of a disability because Medicaid spends more on them than on any other Medicaid eligibility group and not enough is known about the quality of care they receive. In addition, there are opportunities

for innovation in the delivery of services to this population that do not require coordination with the Medicare program, which adds a layer of complexity in serving persons dually eligible for Medicaid and Medicare. The Commission plans to examine issues related to individuals dually eligible for Medicaid and Medicare in future reports to the Congress, including the quality of care they receive.

Recommendations. The Commission makes two recommendations in this chapter. First, it recommends the accelerated advancement of innovative approaches to providing high-quality and cost-effective care for persons with disabilities, especially those with Medicaid-only coverage. Second, the Commission recommends updating and improving quality measurement for persons

with disabilities for use in both the current program and new program innovations.

Several key points informed the Commission's recommendations:

- ▶ **Over 9 million persons qualify for Medicaid based on a disability, and most—5.6 million—rely on Medicaid coverage alone.** Most of the 9.1 million Medicaid enrollees under age 65 who qualified for Medicaid coverage based on a disability in FY 2008 generally relied only on Medicaid for their coverage (Figure 1-1 and Table 1-1). Persons with disabilities tend to have more stability in their Medicaid eligibility status over time and are more likely to have longer periods of continuous enrollment in Medicaid than other Medicaid enrollees.³

TABLE 1-1. Medicaid Enrollment and Benefit Spending by Eligibility Group, FY 2008

| Eligibility Group | Number of Enrollees (millions) | Total Medicaid Benefit Spending (billions) | Medicaid Spending per Full-year Equivalent Enrollee |
|---|--------------------------------|--|---|
| Children | 28.3 | \$68.1 | \$3,025 |
| Adults | 15.4 | 49.5 | 4,651 |
| Aged | 6.0 | 78.9 | 14,945 |
| Disabled | 9.1 | 142.0 | 17,412 |
| <i>Medicaid-only coverage</i> | 5.6 | 98.2 | 19,682 |
| <i>Dually enrolled in Medicaid and Medicare</i> | 3.5 | 43.8 | 13,835 |
| All enrollees | 58.8 | \$338.6 | \$7,267 |

Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chapter are limited to Medicaid spending. Figures for dual eligibles include "partial" duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include "full" duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., long-term services and supports). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC's June 2011 Report to the Congress for methodology. Excludes Medicaid-expansion CHIP enrollees and the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

³ Medicaid enrollees qualifying on the basis of a disability had the longest average number of months enrolled in FY 2008 (10.8 months) compared to non-disabled adults (8.3 months), non-disabled children (9.5 months), and aged enrollees (10.5 months) (MACPAC analysis of MSIS Annual Person Summary (APS) data from CMS).

- ▶ **Medicaid spends more in total and per person on Medicaid-only enrollees qualifying on the basis of a disability than on any other population in Medicaid.** In FY 2008, Medicaid spent \$19,682 per full-year equivalent Medicaid-only enrollee under age 65 who qualified on the basis of a disability, while it spent \$3,025 for children and \$4,651 for adults who were enrolled in Medicaid through non-disability pathways. Medicaid's spending for individuals under age 65 who qualified for Medicaid on the basis of a disability and were dually enrolled in Medicaid and Medicare was \$13,835 in FY 2008. The difference in spending between Medicaid-only and dually eligible enrollees who qualify on the basis of a disability is driven by Medicare being the primary payer for acute care services for dually eligible enrollees. Additionally, some dually eligible individuals receive limited Medicaid coverage that only includes payment of their Medicare premiums and cost-sharing, rather than full Medicaid benefits.

Further, as indicated in the Commission's June 2011 Report to the Congress, individuals qualifying for Medicaid on the basis of a disability accounted for half of the real (inflation-adjusted) growth in Medicaid spending between FY 1975 and FY 2008. Much of the growth for this group was driven by increased enrollment while the remainder was attributable to growth in per capita spending.

- ▶ **Quality measurement for Medicaid enrollees with disabilities would benefit from updating and improvement.** Medicaid-only enrollees with disabilities are among the highest users of health services because of their poor health. They report poorer health status and a greater presence of health conditions and functional impairments than

other Medicaid enrollees. Comorbidities are common among Medicaid enrollees who qualify on the basis of a disability, particularly mental illness. More needs to be known about the quality of care delivered to persons with disabilities. Little is known about whether or not existing quality measures adequately assess quality of care for persons with disabilities, or if the adjustment of existing measures or development of new ones is warranted for this population.

- ▶ **Opportunities exist for the federal government and states to develop, implement, and share innovations that promote service coordination and the development of payment approaches that foster cost-effective service delivery for this population.** Persons with disabilities use a broad range and mix of services. Many Medicaid enrollees with disabilities use long-term services and supports (LTSS) that complement their medical care and help them maintain function and independence. The need for supportive services, which may be lifelong for some individuals, adds a dimension of complexity in providing coverage for persons with disabilities that is not shared by most other Medicaid enrollees.

Opportunities exist, including through the Center for Medicare & Medicaid Innovation within the Centers for Medicare & Medicaid Services, for states and the federal government to promote innovations for persons with disabilities. Innovations that foster more coordination of physical, behavioral, and community support services, and the development of cost-effective service delivery and payment approaches, would benefit this population.

This chapter explores eligibility, enrollment, population characteristics, services, spending, quality measurement, and the potential for service delivery innovation for Medicaid enrollees with disabilities in the following sections:

- ▶ **Chapter 1a: Eligibility and Population Characteristics.** Key Medicaid eligibility policies for persons with disabilities are reviewed. In addition, this section provides an overview of enrollment and population characteristics of persons under age 65 enrolled in Medicaid qualifying on the basis of a disability, including comorbidities, qualifying diagnoses, health status, and socioeconomic and demographic characteristics.
- ▶ **Chapter 1b: Services and Spending.** Services used by Medicaid enrollees with disabilities are examined, including services that may be limited or not covered under Medicare or private health insurance, such as LTSS. This section also explores Medicaid spending patterns of persons under age 65 qualifying on the basis of a disability. State and federal initiatives currently under way that promote opportunities for developing, implementing, and sharing innovative approaches for managing spending and improving care provided to Medicaid-only enrollees with disabilities are also reviewed.

This section highlights the Commission's recommendation to the Secretary of the U.S. Department of Health and Human Services and the states on the need for accelerated program innovations that foster high-quality and cost-effective care for persons with disabilities, particularly those with Medicaid-only coverage.

- ▶ **Chapter 1c: Quality Measurement.** Quality measurement for Medicaid enrollees with disabilities is examined, highlighting the efforts of federal, state, and private organizations to develop quality measures that may be relevant to this population.

This section also includes the Commission's recommendation supporting the evaluation of current quality measures for Medicaid enrollees with disabilities and updating and improving quality assessment as necessary. The recommendation addresses the importance of quality measurement as an integral part of service delivery innovations for this population.

Looking Forward

The Commission plans to examine issues related to individuals dually eligible for Medicaid and Medicare in future reports to the Congress. The Commission will further explore eligibility, population characteristics, service use, spending patterns, and quality measurement for this population.

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CHAPTER

Eligibility and Population Characteristics

More than 9 million individuals under age 65 are enrolled in Medicaid on the basis of a disability. These enrollees are a highly diverse group that includes, for example, infants with birth defects, adults with traumatic brain injuries, children with autism, and young adults with schizophrenia. Many of the Medicaid enrollees who are eligible based on disability have multiple disabling conditions and chronic illnesses. Some people have lifelong disabilities they have had since birth, while others have disabling conditions acquired through disease, chronic illness, or trauma (Box 1a-1).

This section summarizes the Medicaid eligibility pathways and population characteristics of individuals who qualify for Medicaid on the basis of a disability. These individuals are all under age 65 because individuals 65 and older cannot be eligible for Medicaid on the basis of a disability; nearly all Medicaid enrollees age 65 and older are eligible based on being “aged.” Key points of this section include:

- ▶ About two-thirds of Medicaid enrollees who qualify on the basis of a disability do so through one particular pathway: by receiving payments from Supplemental Security Income (SSI), the federal program for persons with disabilities (and aged individuals) who have low levels of income and assets. The remaining one-third are enrolled through one of the many other Medicaid eligibility pathways referred to in this chapter as non-SSI disability pathways.
- ▶ The population eligible for Medicaid on the basis of a disability is large and growing. Between 1975 and 2008, these enrollees were the fastest growing eligibility group and accounted for half of real (inflation-adjusted) Medicaid spending growth.
- ▶ The disabling conditions that may cause an individual to qualify for Medicaid are varied and may be physical, mental, developmental, or intellectual.
- ▶ Most individuals qualifying for Medicaid on the basis of a disability have comorbid conditions in addition to their qualifying diagnoses. Nearly half of the Medicaid-only enrollees eligible on the basis of a disability have a mental illness such as depression,

schizophrenia, or bipolar disorder.¹ The presence of mental illness can pose complex challenges to Medicaid both in terms of care management and controlling spending for these enrollees.

- ▶ Among children with disabilities who receive both Medicaid and SSI, 63 percent are male, 62 percent receive special education or early intervention services, and most are in a household in which a family member works. Among Medicaid-only adults under age 65 with SSI, 61 percent are female, half receive food stamps, and nearly 15 percent are in the two-year waiting period for Medicare.

The following topics are described in this section:

Medicaid eligibility pathways for persons with disabilities. There are multiple ways for individuals to qualify for Medicaid on the basis of a disability. While receipt of SSI is the primary eligibility pathway for persons with disabilities, others exist as well. These other pathways generally still use the SSI definition of disability, but income and asset criteria vary by state.

Enrollment and population characteristics.

Enrollment data for fiscal year (FY) 2008 are presented in this section. About two-thirds of individuals who qualify for Medicaid on the basis of a disability do so through the SSI pathway; the other one-third qualify through non-SSI disability pathways. Further, the majority of individuals under age 65 qualifying on the basis of a disability

are Medicaid-only enrollees (62 percent in FY 2008), while the remaining 38 percent are dually enrolled in Medicaid and Medicare.

- ▶ **Qualifying diagnoses and comorbidities.** As summarized in this section, numerous diagnoses and conditions qualify persons with disabilities for Medicaid, if they are severe enough. Research findings are also included that illustrate the prevalence of comorbidities among Medicaid-only enrollees who qualify based on disability. In addition, data from the Social Security Administration (SSA) on SSI recipients' qualifying diagnoses are used to provide information not available from federal Medicaid data.
- ▶ **Other characteristics.** Survey data are used in this part to describe other characteristics of individuals under age 65 enrolled in Medicaid and SSI. The data presented include demographic and socioeconomic characteristics.

Medicaid Eligibility for Persons with Disabilities

SSI disability pathway. SSI is a federal program that provides cash assistance to low-income persons with disabilities (under age 65) and aged individuals (age 65 and older). In most states, SSI beneficiaries are a mandatory population for state Medicaid programs and are automatically eligible for Medicaid.²

¹ Some Medicaid enrollees with disabilities also have private coverage. MACStats Tables 3A and 4A in the Commission's June 2011 Report to the Congress indicate that 11.5 percent of Medicaid/CHIP children with disabilities who receive SSI report having private coverage, as do 3.8 percent of Medicaid adults with disabilities receiving SSI who are not dually eligible for Medicaid and Medicare. However, for ease in terminology, we refer to Medicaid enrollees who are not dually enrolled in Medicare as "Medicaid-only enrollees" in this chapter.

² In all but 11 states, receipt of SSI automatically entitles a person to Medicaid. Those 11 states—known as "209(b)" states—are Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. In these states, receipt of SSI benefits does not confer automatic Medicaid eligibility because they are permitted to have more restrictive financial (e.g., income as a percent of the federal poverty level, assets) and non-financial (e.g., definition of disability) criteria for determining eligibility than the SSI program. However, these criteria may not be more restrictive than those in effect in the state on January 1, 1972, and must provide for deducting incurred medical expenses from income through Medicaid "spend down" so that individuals may reduce their countable income to the 209(b) income eligibility level. Most 209(b) states use the SSI definition of disability.

BOX 1a-1. Examples of Medicaid Enrollees with Disabilities

Claire: born with a genetic syndrome that is the only known case of its kind

It took doctors a long time to identify her disorder, but Claire had symptoms at birth that indicated multiple and severe physical, developmental, and intellectual disabilities. At almost five years of age, Claire is only as big as an 18- to 24-month-old child, and developmentally and intellectually, she is about 9 months old. She is semi-mobile with a wheelchair but cannot direct where she wants to go or walk independently. She does not understand language and cannot communicate, and she may be losing her hearing (KCMU 2011).

Tina: suffered a ruptured arteriovenous malformation of the brain, similar to a massive stroke, the result of a congenital defect

Tina was in critical care treatment in the months immediately following her brain trauma. She underwent multiple surgeries, followed by intensive rehabilitation and further surgeries. Once stabilized enough to leave the hospital, Tina moved to a rehabilitation center, but still with breathing and feeding tubes. After about 10 months, she was able to come home. At age 20, Tina receives physical therapy at home to help her learn to walk again. She also receives cognitive therapy and occupational therapy to help her with daily activities that maximize her independence (KCMU 2011).

John: suffered a severe spinal-cord injury in an automobile accident, leaving him paralyzed from the neck down

John, age 41, has a number of secondary conditions as a result of his injury and paralysis. He is prone to urinary tract infections, irregular bowel and bladder function, ulcers, breathing problems, hypothermia, and osteoporosis. In addition, he occasionally experiences skin breakdowns and low blood pressure. John has a personal care attendant (PCA) and lives on his own. He receives PCA services 78 hours each week (Brodsky et al. 2000).

Karla: born with microcephaly, cerebral palsy, and spastic quadriplegia

Karla's disabilities are severe enough that she needs constant help and supervision. With assistance, Karla performs many of the basic daily hygiene activities previously done for her by a home health aide. At age 22, she reads at a first-grade level and uses a portable picture-based computer system to communicate (NRCPDS 2012).

Greg: has bipolar disorder

Greg has an extensive record of mental illness, including brief episodes of psychosis and a misdiagnosis of paranoid schizophrenia. He has been relatively medically stable and currently takes a combination of four prescription drugs to manage his bipolar disorder (KCMU 2003).

SSI disability definition. The definition of disability used for SSI—which is also the definition used for adults in the Social Security Disability Insurance (SSDI) program, through which qualifying individuals may obtain Medicare after a 24-month waiting period—is used for nearly all Medicaid disability pathways. This definition was designed to grant eligibility for federal income support when an individual’s ability to work is significantly impaired, rather than when broad criteria concerning functional or health status are met. As a result, there are many individuals who have multiple chronic conditions but who may not be eligible for Medicaid on the basis of a disability. In addition, there are enrollees who could meet the criteria to be considered disabled but who have already obtained Medicaid through a non-disability pathway (e.g., as a low-income child or parent) and therefore have not sought a disability determination.

Conditions that may cause an individual to qualify for Medicaid on the basis of disability include:

- ▶ physical conditions (e.g., quadriplegia, amputation);
- ▶ intellectual or developmental disabilities (e.g., cerebral palsy, autism, Down syndrome); and
- ▶ severe behavioral or mental illnesses (e.g., schizophrenia, bipolar disorder).

However, having a particular condition is generally not sufficient to qualify a person for Medicaid on the basis of a disability. As discussed in Annex 1 to this section, the definition of disability requires that the condition be severe—taking into account the ability to work (for adults) and the presence of functional limitations (for children)—and last at least 12 months or result in death. (Detailed

information on SSI enrollees’ qualifying diagnoses is presented later in this section.)

Besides meeting disability criteria, SSI recipients must also have low levels of income and assets (resources). In 2012, an individual qualifying for SSI cannot have countable income of more than \$698 per month—about 75 percent of the federal poverty level (FPL)³—or countable assets of more than \$2,000 (see Annex 1 for more information on SSI).

Non-SSI disability pathways. The Congress has added a variety of other eligibility pathways over the years with varying policy purposes, such as lessening work disincentives and emphasizing home and community-based alternatives to institutionalization. Generally, individuals still must meet the SSI definition of disability, but their countable income or assets may be above SSI levels. The following are a few of the key Medicaid eligibility pathways for persons with disabilities who do not qualify for SSI:⁴

- ▶ **Poverty level.** States have the option to cover persons with disabilities with income or assets above the level permitted for SSI eligibility.
- ▶ **Medically needy.** Under this option, persons with disabilities who have higher incomes can “spend down” to a state-specified medically needy income level by incurring medical expenses.
- ▶ **Special income level.** Under this option, states can cover institutionalized individuals with incomes up to 300 percent of the SSI benefit rate (approximately \$2,100 per month for an individual, or 224 percent of the FPL); states may also extend this eligibility to individuals who receive home and community-

³ See Table 19 in MACStats for dollar amounts that correspond to the FPL for various family sizes.

⁴ See Table 11 in MACStats for information on states’ income eligibility levels for some of these pathways.

TABLE 1a-1. Persons Eligible for Medicaid on the Basis of a Disability by Eligibility and Age Groups, FY 2008

| | Enrollment of Persons Eligible for Medicaid on the Basis of a Disability (millions) | Medicaid Eligibility Group | | Age Group | |
|--|---|----------------------------|--------------|--------------|--------------|
| | | SSI | Non-SSI | Under 19 | 19 to 64 |
| Total persons under age 65 eligible for Medicaid on the basis of a disability | 9.1 | 65.8% | 34.2% | 15.7% | 84.3% |
| Medicaid-only coverage | 5.6 | 79.9 | 20.1 | 25.4 | 74.6 |
| Dually enrolled in Medicaid and Medicare | 3.5 | 43.2 | 56.8 | 0.1 | 99.9 |

Note: Enrollees qualifying on the basis of a disability are children and adults under age 65. The Supplemental Security Income (SSI) category includes persons with disabilities with incomes above SSI levels who receive state supplementary payments. The non-SSI category includes persons with disabilities who qualify for Medicaid through pathways such as poverty level, medically needy, special income level, and other non-SSI pathways. Individuals with disabilities in 11 “209(b)” states that may use more restrictive eligibility criteria than SSI to determine Medicaid eligibility may be reported in either the SSI or non-SSI category. Excludes the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data from CMS

based waiver services as an alternative to institutionalization.

- ▶ **Working persons with disabilities.** States must cover certain qualified, severely impaired individuals whose earnings would otherwise disqualify them from Medicaid; states can allow certain other working persons with disabilities to buy into Medicaid (see Annex Box 1a-A1).
- ▶ **Home and community-based services (HCBS).** States may extend eligibility to individuals who receive certain HCBS and require an institutional level of care or meet other needs-based criteria that assess functional status.

Enrollment and Population Characteristics

The population eligible for Medicaid on the basis of a disability is large and growing. Between 1975 and 2008, enrollees with disabilities were the fastest growing eligibility group in Medicaid and accounted for half of real (inflation-adjusted) Medicaid spending growth (MACPAC 2011b). Survey and administrative data presented below provide a picture of these enrollees with disabilities, focusing on the Medicaid-only population.

Enrollment

In FY 2008, there were 9.1 million persons under age 65 enrolled in Medicaid on the basis of a disability.⁵ About two-thirds of all persons who

⁵ For purposes of federal program enrollment and spending data, the classification of “disabled” generally refers to Medicaid enrollees under age 65 who qualify for Medicaid on the basis of a disability. In the Medicaid Statistical Information System (MSIS) data that are used throughout this chapter to describe FY 2008 Medicaid enrollment and spending, about 670,000 enrollees age 65 and older are identified in the data as qualifying on the basis of a disability. Given that disability is not a Medicaid eligibility pathway for individuals age 65 and older, MACPAC recodes these 670,000 enrollees to have a basis of eligibility as “aged” throughout this report.

qualify for Medicaid on the basis of a disability do so because they receive SSI benefits; the remainder are eligible through non-SSI pathways (Table 1a-1).

Persons dually eligible for Medicaid and Medicare. As noted throughout this chapter, some individuals enrolled in Medicaid on the basis of a disability (through SSI or non-SSI pathways) are dually eligible for both Medicaid and Medicare. In general, these dually eligible individuals under age 65 are SSDI beneficiaries (see Annex 1) who receive Medicare after a 24-month waiting period (SSA 2011c).⁶ One analysis estimated that there were approximately 500,000 adults enrolled in Medicaid who were receiving SSDI but were in the 24-month waiting period prior to enrollment in Medicare (Dale and Verdier 2003).

Among individuals eligible for Medicaid on the basis of a disability, 38 percent were dual eligibles; the remainder (62 percent) were covered only by Medicaid (Table 1a-1).⁷ (As noted in Chapter 1b, Medicaid-only enrollees also account for the majority of Medicaid spending on persons qualifying based on disability.)

The share of enrollees qualifying through receipt of SSI is smaller among dual eligibles with disabilities (43 percent) than among Medicaid-only enrollees with disabilities (80 percent).⁸

There is no automatic eligibility link between SSDI and Medicaid. Individuals found eligible for SSDI generally meet the Medicaid definition of

disability, but they must also qualify for SSI or meet the requirements for another eligibility pathway to qualify for Medicaid.⁹

Population characteristics

In addition to its size and growth over time, another notable feature about the population of Medicaid enrollees with disabilities is its heterogeneity. A wide range of disabilities, clinical characteristics, health care and other supportive service needs, and socioeconomic and demographic characteristics are represented in this population. The discussion below emphasizes the range of disability diagnoses prevalent in the Medicaid population (focusing on SSI beneficiaries), the extent of multiple chronic conditions (comorbidities), and other population characteristics such as the socioeconomic characteristics of Medicaid enrollees with disabilities.

SSA data on qualifying diagnoses. The most readily available source of data on the disability diagnoses of Medicaid enrollees comes from SSA administrative records. Medicaid administrative data, unfortunately, provide little or no information about the diagnosis that was the original basis for an individual's disability determination. While the SSA data cannot identify all individuals enrolled in Medicaid on the basis of a disability, they permit analyses of individuals under age 65 who receive SSI, who represent a majority of those qualifying for Medicaid based on disability.

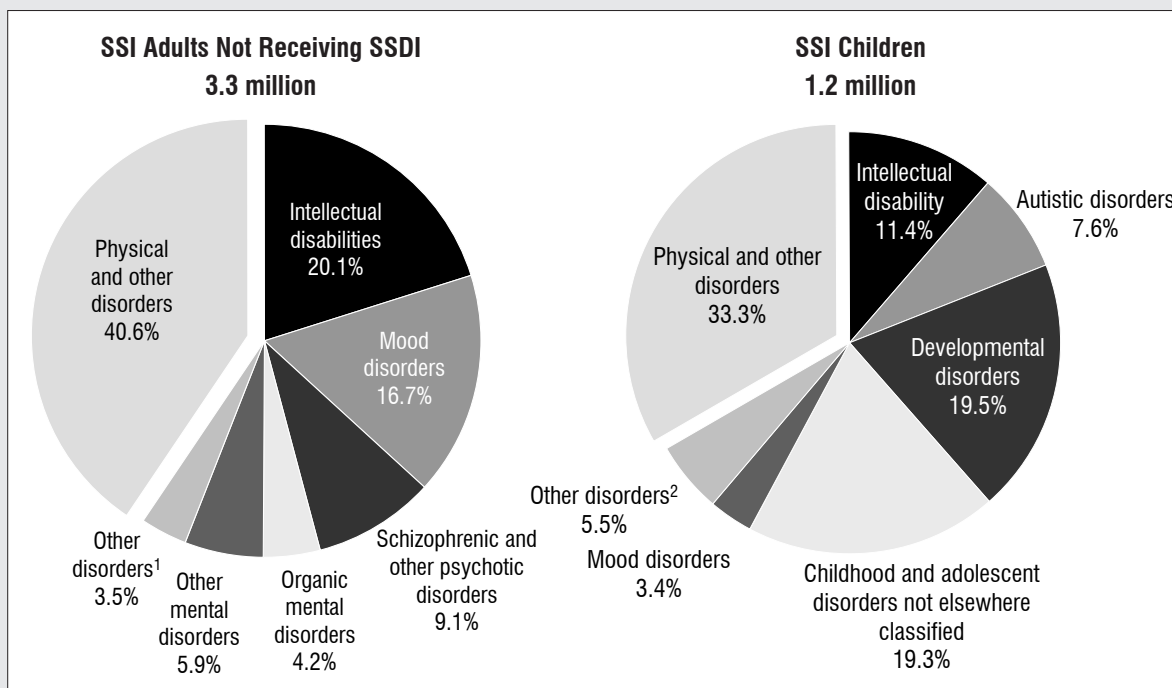
⁶ Some dual eligibles under age 65 may receive Social Security's Old-Age and Survivors Insurance (OASI) benefits. As noted in Annex 1, although SSDI and OASI can both make payments based on the disability of the insured worker, spouse, and/or child in varying circumstances, Medicare eligibility is available only for individuals receiving these Social Security benefits based on their own disability (i.e., disabled worker, disabled widow(er), disabled adult child).

⁷ As noted earlier, a relatively small share of Medicaid enrollees report having private insurance coverage in addition to Medicaid.

⁸ One reason for this difference is that nearly all persons with disabilities dually eligible for Medicaid and Medicare have SSDI income, which in some cases is high enough to disqualify them from receiving cash assistance under SSI. As a result, they must qualify for Medicaid through a non-SSI eligibility pathway.

⁹ For Medicare enrollees who have incomes below specified FPL percentages, Medicaid provides limited coverage of certain Medicare premium and cost-sharing amounts. These limited-benefit pathways under Medicaid for dual eligibles are referred to as Medicare savings programs (MSPs). Individuals enrolled in MSPs receive full Medicaid benefits only if they are also eligible under another Medicaid eligibility pathway (e.g., SSI or poverty level).

FIGURE 1a-1. SSI Adults Not Receiving SSDI (Age 18 to 64) and SSI Children (Under Age 18) by Qualifying Diagnosis, 2010



Note: This figure includes adults who received federal SSI and/or federally administered state supplementation but not SSDI, as well as children who received federal SSI and/or federally administered state supplementation. The diagnostic groupings used by the Social Security Administration (SSA) closely parallel the major ICD-9 classifications commonly used by the medical community to categorize conditions. Physical and other disorders include non-mental disorder conditions such as congenital anomalies; infectious and parasitic diseases; endocrine, nutritional, and metabolic diseases; injuries; neoplasms; and diseases of the blood and blood-forming organs, circulatory system, digestive system, genitourinary system, musculoskeletal system and connective tissue, nervous system and sense organs, respiratory system, and skin and subcutaneous tissues.

¹ Includes autistic disorders (1%), developmental disorders (1%), and childhood and adolescent disorders not elsewhere classified (1%).

² Includes other mental disorders (3%), organic mental disorders (2%), and schizophrenic and other psychotic disorders (<1%).

Source: SSA 2011e

Based on data from SSA, Figure 1a-1 illustrates the qualifying diagnoses of certain SSI recipients—children under 18 as well as adults age 18-64 whose only federal disability income benefit was SSI. Because these individuals do not qualify for SSDI and thus are generally not eligible for Medicare, they reflect the Medicaid-only enrollees who make up the majority of those qualifying for Medicaid on the basis of a disability.

According to SSA data, 3.3 million adults under age 65 qualified for SSI in 2010 on the basis of

a disability¹⁰ and did not receive other federal disability income benefits. As categorized by SSA, mental and intellectual disabilities made up 59 percent of these adults' qualifying diagnoses. A mental disorder includes, for example, schizophrenia, bipolar disorder, psychosis, or depression. Forty-one percent qualified due to a physical or other non-mental disorder—for example, injuries, birth defects, or disease of organs or systems (Figure 1a-1).

¹⁰ By definition, persons eligible on the basis of a disability are under age 65. Those who are eligible for SSI who are age 65 or older are eligible on the basis of being aged.

An even larger proportion of children receiving SSI qualified on the basis of mental or intellectual disabilities. Among the 1.2 million children receiving SSI due to a disability in 2010, 67 percent qualified on the basis of a mental or intellectual disability (Figure 1a-1). While severe mental illness such as schizophrenia represented less than 1 percent of the qualifying diagnoses among children, 20 percent had developmental disorders and 8 percent had autistic disorders. Another 19 percent of children qualified for SSI based on childhood and other adolescent disorders, including attention deficit hyperactivity disorder (ADHD). Only 33 percent of children receiving SSI had qualifying diagnoses of physical or other non-mental disorders.

Comorbidities. A relatively comprehensive picture of the chronic health conditions that affect people with disabilities in Medicaid can be found in Medicaid claims and other sources of data. These data show that comorbidities are common among Medicaid enrollees qualifying on the basis of a disability, including those with Medicaid only as well as those dually eligible for Medicaid and Medicare; many have multiple chronic conditions and co-occurring behavioral health and physical health conditions (Patchias 2011, Kronick 2007). Recent research on chronic conditions among Medicaid-only enrollees qualifying on the basis of a disability (Kronick et al. 2009) found:¹¹

- ▶ There is a high prevalence of mental illness (47 percent), cardiovascular disease (38 percent), and central nervous system diseases (28 percent).
- ▶ Nearly half (45 percent) were diagnosed with three or more chronic conditions; these individuals accounted for 75 percent of the spending for Medicaid-only enrollees with disabilities.

- ▶ Within the highest-cost 1 percent of these enrollees, 87 percent had three or more chronic conditions, and 67 percent had five or more chronic conditions.

Mental illness. Behavioral health conditions are widespread among Medicaid-only enrollees qualifying on the basis of a disability. The presence of mental illness can pose complex challenges to Medicaid both in terms of care coordination and high spending for these enrollees.

As noted earlier, one study found that 47 percent of Medicaid-only enrollees qualifying on the basis of a disability had a mental illness such as depression, psychosis, or bipolar disorder. This was based on data combining medical claims and prescription drug utilization. The analysis of claims data showed that 29 percent received services for a mental health condition. Another 18 percent had used a prescription drug for mental health treatment (Kronick et al. 2009).

Mental illnesses are common co-occurring conditions among the most expensive enrollees. When looking at the pairs of chronic conditions affecting the highest-cost 5 percent of Medicaid-only enrollees qualifying on the basis of a disability, mental illnesses are in three of the top five (Kronick et al. 2009).

Among Medicaid-only enrollees qualifying on the basis of a disability who have one of the five most common chronic physical conditions,¹² approximately two-thirds also have a mental illness (Boyd 2010). Up to 20 percent of Medicaid-only enrollees qualifying on the basis of a disability with one of these five chronic physical conditions also have mental illness *and* a drug or alcohol disorder.¹³

¹¹ The findings in Kronick et al. (2009) exclude Arizona, Delaware, Hawaii, Maryland, Michigan, New Mexico, Oregon, Pennsylvania, and Tennessee because of those states' widespread use of managed care in Medicaid, for which adequate data are not available.

¹² Asthma/chronic obstructive pulmonary disease, congestive heart failure, coronary heart disease, diabetes, and hypertension.

¹³ These numbers are likely too low because of underreported drug and alcohol use.

For those with common chronic physical conditions, health care spending is 60 to 75 percent higher for those with mental illness than for those without; the addition of a substance abuse disorder doubles to triples their health care spending, depending on their conditions.

Although limited to the state of New York, one recent study found that adult Medicaid enrollees with mental health or substance abuse conditions—including persons eligible through non-disability pathways and those dually eligible for Medicaid and Medicare—are sicker, use more services, and are more costly to Medicaid than similar enrollees without these conditions (Coughlin and Shang 2011). The study also found that Medicaid enrollees with substance abuse conditions were less likely to qualify for Medicaid due to a disability, which likely reflects the fact that drug addiction and alcoholism are not health conditions qualifying as a disability under SSI or Medicaid (§1614(a)(3)(J) of the Social Security Act (the Act)). However, the study found a strong correlation between mental health and substance abuse conditions; 22 percent of adult Medicaid enrollees in New York with mental health conditions had substance abuse problems, while 56 percent of Medicaid enrollees with substance abuse problems also had mental health conditions.

Other characteristics. Self-reported health status, income, education, family structure, and work status can provide valuable context for understanding the medical and social needs of low-income persons with disabilities. Administrative data do not contain all of the relevant information needed to create a comprehensive profile of Medicaid enrollees qualifying on the basis of a disability. Survey data such as the National Health

Interview Survey (NHIS) can provide information that is useful in understanding characteristics, in addition to the qualifying diagnoses, of Medicaid-only enrollees under age 65 who are receiving SSI. It should be noted that, especially for children and certain adults, survey responses are often provided by a knowledgeable adult in the family, rather than by individuals with disabilities themselves.

The findings that follow are for non-institutionalized Medicaid-only enrollees under age 65 receiving SSI, based on previously published MACPAC analyses (MACPAC 2011b) as well as new analyses from the same data.¹⁴ The results are presented separately for adults age 19 to 64 and for children under 19, because those age groups reflect most enrollees' pathways to Medicaid.¹⁵

Demographic and socioeconomic characteristics of Medicaid enrollees receiving SSI include:

Adults age 19 to 64

- ▶ Females accounted for 61.4 percent of adults in this age group who have Medicaid-only coverage and SSI. This is significantly lower than the female share of non-elderly Medicaid adults overall (66.3 percent), but higher than that among adults who were privately insured (50.9 percent) or uninsured (44.9 percent).
- ▶ Half of non-elderly Medicaid-only adults with SSI were also receiving food stamps.
- ▶ 14.5 percent of non-elderly Medicaid-only adults with SSI were receiving SSDI. These individuals were most likely in the 24-month waiting period that SSDI recipients face before Medicare coverage begins.

¹⁴ The NHIS is a survey of non-institutionalized individuals. The results exclude individuals residing in nursing homes, for example. The NHIS data in this section are from 2007-2009.

¹⁵ As noted in MACPAC 2011b, many of the measures for children were obtained only for those age 0 to 17 or 2 to 17, rather than 0 to 18. For example, survey responses for ADHD are sought only for children age 2 to 17.

Children

- ▶ Males accounted for the majority (62.9 percent) of children with disabilities who receive both Medicaid and SSI—a significantly higher proportion than among children with Medicaid or CHIP overall (51.4 percent) or privately insured and uninsured children (50.9 percent for both groups).
- ▶ Among children with both Medicaid and SSI, 62.2 percent received special education or early intervention services, compared to 9.8 percent of children with Medicaid or CHIP overall, 5.7 percent of privately insured children, and 6.0 percent of uninsured children.
- ▶ For 61 percent of children with both Medicaid and SSI, the family also received some other form of government assistance. Nearly half (47.6 percent) of children with Medicaid and SSI received food stamps.
- ▶ Among children with both Medicaid and SSI, the majority (54.7 percent) had a family member who worked—42.4 percent had at least one full-time worker and 12.3 percent had only a part-time worker(s).

For health status, the data indicate:

Adults age 19 to 64

- ▶ 57.9 percent of non-elderly Medicaid-only adults with SSI reported being in fair or poor health, compared to 32.2 percent of non-elderly Medicaid adults overall, 6.4 percent of adults with private coverage, and 12.5 percent of uninsured adults.
- ▶ Compared to non-elderly Medicaid adults overall as well as non-elderly adults with private coverage or who are uninsured, non-elderly Medicaid-only adults with SSI were more likely to have chronic conditions (e.g., hypertension, depression, arthritis, bronchitis, coronary heart disease), restrictions in activities of daily living

(ADLs), functional limitations, provider visits, emergency room visits, and at-home care visits.

Children

- ▶ Children with disabilities who receive both Medicaid and SSI were more likely to report fair or poor health, the presence of impairments requiring special equipment (e.g., braces, wheelchair), and limitations in their ability to crawl, walk, run, or play than were children enrolled in Medicaid or CHIP overall, as well as privately insured and uninsured children.
- ▶ Compared to children enrolled in Medicaid or CHIP overall, as well as to privately insured and uninsured children, children with both Medicaid and SSI were more likely to report the presence of ADHD, asthma, autism, cerebral palsy, congenital heart disease, Down syndrome, and other developmental delays.

In its future work, the Commission will continue to examine issues related to persons with disabilities, including persons dually eligible for Medicaid and Medicare.

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Chapter 1a Annex 1

SSI, SSDI, and the Definition of Disability

The Social Security Administration (SSA) administers two separate federal programs that are primarily designed to provide payments to individuals based on disability—Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Individuals are eligible for SSDI based on minimum work history requirements and having made certain contributions through payroll taxes. SSI does not have minimum work or contribution requirements; instead, it is limited to persons under age 65 with disabilities (and individuals age 65 and older) who have low levels of income and assets. Both SSI and SSDI use a similar definition of disability, which most states are required to follow for their Medicaid programs.¹

Definition of Disability

For adults applying for SSI or SSDI, the law defines disability as the inability to engage in any substantial gainful activity (SGA) because of one or more medically determinable physical or mental impairments that can be expected to result in death or last for at least 12 months (§§223(d)(1)(A) and 1614(a)(3)(A) of the Social Security Act (the Act)).² Considering their age, education, and work experience, individuals must not be able to engage in any kind of SGA that exists in the national economy, regardless of whether such work actually exists in the immediate area or whether a specific job vacancy exists (§§223(d)(2)(A) and 1614(a)(3)(B) of the Act). Individuals are generally considered to be engaging in SGA if their earnings (net of impairment-related expenses) exceed a specified monthly amount (§§223(d)(1)(A) and 1614(a)(3) of the Act). For 2012, the monthly SGA amount for an individual is \$1,010 in earnings (SSA 2011a).

For children under age 18, the SSI definition of disability is slightly different. Rather than considering work limitations, it is based on whether the child has any medically determinable physical or mental impairment(s) that cause marked and severe functional limitations, and that can be expected to cause death or last at least 12 months (§1614(a)(3)(C)(i) of the Act).

Individuals apply for SSI and SSDI at local SSA offices. If applicants meet certain basic eligibility criteria (for example, earnings below the SGA amount), the application is

¹ As noted in Section 1a, 11 “209(b)” states may use a more restrictive definition of disability, although most do not.

² Individuals may also qualify because of blindness, which relies on a slightly different definition (§§216(i)(1)(B) and 1614(a)(2) of the Act).

forwarded for a medical disability determination. Federally funded state disability determination service (DDS) agencies—often within what many states call their department of human services or department of vocational rehabilitation—are responsible for developing medical evidence and rendering the determination of whether individuals have disabilities or are blind under the law.

Supplemental Security Income

SSI, which is authorized under Title XVI of the Act, is a means-tested program that provides cash assistance payments to people who are aged, blind, or disabled. In 2012, the monthly federal benefit rate—that is, the maximum monthly amount of SSI payments, which defines the upper income limit for SSI eligibility—is \$698 for an individual (about 75 percent of the FPL)³ and \$1,048 for a couple.⁴ The SSI limits on countable assets are \$2,000 for an individual and \$3,000 for a couple.

Although individuals are not precluded from working while they receive SSI benefits, their earnings generally must remain below the SGA amount in order to continue meeting the program's definition of disability (§1614(a)(3)(E) of the Act). In addition, their countable income (both earned and unearned) must remain below the monthly federal benefit rate.⁵

The monthly benefit rate may be reduced if individuals have other income. For the two basic categories of individuals under age 65 who can receive SSI, the average SSI payments (as of January 2012) were as follows:

- ▶ Adults (age 18-64) with a disability received an average monthly benefit of \$533.50.
- ▶ Children under age 18 with a disability received an average monthly benefit of \$620.20.

In January 2012, approximately 4.8 million adults and 1.3 million children received SSI payments on the basis of a disability (SSA 2012a).

As previously noted, receipt of SSI benefits automatically entitles a person to Medicaid in all but 11 “209(b)” states, which are permitted to have more restrictive financial (e.g., income as a percent of FPL, assets) and non-financial (e.g., definition of disability) criteria for determining Medicaid eligibility than the SSI program.

Social Security Disability Insurance

SSDI, which is authorized under Title II of the Act, provides benefits to persons with disabilities or blindness who are insured by workers' contributions to the Social Security Trust Fund. These contributions are based on earnings as required by the Federal Insurance Contributions Act. Certain dependents (spouses and children) of insured individuals may also qualify for benefits.

Eligibility for SSDI requires a work history (on the part of the claimant, a parent, or a spouse). As with SSI, SSDI generally requires beneficiaries' earnings remain below the SGA (§221(m)(2)(B) of the Act).

There are three basic categories of individuals who can qualify for SSDI benefits based on disability (their own disability or that of a family member):

- ▶ disabled workers—insured workers under Social Security's full retirement age with a disability (average monthly benefit in January 2012 of \$1,110.60);

³ See Table 19 in MACStats for dollar amounts that correspond to the FPL for various family sizes.

⁴ Many states pay a supplemental benefit to persons in addition to their federal benefits.

⁵ Certain amounts and types of income are not counted for SSI purposes. For example, there is a general income disregard of \$20 per month; in addition, the first \$65 of monthly earnings and half of all earnings above \$65 are excluded (§1612(b) of the Social Security Act). Thus individuals can have gross income in excess of 75 percent FPL and still qualify for SSI because their countable income is below that level.

BOX 1a-A1. The Ticket to Work and Work Incentives Improvement Act of 1999

The Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA, P.L. 106-170) revised several aspects of the SSDI and SSI programs as a means of promoting employment for persons with severe disabilities. Because access to health care and health insurance was cited as critical to supporting the employment of persons with disabilities, TWWIIA also gave states additional options to expand Medicaid coverage to employed persons with disabilities.

TWWIIA added two optional Medicaid pathways for states to provide to persons with disabilities. In both cases, the state has full discretion to set financial eligibility criteria (income and assets). These pathways are generally referred to as Medicaid “buy-ins” because enrollees can be charged income-related premiums at levels that are not generally permitted under Medicaid. States may also impose cost sharing such as copayments and deductibles. The two TWWIIA pathways are as follows:

- ▶ States may extend Medicaid eligibility to working-age individuals who would be eligible for SSI if not for their earnings. To be eligible under this pathway, individuals must be employed persons age 16 to 64 who meet the SSI disability definition.
- ▶ States may continue Medicaid coverage for working enrollees whose medical conditions remain severe, but who would otherwise lose SSI eligibility due to medical improvement as determined at a regularly scheduled disability review. States can only offer coverage under this pathway if they also extend eligibility under the previous pathway.

The level of services covered under the buy-in programs is the same as for other Medicaid enrollees.

- ▶ children of disabled workers—children of a parent entitled to SSDI (average monthly benefit in January 2012 of \$330.60), where the child must be under age 18, a full-time student age 18, or a disabled adult child age 18 or older; and
- ▶ spouses of disabled workers—spouses of a worker entitled to SSDI, where the spouse must be age 62 or older or care for an entitled child who is under age 16 or is disabled (average monthly benefit in January 2012 of \$298.70).

In January 2012, 8.6 million disabled workers, 1.9 million children (including a small number of disabled adult children), and 162,000 spouses received SSDI benefits (SSA 2012a).

Besides SSDI, payments for persons with disabilities may also be made under Social Security’s Old-Age and Survivors Insurance (OASI). These payments are for disabled adult children of retired or deceased

workers and for certain disabled widows and widowers. About 1.1 million disabled individuals (852,000 disabled adult children and 245,000 disabled widows and widowers) received OASI benefits in December 2010 (SSA 2011e).

For individuals who receive SSDI or OASI benefits on the basis of their own disability (i.e., disabled worker, disabled widow(er), disabled adult child), Medicare coverage is generally available after a 24-month waiting period. Non-disabled children and spouses do not qualify for Medicare by virtue of receiving SSDI benefits through a disabled worker.

Chapter 1a Annex 2

BOX 1a-A2. Major Legislative Milestones and Key Provisions in the Evolution of Medicaid's Role for Persons with Disabilities

- 1965** The Medicaid program was enacted as Title XIX of the Social Security Act (P.L. 89-97).
- ▶ Required states to cover populations receiving cash assistance, including adults receiving Aid to the Permanently and Totally Disabled or Old Age Assistance, and families receiving Aid to Families with Dependent Children.
 - ▶ Permitted states to offer Medicaid coverage to the medically needy, which included those individuals who would meet the eligibility requirements for cash assistance if their medical expenses were deducted from their incomes.
- 1972** The Social Security Amendments of 1972 (P.L. 92-603):
- ▶ Established the Supplemental Security Income (SSI) program, which replaced the state-based Aid to the Permanently and Totally Disabled and Old Age Assistance programs.
 - Generally set national income and assets standards for SSI and a uniform definition of disability.
 - Required states to provide Medicaid coverage to all their federally qualified SSI recipients or to all individuals with disabilities using their state's eligibility standard for disabilities in effect in 1972 (known as 209(b) states).
 - ▶ Expanded Medicare to cover individuals with disabilities who have received Social Security Disability Insurance (SSDI) for 24 months.
- 1981** The Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) established the Section 1915(c) home and community-based services (HCBS) waiver program to allow states to provide long-term services and supports in the community to individuals who, but for such services, would require an institutional level of care.
- Permitted states to target specific groups, limit the geographic area in which services are available, and cap the number of enrollees eligible for services under HCBS waivers.
 - Required that waiver programs demonstrate cost neutrality.

BOX 1a-A2, Continued

- 1982** The Tax Equity and Fiscal Responsibility Act of 1982 (P.L. 97-248) established the “Katie Beckett” option, which allowed states to provide Medicaid to children with disabilities at home rather than in institutions:
- ▶ The child must be under 19 years of age, meet the SSI definition of disability, and meet the medical-necessity requirement for institutional care.
 - ▶ Permitted Medicaid coverage of home care benefits so long as the estimated cost to Medicaid is no higher than it would be if the child were institutionalized.

- 1986** The Omnibus Budget Reconciliation Act of 1986 (P.L. 99-509) established several new Medicaid eligibility categories:
- ▶ Gave states the option to provide full Medicaid benefits to individuals age 65 and older and individuals qualifying on the basis of a disability with income below a state-established level that does not exceed 100 percent of the federal poverty level (FPL).
 - ▶ Required states to provide full Medicaid benefits to “qualified severely impaired individuals” under age 65 who are working despite severe mental or physical impairments, as long as those individuals received SSI disability or blindness benefits, state supplementary payments, or payments under Section 1619(a) of the Social Security Act and were otherwise eligible for Medicaid.
 - ▶ Gave states the option to pay the Medicare premiums and cost sharing for low-income qualified Medicare beneficiaries (QMBs) with incomes at or below 100 percent FPL.

- 1988** The Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360):
- ▶ Required states to pay the Medicare premiums and cost sharing for QMBs.
 - ▶ Created a minimum level of asset and income protection for the spouses of individuals living in a nursing home in order to prevent spousal impoverishment.

Most of the MCCA was repealed in 1989, but the Medicaid provisions of the bill remained in law.

- 1990** The Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508) required states to pay Medicare premiums for beneficiaries with incomes between 100 and 120 percent FPL (specified low-income Medicare beneficiaries or SLMBs).

The Supreme Court ruling, *Sullivan v. Zebley*, mandated that, if children seeking SSI benefits do not qualify on the basis of medical standards alone, the SSA must perform an individualized functional assessment of how each child’s impairment limits his or her ability to act and behave in age-appropriate ways.

BOX 1a-A2, Continued

1997 The Balanced Budget Act of 1997 (P.L. 105-33):

- ▶ Allowed states to provide Medicaid coverage to working individuals with disabilities with net family income up to 250 percent FPL, as long as their resources do not exceed the SSI resource standard.
 - States that use this option can charge premiums and impose cost sharing on a sliding scale based on income.
- ▶ Required states to pay Medicare premiums for Medicare beneficiaries with incomes between 120 and 135 percent FPL (qualifying individuals or QIs).

1999 The U.S. Supreme Court ruled in *Olmstead v. L.C.* (119 S. Ct. 2176) that persons with disabilities who are capable of living in the community should have the option to reside in the most integrated setting appropriate to their needs; subsequent federal guidance to states discussed the role of Medicaid in meeting this goal.

The Ticket to Work and Work Incentives Improvement Act of 1999 (P.L. 106-170) gave states the option to extend eligibility to certain working persons, subject to premium payments (“buy-in”), who had been eligible for Medicaid on the basis of a disability, but who would otherwise lose eligibility because their earnings were too high or because they were no longer considered disabled due to medical improvement.

2003 The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L. 108-173) established for people on Medicare a voluntary outpatient prescription drug benefit, known as Part D, which went into effect on January 1, 2006.

- ▶ Individuals dually eligible for Medicare and Medicaid who had previously received their prescription drugs through Medicaid switched to drug coverage through a private Medicare Part D plan.

2005 The Deficit Reduction Act of 2005 (P.L. 109-171):

- ▶ Included the Family Opportunity Act, which gave states the option to extend Medicaid coverage to children with disabilities with family incomes up to 300 percent FPL.
 - Permitted states to charge income-related premiums:
 - Under 200 percent FPL, premiums and cost sharing limited to 5 percent of family income;
 - Between 200 and 300 percent FPL, premiums and cost sharing limited to 7.5 percent of family income.
 - Parents must participate in ESI if the employer covers at least 50 percent of the premium.
- ▶ Added Section 1915(i) to the Social Security Act, to permit states to provide HCBS waiver services to persons with disabilities with incomes up to 150 percent FPL as a state plan option:
 - Permitted states to provide HCBS to individuals who do not require an institutional level of care.
 - Permitted states to establish enrollment caps and maintain waiting lists, and to provide services under this option only in certain parts of a state.

BOX 1a-A2, Continued

2010 The Patient Protection and Affordable Care Act (P.L. 111-148):

- ▶ Created the Community First Choice Option in Medicaid to allow states, through a state plan option, to provide statewide home and community-based attendant supports and services to individuals who, but for these services, would require institutional care.
 - Allows states to receive a six percentage point increase in federal matching payments for expenditures related to this option.
- ▶ Modified the Section 1915(i) HCBS state plan option:
 - Expanded the scope of services to include “other services requested by the state as the Secretary may approve.”
 - Removed states’ ability to limit the number of eligible individuals who can receive HCBS state plan option services.
 - Required statewide coverage, but provided states the ability to target specific populations (e.g., individuals with specific conditions).
 - Provided an option for states to provide HCBS to an additional group of individuals with incomes up to 300 percent of the SSI benefit rate who must be eligible for HCBS waivers (i.e., by meeting an institutional level of care requirement).

Note: States may be able to provide coverage for individuals at higher eligibility levels than indicated in this table through the use of income and asset disregards.

CHAPTER 1b

Services and Spending

Medicaid enrollees under 65 who qualify on the basis of a disability have extensive health needs that arise from a variety of physical and behavioral health conditions. In addition to acute care services, many Medicaid enrollees with disabilities use long-term services and supports (LTSS) that complement their medical care and help them maintain function and independence. The need for a broad range of services, which may be lifelong for some individuals, adds a dimension of complexity to providing coverage for persons with disabilities that is not shared by most other Medicaid enrollees.

As discussed in Chapter 1a, Medicaid enrollees who qualify on the basis of a disability are individuals under age 65 who meet a definition of disability that generally follows the one that is used for the federal Supplemental Security Income program. The majority of these individuals are Medicaid-only enrollees for whom Medicaid covers both acute and long-term services and supports. For dual eligibles, Medicare is the primary payer of their acute care services, meaning that Medicaid reflects only a portion of their total spending picture.¹ As a result of this difference in coverage, it is important to note that all dollar amounts presented in this chapter are limited to Medicaid spending. Future Commission work will present a more complete picture of total spending, both Medicaid *and* Medicare, for dual eligibles using linked Medicaid and Medicare data.

Owing to the range of health conditions they have, individuals under age 65 who qualify for Medicaid on the basis of a disability represent a disproportionate share of Medicaid spending. Furthermore, different subgroups within the population—for example, individuals who live in a nursing home or other institution—have different service use and spending patterns. In particular, this section of the chapter presents information on Medicaid spending for the overall population of individuals under age 65 who qualify on the basis of a disability and then highlights differences between those who are Medicaid-

¹ The total population of persons dually eligible for Medicaid and Medicare includes both non-elderly individuals and those age 65 and older; however, this chapter focuses on individuals under age 65 who qualify for Medicaid on the basis of a disability.

only enrollees and those who are dually eligible for Medicaid and Medicare.²

Given that individuals enrolled in Medicaid on the basis of a disability are a complex, high-cost population, policymakers are exploring ways to manage their spending while encouraging the provision of high-quality services. For example, a majority of states currently use or are actively considering some form of managed care as an option for persons with disabilities. These arrangements may have the potential to better coordinate the physical, behavioral, and LTSS needs of Medicaid enrollees with disabilities, but much depends on the specifics of how a given state's program is designed. As discussed in this section, additional federal and state efforts are under way to encourage program improvements for Medicaid enrollees with disabilities.

Key points include:

- ▶ In addition to covering basic medical services, Medicaid provides long-term services and supports and other important benefits for persons with disabilities that may be limited or not covered under Medicare or private health insurance.
- ▶ Individuals under age 65 enrolled in Medicaid on the basis of a disability accounted for only 15 percent of the Medicaid population in fiscal year (FY) 2008, but 42 percent of total Medicaid spending.
- ▶ Among individuals under age 65 qualifying on the basis of a disability, most Medicaid enrollment (62 percent in FY 2008) and Medicaid spending (69 percent) is for Medicaid-only enrollees, rather than dual

eligibles who are enrolled in both Medicaid and Medicare.

- ▶ Among Medicaid-only enrollees who make up the majority of Medicaid spending for individuals under age 65 qualifying on the basis of a disability, nearly 75 percent of their Medicaid spending was for acute care in FY 2008 and the remainder was for LTSS.
- ▶ Among individuals enrolled on the basis of a disability, Medicaid spending on LTSS for an average Medicaid-only enrollee (\$5,040 in FY 2008) is lower than for an average dual eligible (\$8,784), indicating less use or intensity of these services for Medicaid-only enrollees.
- ▶ Opportunities exist for states and the federal government to develop, implement, and share innovative approaches to service delivery for persons with disabilities.

In light of these issues, the Commission recommends the accelerated advancement of targeted, efficient, and innovative approaches to providing high-quality care for persons with disabilities, especially those with Medicaid-only coverage.

Services Available under Medicaid

In addition to covering basic medical services, Medicaid provides important benefits for persons with disabilities that may be limited or not covered under Medicare or private health insurance. For some enrollees, particularly children, the depth of a particular Medicaid benefit may also exceed that of other payers.

² In the Medicaid Statistical Information System (MSIS) data that are used throughout this chapter to describe FY 2008 Medicaid enrollment and spending, about 670,000 enrollees age 65 and older are identified in the data as qualifying on the basis of a disability. Given that disability is not a Medicaid eligibility pathway for individuals age 65 and older, MACPAC recodes these 670,000 enrollees to have a basis of eligibility as "aged" throughout this report.

Breadth of benefits

As described in the Annex to this section, Medicaid allows states the option of covering a variety of LTSS that may help enrollees with disabilities maintain function and independence. These LTSS range from nursing and related care in specialized facilities to personal care and other support services that enable individuals to remain in their own homes.

When Medicaid was first enacted, mandatory coverage for LTSS was limited to nursing facility services for individuals age 21 and older. In 1970, coverage of home health was made mandatory for individuals entitled to nursing facility services. Since that time, the Congress has amended the Medicaid statute numerous times to provide options for covering a wide range of LTSS that allow persons with disabilities to live independently in home and community settings. Judicial decisions have played a role as well. For example, the Supreme Court ruled in *Olmstead v. L.C.* (119 U.S. 2176 (1999)) that persons with disabilities who are capable of living in the community should have the option to reside in the most integrated setting appropriate to their needs. Subsequent federal guidance to states discussed the role of Medicaid in meeting this goal (CMS 2000). Over time, Medicaid spending on non-institutional LTSS as a share of total LTSS has grown substantially. In FY 1995, 18 percent of Medicaid LTSS spending occurred in a non-institutional setting; by FY 2009, the figure had risen to 44 percent (Eiken et al. 2011).

For persons with disabilities and other individuals who would otherwise require care in an institution such as a nursing home, the establishment of home and community-based services (HCBS) waiver

authority in 1981 was a key development. For most Medicaid-covered services, states may set limits based on criteria such as medical necessity but generally must offer the services to all enrollees on a statewide basis. Under HCBS waivers, states may provide a wide range of services (including those not otherwise covered for their general Medicaid populations) to individuals who would otherwise require institutionalization. States may exercise control over those services by targeting specific groups of enrollees, limiting the geographic area in which services are available, and capping enrollment. HCBS waivers are required to be cost neutral, meaning that the estimated Medicaid cost of providing services to individuals enrolled in an HCBS waiver cannot be more than the estimated Medicaid cost of providing services to those individuals in an institution.

In addition, although they are not a specifically defined category of benefits in federal Medicaid law, state Medicaid programs typically cover a broader range of behavioral health services than Medicare or private insurance. Examples include intensive case management, residential care for mental health and substance abuse disorders, and services provided in home and community settings rather than in hospitals or professional settings such as clinicians' offices (Garfield et al. 2010, Shirk 2008). Given that a large percentage of Medicaid enrollees who are eligible on the basis of a disability have behavioral health conditions and that mental illness is a common co-occurring condition among the most expensive enrollees, there is an increasing federal and state focus on developing programs to better coordinate physical and behavioral health care, which may include both acute services and LTSS.³

³ For example, the Integrated Care Resource Center is a technical assistance project established by the Centers for Medicare & Medicaid Services that is designed to help inform states about innovative solutions for delivering coordinated health care for Medicaid's high-need, high-cost enrollees, with the goal of improving the quality and reducing the costs of care (ICRC 2012).

Depth of benefits

Even when a particular benefit is not unique to Medicaid, the program may differ from private insurance and other payers—and from state to state—in the amount, duration, and scope of the covered benefit. For example, under the Blue Cross and Blue Shield private insurance plans offered to federal employees, there are annual caps on the number of physical, occupational, speech, and cognitive therapy visits that are covered (OPM 2012). In general, states may also vary the extent to which a covered benefit is available to Medicaid enrollees by defining both medical necessity and the amount, duration, and scope of covered services.

For children in Medicaid, however, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services provide an exception to benefit limits that might otherwise apply. Under EPSDT requirements for children under age 21, states must cover any necessary service named in the Medicaid statute (including optional services not otherwise covered by the state) “to correct or ameliorate defects and physical and mental illnesses and conditions” that are discovered when a child receives an EPSDT screening service (§1905(r) of the Social Security Act (the Act)). For example, dental benefits, which are of particular importance for children with disabilities who are at increased risk for oral health problems (CMS 2004), are available for children under EPSDT but may be limited or not available for adults with Medicaid. Whereas caps or other limits unrelated to medical necessity may apply to children with private insurance, EPSDT precludes states from placing similar limits on services for children in Medicaid (Rosenbaum et al. 2008).

Interaction with other programs

Although a detailed discussion is beyond the scope of this chapter, Medicaid coverage may interact with a variety of other programs that serve persons with disabilities. For example:

- ▶ Under the Individuals with Disabilities Education Act, public schools must provide special education and related services necessary for children with disabilities. For children enrolled in Medicaid, these related services (e.g., physical, occupational, and speech therapies) may be financed by Medicaid if they are otherwise covered by Medicaid and if the school-based providers meet the same requirements (e.g., state licensure) as other Medicaid providers (Herz 2009).
- ▶ Medicaid’s optional targeted case management benefit can be used to aid enrollees in gaining access to needed medical, social, educational, and other services. For example, a case manager might help enrollees with intellectual or developmental disabilities schedule and obtain their Medicaid services, but also assist them in applying for food stamps or other non-Medicaid assistance.
- ▶ Although Medicaid can provide a variety of home and community-based services, the program cannot pay for room and board outside of institutions, and the availability of affordable, accessible housing for persons with disabilities may affect their ability to live in a community setting. A recent initiative of the U.S. Department of Housing and Urban Development provided funding to support rental assistance vouchers for non-elderly persons with disabilities, including nearly 1,000 individuals who live in nursing homes or other institutional settings—often financed by Medicaid—but who could move into the community with assistance (Lipson and Williams 2011).

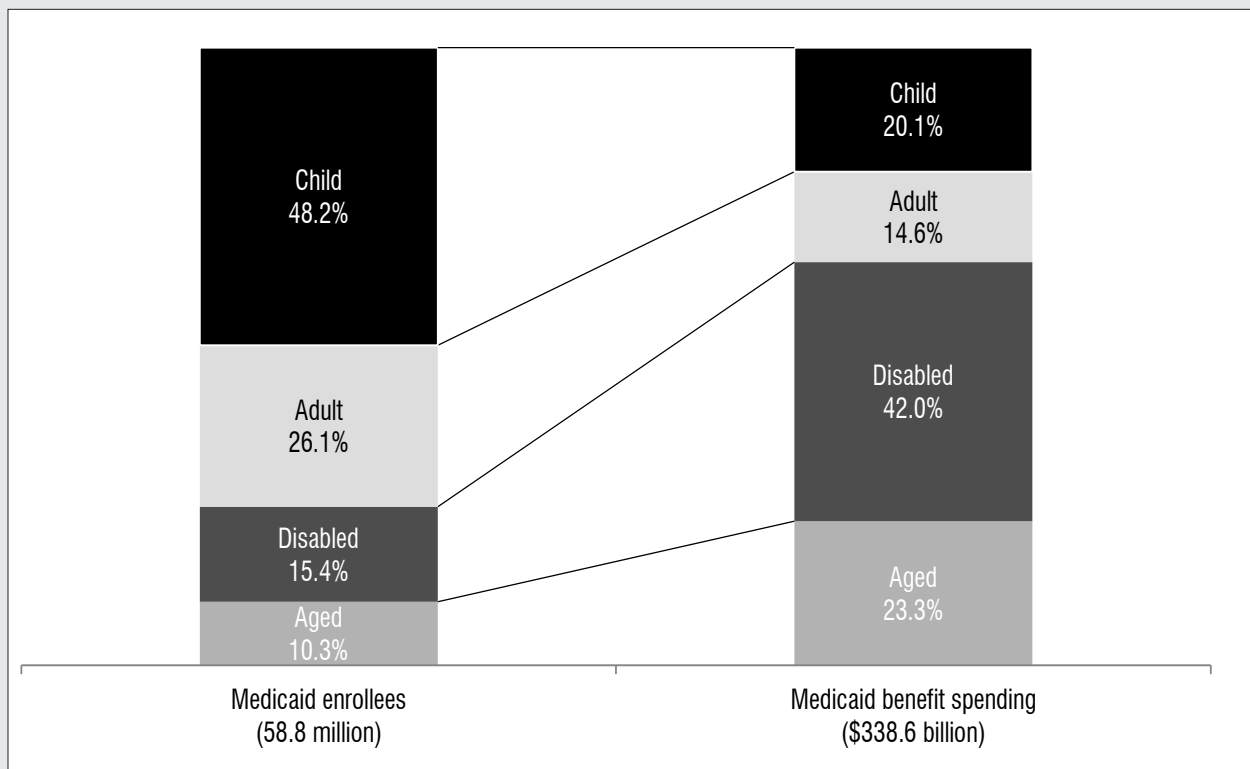
Medicaid Spending for Individuals Under Age 65 Enrolled on the Basis of a Disability

In FY 2008, Medicaid benefit spending (including both state and federal funds) on all Medicaid enrollees totaled \$339 billion. Owing to the range and complexity of health conditions they have, children and adults under age 65 who qualify for Medicaid on the basis of a disability represent a disproportionate share of this spending. As shown in Figure 1b-1, individuals under age 65 enrolled on the basis of a disability accounted for 15 percent of the Medicaid population in FY 2008 (9.1 million

enrollees), but 42 percent of Medicaid spending (\$142 billion). In contrast, non-disabled children and non-disabled adults under age 65 accounted for about three-quarters of enrollees but only about one-third of Medicaid spending.

The large share of total Medicaid spending for persons under age 65 enrolled on the basis of a disability reflects their high per person spending, which averaged \$17,412 for a full-year equivalent enrollee in FY 2008 (Table 1b-1). This amount far exceeds average Medicaid spending among children (\$3,025) or adults under age 65 (\$4,651) enrolled in Medicaid through non-disability pathways.

FIGURE 1b-1. Medicaid Enrollment and Benefit Spending by Eligibility Group, FY 2008



Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Includes dual eligibles enrolled in both Medicaid and Medicare (nearly all of whom are in the aged and disabled eligibility groups); however, all dollar amounts presented in this chapter are limited to Medicaid spending. Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC 2011b for methodology. Excludes Medicaid-expansion CHIP enrollees and the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

TABLE 1b-1. Medicaid Enrollment and Benefit Spending by Eligibility Group, FY 2008

| Eligibility Group | Number of Enrollees (millions) | Total Medicaid Benefit Spending (billions) | Medicaid Spending per Full-year Equivalent Enrollee |
|---|---------------------------------------|---|--|
| Children | 28.3 | \$68.1 | \$3,025 |
| Adults | 15.4 | 49.5 | 4,651 |
| Aged | 6.0 | 78.9 | 14,945 |
| Disabled | 9.1 | 142.0 | 17,412 |
| <i>Medicaid-only coverage</i> | 5.6 | 98.2 | 19,682 |
| <i>Dually enrolled in Medicaid and Medicare</i> | 3.5 | 43.8 | 13,835 |
| All enrollees | 58.8 | \$338.6 | \$7,267 |

Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chapter are limited to Medicaid spending. Figures for dual eligibles include “partial” duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include “full” duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., LTSS). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC 2011b for methodology. Excludes Medicaid-expansion CHIP enrollees and the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

As is typical of health care spending for any group, Medicaid spending for enrollees with disabilities is highly concentrated among a small number of individuals. In FY 2008, Medicaid spending per full-year equivalent enrollee under age 65 qualifying on the basis of a disability averaged more than \$100,000 for the top 5 percent of spenders. These individuals accounted for nearly half of total Medicaid spending among persons enrolled in the program on the basis of a disability.⁴

Medicaid spending for Medicaid-only enrollees and dual eligibles

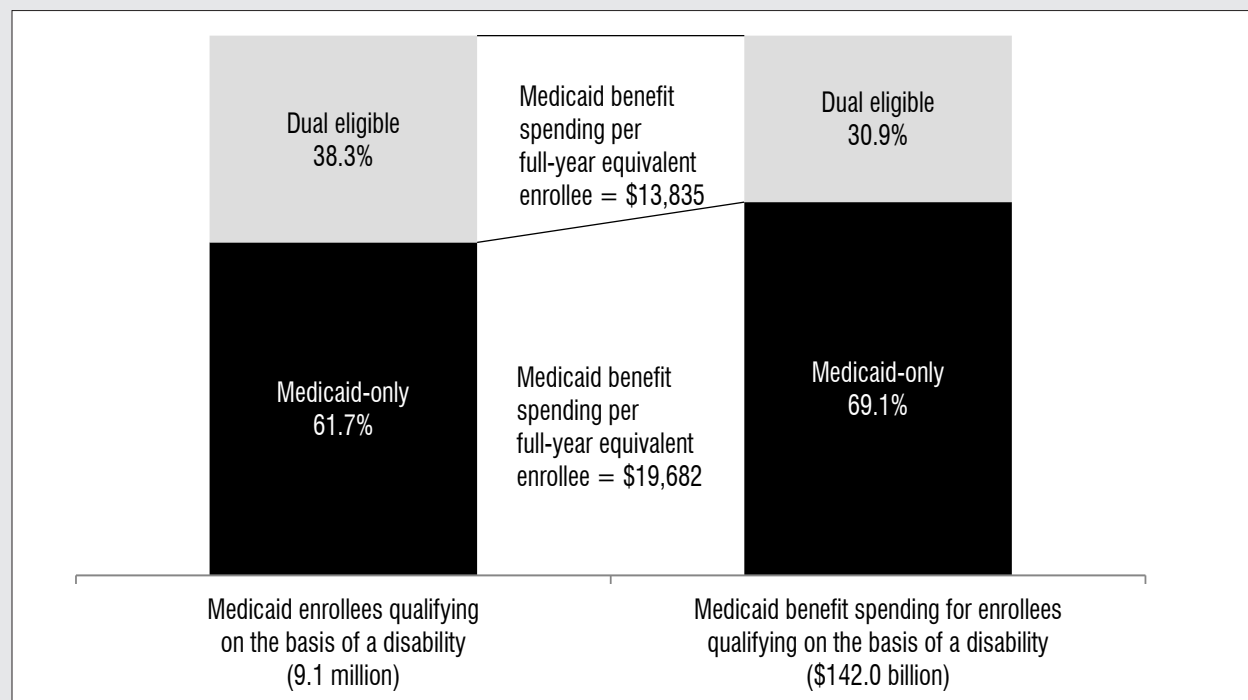
Most individuals under age 65 enrolled in Medicaid on the basis of a disability (62 percent in FY 2008) are Medicaid-only enrollees (Figure 1b-2). Similarly, the majority of Medicaid spending on individuals under age 65 qualifying on the basis of a disability (69 percent in FY 2008) is for Medicaid-only enrollees.

As shown in Figure 1b-2, among individuals under age 65 enrolled in Medicaid on the basis of a disability, Medicaid spending per enrollee is higher for Medicaid-only enrollees than for individuals dually eligible for Medicaid and Medicare. However, this finding does not necessarily indicate that the Medicaid-only population has higher overall spending. Instead, the differences in Medicaid spending between Medicaid-only enrollees and dual eligibles shown in this section are driven in large part by two factors:

- ▶ For all individuals dually eligible for Medicaid and Medicare, Medicare finances a significant portion of their acute care spending (e.g., hospital and physician services, prescription drugs). Because the figures in this chapter are limited to Medicaid, they do not reflect the full range of health care spending for dual eligibles. In comparison, Medicaid finances the full range of health care spending

⁴ Data not shown; MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS.

FIGURE 1b-2. Medicaid Enrollment and Benefit Spending among Medicaid-only and Dual Eligible Enrollees Under Age 65 Qualifying on the Basis of a Disability, FY 2008



Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chapter are limited to Medicaid spending. Figures for dual eligibles include “partial” duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include “full” duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., LTSS). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC 2011b for methodology.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data

for most Medicaid-only enrollees qualifying on the basis of a disability.⁵

- Figures in this chapter reflect Medicaid spending for both “partial” and “full” dual eligibles. For partial dual eligibles, Medicaid coverage is limited to payment of Medicare premiums and, in some cases, cost sharing. For full dual eligibles, Medicaid pays Medicare premiums and cost sharing, but also covers additional benefits not available under Medicare (e.g., LTSS). Again, in comparison, Medicaid finances the full range of health care spending for most Medicaid-only enrollees qualifying on the basis of a disability.

Future Commission work will provide a more comprehensive picture of total spending, both Medicaid and Medicare, for dual eligibles using linked Medicaid and Medicare data. In this chapter, all dollar amounts are limited to Medicaid spending.

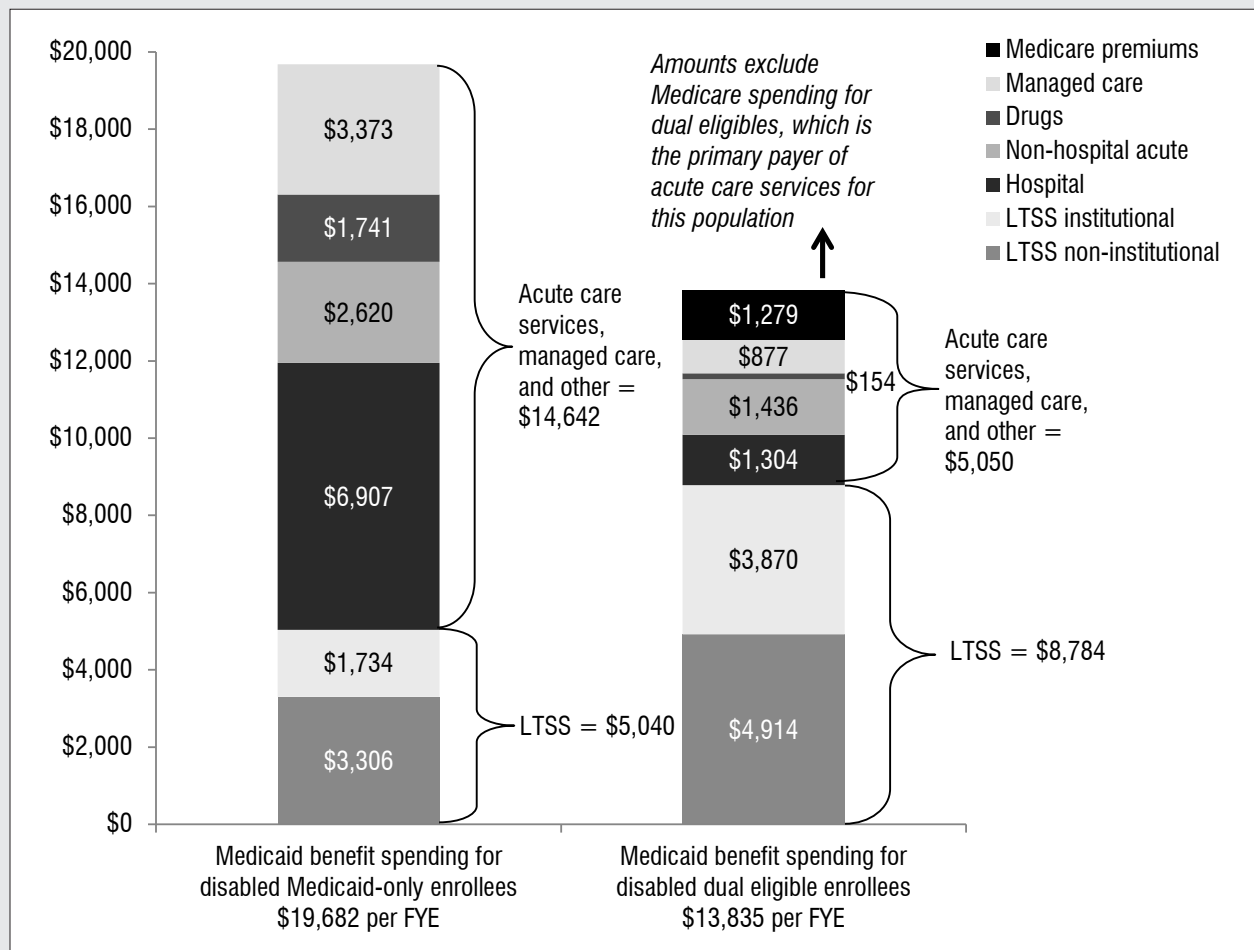
Composition of Medicaid spending on Medicaid-only enrollees and dual eligibles

Looking at the overall population of individuals under age 65 enrolled in Medicaid on the basis of a disability, 37 percent of their Medicaid spending was for LTSS in FY 2008.⁶ The remaining

⁵ As noted in Chapter 1a, a relatively small share of Medicaid-only enrollees report having private insurance coverage in addition to Medicaid.

⁶ Data not shown; MACPAC analysis of MSIS APS data and CMS-64 FMR net expenditure data from CMS.

FIGURE 1b-3. Composition of Medicaid Benefit Spending Per Full-Year Equivalent Enrollee among Medicaid-only and Dual Eligible Enrollees Under Age 65 Qualifying on the Basis of a Disability, FY 2008



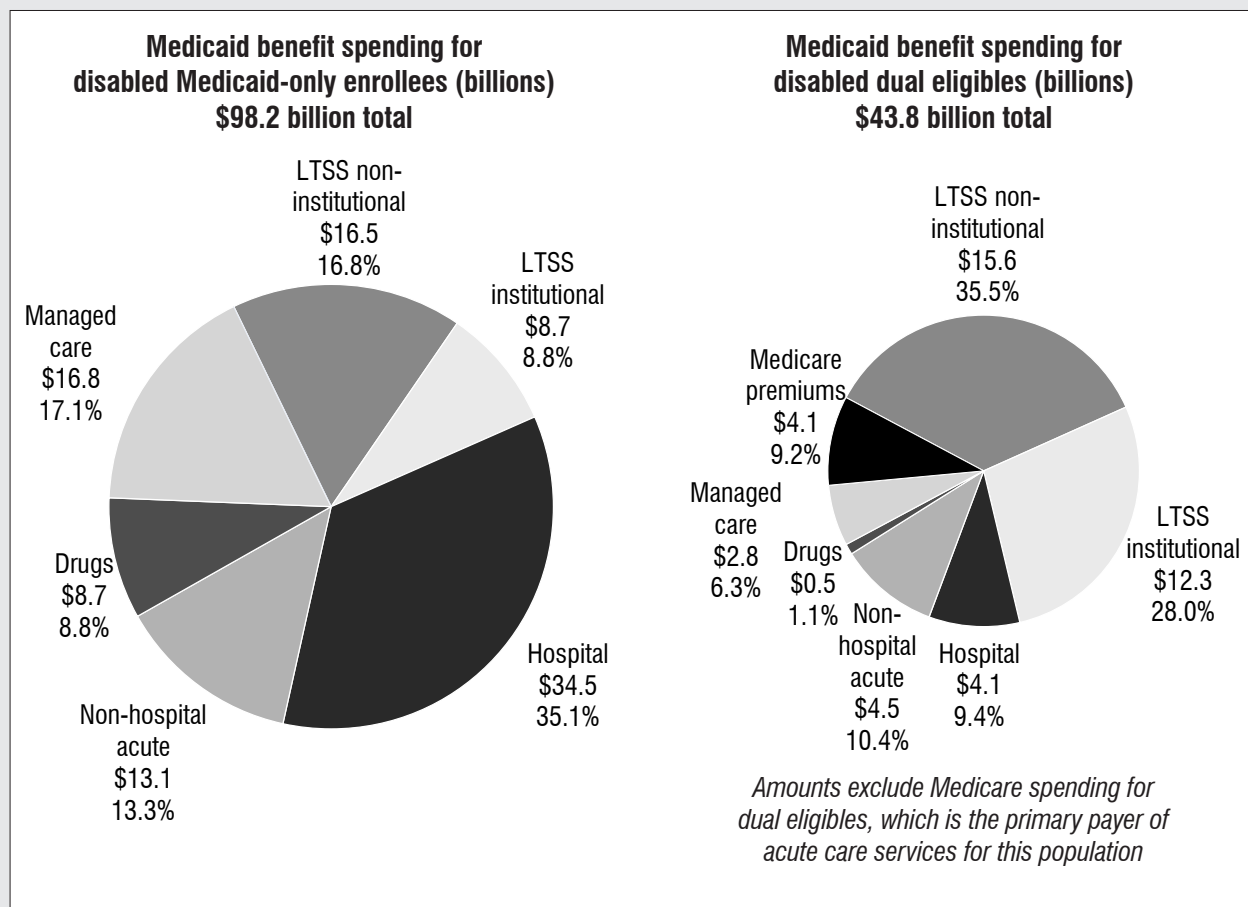
Notes: FYE is full-year equivalent. Enrollees qualifying on the basis of a disability are children and adults under age 65. Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chapter are limited to Medicaid spending. Figures for dual eligibles include “partial” duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include “full” duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., LTSS). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC 2011b for methodology. “Managed care” category may include a variety of acute care services and, in some cases, LTSS. “Hospital” includes inpatient, outpatient, and mental health facility. “LTSS non-institutional” includes HCBS waiver, personal care, home health, rehabilitation, private duty nursing, hospice, and targeted case management. “LTSS institutional” includes nursing facility and intermediate care facility for persons with intellectual disabilities. Excludes the U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

63 percent was for hospital and other acute care, prescription drugs, managed care, and Medicare premiums. However, these figures for the overall population mask substantial differences in the composition of Medicaid spending for those who have Medicaid-only coverage and those who are dually eligible for Medicaid and Medicare.

For example, among individuals under age 65 enrolled in Medicaid on the basis of a disability, Medicaid spending on LTSS for an average Medicaid-only enrollee is lower (\$5,040 in FY 2008, Figure 1b-3) than for an average dual eligible with disabilities (\$8,784), indicating less use or intensity of these services for Medicaid-only enrollees. In addition, Medicaid spending on LTSS is more

FIGURE 1b-4. Composition of Total Medicaid Benefit Spending among Medicaid-only and Dual Eligible Enrollees Under Age 65 Qualifying on the Basis of a Disability, FY 2008



Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Dual eligibles are enrolled in both Medicaid and Medicare; however, all dollar amounts presented in this chapter are limited to Medicaid spending. Figures for dual eligibles include “partial” duals for whom Medicaid coverage is limited to payment of Medicare premiums and cost sharing; they also include “full” duals for whom Medicaid also covers additional benefits not available under Medicare (e.g., LTSS). Medicaid benefit spending from MSIS data has been adjusted to reflect CMS-64 totals; see MACStats section of MACPAC 2011b for methodology. “Managed care” category may include a variety of acute care services and, in some cases, LTSS. “Hospital” includes inpatient, outpatient, and mental health facility. “LTSS non-institutional” includes HCBS waiver, personal care, home health, rehabilitation, private duty nursing, hospice, and targeted case management. “LTSS institutional” includes nursing facility and intermediate care facility for persons with intellectual disabilities. Excludes U.S. territories.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS

heavily skewed toward home and community-based services among Medicaid-only enrollees qualifying on the basis of a disability (Figure 1b-3).

Among Medicaid-only enrollees under age 65 qualifying on the basis of a disability, most Medicaid spending is for acute care services (74 percent in FY 2008, Figure 1b-4). The following discusses spending for this population in more detail.

Hospital services. Focusing on the Medicaid-only enrollees in Figure 1b-4—who account for the bulk of Medicaid spending on individuals under age 65 qualifying on the basis of a disability—hospital services (inpatient, outpatient, and mental health facility) exceed LTSS as a share of Medicaid spending (35 percent for hospital services in FY 2008, compared to 26 percent for LTSS).

Among Medicaid-only enrollees qualifying on the basis of a disability, those with the highest hospitalization rates have multiple physical and behavioral health conditions. In particular, mental illness is common among the highest-cost, most frequently hospitalized enrollees, and the presence of mental illness and drug and alcohol disorders is associated with substantially higher per capita costs and hospitalization rates (Boyd et al. 2010). The prevention of unnecessary hospital readmissions presents one opportunity to improve the quality of care provided to this population while also reducing costs (Gilmer and Hamblin 2010).

Other acute services and managed care. Again focusing on the Medicaid-only enrollees under age 65 who qualify on the basis of a disability in Figure 1b-4, other major sources of spending include non-hospital acute care (13 percent in FY 2008), prescription drugs (9 percent), and managed care (17 percent).

Historically, many persons with disabilities have been excluded or exempted from mandatory enrollment in Medicaid managed care plans. As noted in MACPAC's June 2011 Report to the Congress, more could be known about which program features might work best for different populations. For example, individuals with complex medical needs may benefit from particular methods of care management and may require the inclusion of additional providers in plan networks. In addition, to ensure continuity of services and coordination of benefits, mandatory enrollment and auto-assignment processes for enrollees with disabilities may differ from those typically used for non-disabled children and adults. Risk adjustment of payments to managed care plans is also an important consideration, given the diversity of health needs and high costs among persons with disabilities (MACPAC 2011b).

Today, a majority of states currently use or are actively considering some form of managed

care as an option for persons with disabilities in Medicaid (Gifford et al. 2011, Smith et al. 2011). However, the extent to which some or all of the services frequently used by this population (e.g., prescription drugs, behavioral health services, LTSS) are included in a Medicaid managed care contract varies, as does the inclusion of certain populations. In addition, the term "managed care" may refer to several different arrangements, including comprehensive risk-based plans and limited-benefit plans that provide a contracted set of services in exchange for a capitated (per member per month) payment, as well as primary care case management (PCCM) programs that typically pay primary care providers a small monthly fee to coordinate enrollees' care (MACPAC 2011b). Although more than half of individuals under age 65 qualifying for Medicaid on the basis of a disability were enrolled in some form of managed care in FY 2008, they were more likely to be enrolled in limited-benefit plans (which typically cover only behavioral health, transportation, or dental services) than in comprehensive risk-based plans or PCCM programs (Table 1b-2).

LTSS. As shown in Figure 1b-4, among individuals under age 65 enrolled in Medicaid on the basis of a disability, LTSS account for a much smaller share of Medicaid spending for Medicaid-only enrollees (26 percent in FY 2008) than for dual eligibles (63 percent). As noted earlier, this difference is driven in large part by the fact that Medicare is the primary payer of acute care services for dual eligibles.

In addition, 16 percent of Medicaid-only enrollees under age 65 qualifying on the basis of a disability were LTSS users, and they accounted for about half of Medicaid spending on that group in FY 2008. Among dual eligibles under age 65 qualifying for Medicaid on the basis of a disability, 22 percent were LTSS users, and they accounted

TABLE 1b-2. Percentage of Medicaid Enrollees in Managed Care by Type of Arrangement, FY 2008

| Type of Arrangement | Children | Adults | Disabled | Aged |
|--------------------------------|--------------|--------------|--------------|--------------|
| Any managed care | 84.6% | 57.1% | 58.8% | 35.2% |
| Comprehensive risk-based plans | 60.0 | 43.8 | 28.5 | 11.7 |
| Limited-benefit plans | 36.6 | 23.6 | 36.4 | 27.4 |
| Primary care case management | 19.0 | 8.9 | 13.3 | 2.3 |

Notes: Enrollees qualifying on the basis of a disability are children and adults under age 65. Managed care types do not sum to total because individuals are counted in every category for which a payment was made on their behalf during the year. Enrollees are counted as participating in managed care if at least one managed care payment was made on their behalf during the fiscal year; this method underestimates participation somewhat because it misses enrollees who entered managed care late in the year but for whom a payment was not made until the following fiscal year.

Source: MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data from CMS

for about three-quarters of Medicaid spending on that group.⁷ For dual eligibles, one long-standing barrier to high-quality, cost-effective care has been a lack of coordination between acute care services (covered primarily by Medicare), with LTSS and other services covered by Medicaid (Bella 2011, MedPAC 2010). However, even among Medicaid-only enrollees for whom Medicaid covers both acute care services and LTSS, only a small number of states have implemented or are considering policies to coordinate these benefits—for example, through managed care models under which a single entity assumes responsibility for arranging the full range of acute care services and LTSS covered by a state’s Medicaid program in exchange for a fixed payment (Gifford et al. 2011, Bella and Palmer-Barnette 2010, Edwards et al. 2009).

Medicaid Innovations for Persons with Disabilities

Given the complex health care needs of and high spending for persons with disabilities, opportunities exist for states and the federal government to develop, implement, and share innovative approaches to service delivery for this population. Enrollees with Medicaid-only coverage present a particular opportunity for states, given that innovations for this population do not require coordination with the Medicare program—an issue that adds a layer of complexity in serving persons dually enrolled in Medicaid and Medicare. While efforts are under way to encourage innovative program improvements for Medicaid enrollees, the Commission supports the development of additional programmatic improvements designed to address the cost-effectiveness and quality of services provided to Medicaid enrollees with disabilities.

⁷ Data not shown; LTSS user figures are based on MACPAC analysis of Medicaid Statistical Information System (MSIS) Annual Person Summary (APS) data and CMS-64 Financial Management Report (FMR) net expenditure data from CMS. The analysis reflects a method for identifying LTSS users that differs from the one that was used to develop Figures 5-7 in the MACStats section of MACPAC 2011b. The new method identifies a much smaller share of the Medicaid population as LTSS users and results in higher spending per LTSS user.

Opportunities for innovation. With budget constraints at both the federal and state levels, policymakers are exploring ways to manage spending while encouraging the provision of high-quality services for persons with disabilities. For example, the development of programs to better coordinate physical and behavioral health care present an opportunity to reduce unnecessary hospital readmissions. States are increasingly looking to managed care as one way to achieve this coordination—as well as obtain greater spending predictability, and potentially savings, in their Medicaid programs. In developing managed care options, states may make use of a variety of arrangements that address the need for behavioral health and other specialty services among persons with disabilities. With regard to LTSS, states have a number of state plan and waiver options available for serving enrollees in home and community-based settings. Some of these options, including HCBS waivers and the HCBS state plan option, allow states to target specific groups of enrollees in need of specialized services, such as persons with intellectual and developmental disabilities.

CMS Innovation Center activities. Federal statute provides the Secretary of the U.S. Department of Health and Human Services (the Secretary) with the authority to test and evaluate Medicaid program and policy innovations through the Center for Medicare & Medicaid Innovation (the Innovation Center) within the Centers for Medicare & Medicaid Services (§1115A of the Act). The Innovation Center has introduced 16 initiatives that focus on improving patient safety, promoting care that is coordinated across health care settings, investing in primary care transformation, creating new bundled payments for care episodes, and meeting the complex needs of dual eligibles (CMS 2012b).

Among Innovation Center initiatives, the potential exists to advance service delivery options that include innovations in payment and quality measurement for persons with disabilities, including those with Medicaid-only coverage. For example, the Health Care Innovation Challenge will award up to \$1 billion in grants to applicants who put into practice new ideas for achieving better health, improved care and lower costs for persons enrolled in Medicare, Medicaid, and CHIP, particularly those with the greatest health care needs. Other Innovation Center initiatives, such as the Partnership for Patients, examine ways to reduce hospital-acquired conditions and preventable hospital readmissions, an effort relevant to Medicaid enrollees with disabilities for whom hospital services account for a large share of Medicaid spending. In order to encourage the timely dissemination of information, all Innovation Center initiatives include a “diffusion” element to provide best practices, lessons learned, and improved care strategies so that the innovation is not limited to a single demonstration site or particular community (CMS 2012b).

In addition to the support provided through the Innovation Center, the Integrated Care Resource Center—a technical assistance project established by CMS—provides states with help in coordinating health care for Medicaid enrollees with high-cost, chronic needs as well as dual eligibles (ICRC 2012). Many states are also taking advantage of recently enacted options for persons with disabilities that are outlined in Box 1b-1.

BOX 1b-1. Recently Enacted Statutory Provisions Providing States with Options to Serve Persons with Disabilities

Several recently enacted statutory provisions in the Patient Protection and Affordable Care Act (P.L. 111-148, as amended) provide tools for Medicaid to improve the delivery of services for persons with disabilities. While these tools provide states more options to address the needs of this population, many of the options have limitations in their scope as they are primarily targeted at increasing access to LTSS in home and community-based settings (Edwards 2011). They include:

- ▶ **Modification of HCBS.** The modification of the HCBS state plan option, which was first created by the Deficit Reduction Act of 2005 (P. L. 109-171), increases the scope of benefits covered in the option, removes states' ability to cap enrollment, requires statewide coverage, provides states with the ability to offer the benefit to additional individuals, and provides states with the ability to target the option to specific populations (e.g., individuals with specific conditions). Seven states (Idaho, Iowa, Colorado, Louisiana, Nevada, Oregon, and Wisconsin) have taken up the option as of March 2012 (CMS 2012a).
- ▶ **Money Follows the Person.** The extension for five years (through 2016) of the Money Follows the Person (MFP) rebalancing demonstration, which was originally established in the Deficit Reduction Act of 2005. This demonstration program provides states with an enhanced federal medical assistance percentage (FMAP) for 12 months for each Medicaid enrollee transitioned from an institution to the community during the demonstration period. Forty-three states and the District of Columbia have implemented MFP programs, with over 15,000 individuals transitioned back into the community as of June 2011 (Denny-Brown et al. 2011).
- ▶ **Community First Choice Option.** The establishment of the Community First Choice Option in Medicaid to allow states, through a state plan option, to provide statewide home and community-based attendant supports and services to individuals who require an institutional level of care with incomes up to 150 percent FPL, or greater if the state has a higher income level for an individual who has been determined to require an institutional level of care under the state plan. This option, which became available October 1, 2011, allows states to receive a six percentage point increase in federal matching payments for spending related to this option.
- ▶ **State Balancing Incentive Payments Program.** The establishment of the State Balancing Incentive Payments Program to provide enhanced federal matching payments to states in order to increase the proportion of Medicaid LTSS dollars that go toward HCBS and decrease the proportion that go toward institutional services. Total funding over four years (from October 2011 to September 2015) cannot exceed \$3 billion in federal enhanced matching payments. New Hampshire will be the first state to receive grant funds under the program to run from April 1, 2012 through September 2015 (CMS 2012c).
- ▶ **Health Homes for Individuals with Chronic Conditions.** The establishment of the state option to receive enhanced federal support for the provision of health home services to eligible children and adults with chronic conditions. This provision became effective on January 1, 2011. States can have more than one health home model operating at once and can adapt existing models. Eligible individuals for whom a state may choose to offer a health home include those with chronic conditions—defined as a mental health condition, a substance use disorder, asthma, diabetes, heart disease, or being overweight (body mass index over 25) or other conditions as defined by the Secretary. Enrollees must select among state-designated health home providers. The health home population the state covers must consist of individuals who have at least two of the previously listed chronic conditions, one chronic condition and be at risk for another, or one serious and persistent mental health condition. As of March 2012, five state plan amendments (SPAs) have been approved (two in Missouri, two in Rhode Island, one in New York), three SPAs are under review (North Carolina, Oregon, Washington), CMS is providing technical assistance for six draft SPAs, and CMS has issued 15 planning grants to states (CMS 2012a).

Commission Recommendation

Despite federal and state efforts, a more targeted focus on persons with disabilities, particularly Medicaid-only enrollees with disabilities, should be a priority for the CMS Innovation Center and other federal and state efforts. The development of innovative programs for persons with disabilities would help promote high-quality and cost-effective care for this population.

Recommendation 1.1

The Secretary and the states should accelerate the development of program innovations that support high-quality, cost-effective care for persons with disabilities, particularly those with Medicaid-only coverage. Priority should be given to innovations that promote coordination of physical, behavioral, and community support services and the development of payment approaches that foster cost-effective service delivery. Best practices regarding these programs should be actively disseminated.

Rationale

Enrollees who qualify for Medicaid on the basis of a disability have extensive service needs and represent the largest share of Medicaid spending compared to all other Medicaid enrollee groups. This presents unique challenges to addressing the delivery of services and payment options for this population. This recommendation encourages the acceleration of innovative efforts to provide high-quality and cost-effective care to this population.

Medicaid-only enrollees with disabilities present key opportunities for innovation.

Given the complex health care needs of and high spending for persons with disabilities, particularly those with Medicaid-only coverage, key opportunities exist for states and the federal government to develop, implement, and share innovative approaches to providing cost-effective, high-quality service delivery options for this population. Enrollees with Medicaid-only coverage present a particular opportunity for states, given that innovation for this population does not require coordination with the Medicare program—an issue that adds a layer of complexity in serving persons dually enrolled in Medicaid and Medicare.

Innovation should focus on Medicaid-only persons with disabilities.

Ensuring that persons with disabilities with Medicaid-only coverage are a primary focus of these innovative efforts may lead to approaches that better provide cost-effective and high-quality care for this population. Most of the enrollees under age 65 who qualify for Medicaid based on a disability—62 percent (5.6 million people)—rely on Medicaid as their only source of coverage, while 38 percent (3.5 million people) are enrolled in both Medicaid and Medicare. Medicaid spends a substantial amount in total and on a per capita basis on Medicaid-only enrollees under age 65 who qualify for Medicaid based on a disability. Medicaid spent \$98.2 billion in total in FY 2008 (\$19,682 per full-year equivalent enrollee) on Medicaid-only enrollees qualifying on the basis of a disability and \$43.8 billion in total in FY 2008 (\$13,835 per full-year equivalent enrollee) on persons with disabilities enrolled in both Medicaid and Medicare.⁸ Further, Medicaid-only enrollees report poorer health status and a greater presence of health conditions and functional impairments compared to all Medicaid enrollees.

⁸ This difference in Medicaid spending is due in large part to the fact that: (1) Medicare covers a significant portion of acute care costs for dual eligibles, and (2) some dual eligibles receive limited Medicaid coverage that only includes payment of their Medicare premiums and cost sharing, rather than full Medicaid benefits.

Coordination of care is a priority for innovation. Physical health services, including oral health services, are often disconnected from behavioral health and community support services needed by persons with disabilities. The lack of coordination among the diverse services used by persons with disabilities may lead to fragmented and inefficient delivery of services to a population that often has extensive and complex health care needs. Innovative efforts that focus on care coordination and better management of service use can provide approaches that promote more cost-effective and higher quality service delivery for persons with disabilities.

Payment approaches should support cost-effective care. Innovative payment approaches that foster cost-effective care should support coordination of physical, behavioral, and community support services rather than act as a disincentive to such coordination. Accurate risk adjustment of payments to providers is important to account for the high costs and high needs of persons with disabilities.

Current innovation efforts present opportunities to focus on persons with disabilities. While the CMS Innovation Center has introduced many initiatives that are relevant to high-need, high-cost populations in Medicaid, it has the potential to foster innovation specifically for persons with disabilities, and the Commission encourages the Innovation Center to take this opportunity. For example, the Health Care Innovation Challenge presents a prime opportunity to support new care coordination and payment approaches for delivering high-quality, cost-effective care for persons with disabilities as well as to play a role in disseminating best practices and lessons learned from these initiatives.

Timely dissemination of best practices is helpful to states. States are moving forward with different approaches to address the challenges of providing care for this population with extensive service needs and high spending. As innovative, cost-effective programs serving persons with disabilities are being developed and implemented, states would benefit from timely dissemination of information about these programs to help them model their own innovative and effective approaches to improving services for this population.

Implications

Federal spending: There is no immediate and direct impact on the federal budget.

State spending: There is no immediate and direct impact on state budgets.

Beneficiaries: Enrollees with disabilities would benefit from the continued development and support of program innovations that will potentially provide higher quality and more coordinated care.

Providers: Innovations that support better coordination of care for the extensive and complex needs of persons with disabilities would allow providers to deliver more cost-effective and high-quality care to persons with disabilities.

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Chapter 1b Annex 1

Medicaid Long-Term Services and Supports

There is no universal definition of Medicaid long-term services and supports (LTSS). In fact, the definitions used by analysts vary, making it difficult to compare service use and spending figures across studies. In addition, the actual services provided under a given benefit may vary by state. The following briefly describes a range of mandatory and optional¹ Medicaid benefits provided under regular state plan rules that might be considered LTSS, drawing from language in federal statute, regulations, and guidance. If a state covers these services under its state plan, it may set limits by defining medical necessity criteria and the amount, duration, and scope of services provided, but it generally must offer the services to all enrollees on a statewide basis. As noted at the end of this Annex, there are additional options for states wishing to provide targeted LTSS for particular groups of enrollees.

State plan services

Nursing facility. Mandatory for most enrollees age 21 or older.² Includes services furnished in a facility that provides skilled nursing, rehabilitation, or health-related services for individuals who do not require hospital care, but whose mental or physical condition requires services that go beyond the level of room and board.

Intermediate care facility for persons with intellectual disabilities (ICF-ID).³

Optional. Includes items and services furnished in a facility whose primary purpose is to furnish health or rehabilitative services to persons with intellectual disabilities or related conditions, and which provides services above the level of room and board.

Mental health facility for individuals under age 21 or age 65 and older. Optional.

For individuals under age 21, includes services provided by a psychiatric hospital, an inpatient psychiatric program in a hospital, or by an accredited psychiatric facility. For individuals age 65 and older, includes inpatient hospital and nursing facility services

¹ As discussed earlier, EPSDT requires states to cover any medically necessary service (including LTSS) for children under age 21, regardless of its mandatory or optional status.

² As with other mandatory services, states are not required to cover nursing facility services for Medicaid enrollees who qualify under medically needy eligibility rules, which are generally used to allow individuals with incomes above regular Medicaid eligibility levels to “spend down” to a medically needy income level by incurring medical expenses.

³ Although the statute refers to ICF services for persons with “mental retardation,” a proposed rule from CMS published in the Federal Register on October 24, 2011, would replace this statutory term with “intellectually disabled” throughout federal Medicaid regulations.

provided in institutions for mental diseases (IMD). Federal Medicaid funds are not available for services provided to individuals age 21 to 64 who reside in an IMD.

Home health. Mandatory for enrollees who are entitled to nursing facility services.⁴ Includes nursing services, home health aide services, and medical supplies, equipment, and appliances suitable for use in the home; may include physical therapy, occupational therapy, or speech pathology and audiology services.

Personal care. Optional. May include a range of human assistance provided to persons with disabilities and chronic conditions of all ages which enables them to accomplish tasks—such as bathing, dressing, doing household chores, and performing other routine activities—that they would normally do for themselves if they did not have disabilities. States have the option of offering a self-directed model that allows targeted groups of enrollees to use Medicaid funds for the purchase of personal assistance and related services under an approved plan and budget, and to manage the individuals who provide their services.

Rehabilitation. Optional. Includes any medical or remedial services recommended by a physician or other licensed practitioner for maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level. The specific services covered, providers rendering the services, and the settings in which the services are delivered vary by state.

Targeted case management. Optional. Includes services furnished to assist state-specified groups of enrollees who reside in, or are transitioning to, a community setting in gaining access to needed medical, social, educational, and other services. Targeted case management services include

assessments, development of care plans, referral and related activities, and monitoring and follow-up activities; they exclude the direct delivery of underlying medical, educational, social, and other services.

Private duty nursing. Optional. Includes nursing services for enrollees who require more individual and continuous care than is available from a visiting nurse or routinely provided by the staff of a hospital or nursing facility.

Hospice. Optional. Includes services covered by the Medicare definition of hospice, which consists of a range of services (e.g., nursing care, home health aide and homemaker services, counseling) provided under a written plan by a hospice program to a terminally ill individual.

Home and community-based attendant services and supports (Community First Choice). Optional. For individuals who require an institutional level of care, includes home and community-based services related to accomplishing activities of daily living (ADLs) such as bathing and dressing, instrumental ADLs such as performing household chores, and health-related tasks. A variety of additional requirements apply. The Community First Choice option differs from other HCBS state plan and waiver options in that states cannot provide a targeted package of services or limit coverage to targeted groups. States receive a six percentage point increase in federal matching funds for services provided under this option.

Options for targeting Medicaid LTSS

Home and community-based services (HCBS) waivers and the HCBS state plan option offer states two ways of providing targeted LTSS

⁴ Individuals not entitled to nursing facility services may include medically needy enrollees and enrollees under age 21 in states electing not to cover the services for those individuals.

without meeting certain benefit requirements that would otherwise apply. Waiver authority under Section 1115 of the Social Security Act may also be used to provide HCBS and other LTSS, sometimes as a part of broader changes to a state's Medicaid program.

HCBS waivers. Optional. Under HCBS waivers, states may offer individuals requiring an institutional level of care a wide range of services that enable them to remain in the community, including services not necessarily covered for the rest of the state's Medicaid population. These may include case management, home health aide, homemaker, personal care, adult day, habilitation, respite, and such other services requested by the state as the Secretary of Health and Human Services may approve. Day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services may also be included for individuals with chronic mental illness. States may target specific groups, limit the geographic area in which services are available, and cap the number of enrollees eligible for services under HCBS waivers. HCBS waivers are required to be cost neutral, meaning that the estimated Medicaid cost of providing services to individuals enrolled in an HCBS waiver cannot be more than the estimated Medicaid cost of providing services to those individuals in an institution.

These waivers most frequently target individuals age 65 or older and individuals with disabilities under age 65 (nearly half of all participants are in aged or aged/disabled HCBS waivers) and persons with intellectual and developmental disabilities (about 40 percent). The remainder (which account for about 10 percent of total enrollment in HCBS waivers) serve children with special needs and

persons with physical disabilities, traumatic brain and spinal cord injuries, HIV/AIDS, and mental health needs (KCMU 2011).

States may use a variety of waiver authorities in order to tailor the delivery of medical and support services for their Medicaid enrollees, including persons with disabilities, but managing these waivers can be administratively burdensome. For example, although HCBS waivers are authorized under Section 1915(c) of the Social Security Act, states wishing to provide HCBS waiver and other state-covered services through a managed care delivery system must also obtain a 1915(b) waiver. Enrollees and states may benefit from the coordination of care achieved under these waiver authorities, but their separate application, reporting, and renewal requirements may also complicate the administration of a state's Medicaid program (Weinberg 2011).⁵

HCBS state plan option. Optional. The HCBS state plan option is similar to HCBS waivers in terms of the range of services that may be offered and the ability to target specific groups, but differs in that individuals with incomes up to 150 percent FPL are not required to need an institutional level of care in order to be eligible; they must instead meet needs-based criteria specified by the state that assess functional status and are less stringent than the institutional level of care criteria.⁶ In addition, eligibility for targeted groups must be statewide and enrollment cannot be capped. States can, however, modify their needs-based criteria if actual enrollment exceeds projections.

⁵ For 1915(b)/(c) combination waivers that serve dual eligibles, states may request an approval period of five years that would result in an aligned renewal period for the waivers (CMS 2010).

⁶ States may also provide HCBS state plan option services to individuals with incomes up to 300 percent of the federal Supplemental Security Income (SSI) benefit rate (about 224 percent of the FPL) who are eligible for HCBS services under a waiver and therefore would generally require an institutional level of care.

CHAPTER 1C

Quality Measurement

Medicaid enrollees with disabilities tend to have service-intensive health care needs that may render them vulnerable to quality problems. More likely than other enrollees to be in poor health, Medicaid enrollees with disabilities often have multiple chronic conditions and functional impairments that require complex treatment plans and coordination across a number of providers, as well as with social support systems. While only 15 percent of Medicaid enrollees under age 65 were enrolled in Medicaid on the basis of a disability in fiscal year 2008, these individuals accounted for 42 percent of total Medicaid spending, creating both challenges and opportunities in terms of providing high-quality, cost-effective care. Shortcomings in the quality of care obtained by Medicaid enrollees with disabilities stand to have a negative impact on health outcomes, as well as add to the costs of caring for this relatively high-need, high-cost population.

At present, little is known about the quality of care received by Medicaid enrollees with disabilities. Due to data limitations, it is not always possible to identify enrollees with disabilities for purposes of quality assessment, making it difficult to evaluate how well they are served and whether there are quality problems particular to this population. Furthermore, there is no consensus on whether the measures commonly used to assess quality of care for Medicaid enrollees—such as hospital readmissions, preventable hospitalizations, and emergency department visits—are sufficient for assessing the care provided to persons with disabilities. Existing quality measures may need adjustments to accurately gauge the experiences of persons with disabilities, and additional research and measure improvement may be needed to more completely assess the quality of their care. However, addressing these quality measurement issues will require further research and investment in the scientific evidence base (Iezzoni 2010).

There have been recent efforts at the federal and state levels, as well as by private organizations, to identify and develop quality measures applicable to Medicaid enrollees with disabilities and to incorporate such measures into quality assessment. Some of these activities are highlighted below.¹ These initiatives provide a foundation for a needed acceleration of work to assess and ensure quality of care for Medicaid enrollees with disabilities.

This chapter includes a recommendation to support the improvement of quality measures for Medicaid enrollees with disabilities. The Commission recommends that the Secretary of the U.S. Department of Health and Human Services (the Secretary), in partnership with the states, update and improve quality assessment for Medicaid enrollees with disabilities. As the federal government and states develop new programs and service delivery innovations, the Secretary should prioritize quality measures for Medicaid enrollees with disabilities to monitor the impact of service delivery innovations on this population.

Selected Federal Quality Measurement Development Activities

Recent federal initiatives to strengthen quality measurement have included components relating to the development of quality of care measures for persons with disabilities.

Agency for Healthcare Research and Quality (AHRQ) initiatives. As part of an effort to track disparities in quality and access to care for persons with disabilities, AHRQ convened a meeting of experts in April 2010 to explore the development

of quality measures for this population (Iezzoni 2010).² The panel addressed alternative definitions of disability and their implications for quality measurement, the scientific evidence base for quality measure development, data issues for measuring quality, and research priorities for developing quality measures for persons with disabilities. Key findings from this meeting include:

- ▶ Quality measures for common health conditions that can be severely disabling (e.g., asthma, diabetes, heart failure) are in widespread use, but generally do not address special considerations for persons with disabilities.
- ▶ Few quality measures specifically address disability-related issues, and there is a particular dearth of measures relating to patient functioning, wellness, and quality of life.
- ▶ Because people with disabilities are often excluded from clinical trials, little scientific evidence is available to guide development of quality measures for this population.³

To help develop AHRQ's research agenda, meeting participants identified issues for future investigation, including:

- ▶ the potential impact of varying approaches to disability determination on quality measurement for persons with disabilities;
- ▶ the potential need for special consideration of persons with disabilities when developing quality measures for large populations; and
- ▶ the selection of critical outcomes that should be tracked in disability-related quality research.

While the experts at the meeting were not asked to reach consensus regarding priorities or next

¹ The quality activities highlighted do not include long-term services and supports (LTSS) quality measurement efforts.

² The meeting was organized by AHRQ's Division of Priority Populations Research within the Office of Extramural Research, Education, and Priority Populations.

³ Exceptions include certain well-studied disabling conditions such as spinal cord injuries and multiple sclerosis.

steps, the suggestions they offered included the development of both a specific set of quality measures for persons with disabilities and methods for collecting information on experiences obtaining care among persons with disabilities.

As a first step in implementing recommendations from the April 2010 meeting, AHRQ recently commissioned a report as part of its *Closing the Quality Gap: Revisiting the State of the Science* series, which focuses on gathering evidence about effective methods for closing the quality gap. One of the eight reports in the series, *QI Measurement of Outcomes for People with Disabilities*, addresses how health care outcomes are assessed for persons with disabilities. The main objective of the report is to analyze how health outcomes for general medical care have been evaluated for this population, particularly in the areas of care coordination and quality improvement. The analysis in the report poses three key research questions:

- ▶ How are outcomes related to basic medical needs assessed for persons with disabilities living in the community?
- ▶ What measures have been used to examine coordination among health providers for persons with disabilities living in the community?
- ▶ In evaluating coordination between health providers and community organizations, what measures have been used to examine effectiveness of care for persons with disabilities living in the community? (AHRQ n.d.)

To address these questions, researchers screened more than 15,000 articles to examine available outcomes for medical care and care coordination for persons with disabilities. While this report is

not final,⁴ initial conclusions indicate that there is little research examining health outcomes from the perspective of disability as a comorbidity. More research is needed on care coordination and quality improvement for persons with disabilities, and future research may benefit from an organized database collection of “critically assessed outcome measures.” The collection of information on health outcomes for persons with disabilities is “essential for evaluating quality of care” (AHRQ n.d.).

Core quality measures for adults and children.

The Centers for Medicare & Medicaid Services (CMS) released a core set of quality measures for children enrolled in Medicaid and CHIP in December 2009 and for adults enrolled in Medicaid in January 2012.⁵ These core measure sets were developed based on a review of existing quality measures already in use by states, quality entities, associations, and others, and focused on a broad array of health care services, settings, and providers. While the pediatric and adult core measure sets are voluntary, states are encouraged to report to CMS on as many of the measures as feasible. If used by states, both sets of measures should be reported across an entire state and across all delivery systems, including fee-for-service, primary care case management, and risk-based managed care. Refinements to the measures will take place over the next several years. Annexes 1 and 2 to this chapter present the pediatric and adult core measure sets.

The 24 pediatric core measures address the following areas:

- ▶ prevention and health promotion;
- ▶ management of acute conditions;
- ▶ management of chronic conditions; and
- ▶ family experiences of care.

⁴ Public comments closed on February 6, 2012.

⁵ The Children’s Health Insurance Program Reauthorization Act (P.L. 111-3) and the Patient Protection and Affordable Care Act (P.L. 111-148), respectively, required the development of these measure sets.

These core measures are intended to be used for the pediatric Medicaid and CHIP enrollee populations as a whole, but are not specific to children with disabilities beyond the inclusion of behavioral health measures.

The 26 core quality measures for adult Medicaid enrollees cover the same four areas mentioned above and include the additional areas of care coordination and service availability. The measures are intended to apply to all Medicaid adults. There are several measures targeting behavioral health conditions, but no other measures are specific to adults with disabilities.

Both the pediatric and adult measure sets address care for certain chronic conditions (such as asthma and diabetes) that are not necessarily disabling, but that are often present as comorbidities in persons with disabilities, and that may develop into disabling conditions.

Expert workgroups played a significant role in reviewing and evaluating the proposed quality measures for inclusion in the final core sets. In reviewing proposed pediatric measures, workgroup members determined that few or no valid and/or feasible measures existed for several areas including: specialty care, care for substance abuse, and mental health treatment (Mangione-Smith 2010). The adult measures workgroup concluded that the measures not recommended for inclusion in the core set addressed very narrow clinical conditions, excluded key populations (e.g., persons dually eligible for Medicaid and Medicare and persons with LTSS needs), presented potential data-collection challenges for states, or duplicated other, more highly rated measures included in the set (DHHS 2012).

Quality measurement for health homes. States may receive federal matching funds to provide coordinated care through a health home for eligible Medicaid enrollees with chronic conditions.⁶ Providers serving as health homes must report certain quality measures to the state in order to receive payment (§1945(g) of the Social Security Act).

CMS recently selected a draft core set of quality measures (Table 1c-1) for CMS-approved health homes that states must ultimately report to the federal government. As with the core measure sets for Medicaid generally, the draft core set for health homes includes several behavioral health measures, but no other measures pertaining specifically to persons with disabilities.

Selected State Quality Measurement Activities

Several states are moving forward with new approaches for serving persons with disabilities. As states implement these new programs, they face decisions about how to measure and assess the quality of care furnished to persons with disabilities. One question is whether to employ existing quality measurement tools—such as the Healthcare Effectiveness Data and Information Set (HEDIS[®]) and Consumer Assessment of Healthcare Providers and Systems (CAHPS[®]) surveys (both explained in more detail below)—adapt these instruments, or develop additional measurement tools.

To help determine the extent to which states are engaged in the development of quality measures for persons with disabilities, MACPAC reviewed findings from a recent 50-state Medicaid managed care survey. MACPAC identified clinical quality

⁶ Section 1945(h) of the Social Security Act defines a health home as a designated provider (including a provider that operates in coordination with a team of health care professionals) or a health team selected by an eligible individual with chronic conditions to provide health home services.

TABLE 1c-1. Draft Required Measures for CMS-approved Health Homes, 2011

| Draft Measure | Measure Source(s) |
|---|--|
| Adult body mass index (BMI) assessment | HEDIS |
| Ambulatory care-sensitive condition admission | National Quality Measures Clearinghouse (NQMC); Rosenthal 2010 |
| Care transition – transition record transmitted to health care professional | NQMC; National Quality Forum (NQF) |
| Follow-up after hospitalization for mental illness | HEDIS |
| Plan all-cause readmission | HEDIS |
| Screening for clinical depression and follow-up plan | NQF |
| Initiation and engagement of alcohol and other drug dependence treatment | HEDIS |

Source: MACPAC communication with CMS staff, March 2012

and access measures that have been developed by states (i.e., not adapted from HEDIS) for quality assessment and that may be relevant for monitoring the quality of care provided to Medicaid enrollees with disabilities and to persons dually eligible for Medicaid and Medicare. These measures fall into the following categories: hospitalizations/emergency room (ER) visits; mental health/substance abuse; chronic care; access, utilization, and costs; care coordination; satisfaction and quality of life; and additional measures. Annex 3 provides additional detail on these state-developed measures.

Several states have also started designing strategies for measuring quality of care specifically for Medicaid enrollees with disabilities and other high-need, high-cost populations. Examples of these state efforts include the following:

- ▶ California, in implementing a new Section 1115 demonstration waiver to require enrollment in managed care of persons with disabilities and persons dually eligible for Medicaid and Medicare, is considering a

dashboard to monitor the performance of all Medi-Cal managed care plans. The California Department of Health Care Services and the California HealthCare Foundation are developing a framework and specific measures for the dashboard. The state is determining what portion of the dashboard measures should be applicable to persons with disabilities and persons dually eligible for Medicaid and Medicare. State officials expect to use and report on a single set of measures, stratified by population, by 2013. Thirteen proposed measures address adult Medicaid enrollees with disabilities (Table 1c-2).

- ▶ Missouri's recently approved state plan amendment (SPA) for health homes includes quality measures that target persons with behavioral health conditions. The quality measurement goals outlined in the SPA include: improving health outcomes for persons with mental illness, reducing substance abuse, increasing patient empowerment and self-management, improving coordination of care, improving preventive care, improving

TABLE 1c-2. Selected Recommended Measures for California Medi-Cal Dashboard, 2011

| Measure | Source | Population |
|--|--------|-----------------------------------|
| Cervical cancer screening | HEDIS | Adults with disabilities |
| Comprehensive diabetes care | HEDIS | Adults with disabilities |
| Risk-adjusted average length of hospital stay | NQF | Adults with disabilities |
| Medication possession ratio | Other | Adults with disabilities |
| Antidepressant medication management | HEDIS | Adults with disabilities |
| Follow-up after hospitalization for mental illness | HEDIS | Adults with disabilities |
| Initiation and engagement of alcohol and other drug dependence treatment | HEDIS | Adults with disabilities |
| Waiver waiting lists | Other | Adults with disabilities; seniors |
| Services in community vs. institution | Other | Adults with disabilities; seniors |
| Getting care quickly | CAHPS | Adults with disabilities |
| Getting needed care | CAHPS | Adults with disabilities |
| Percentage of long-term stays with pressure sores | Other | Adults with disabilities; seniors |
| Percentage of residents who lose too much weight | Other | Adults with disabilities; seniors |

Source: *Monitoring Medi-Cal: Recommendations for measuring the performance of California's Medicaid program.* California HealthCare Foundation, January 2011

diabetes care, improving asthma care, and improving cardiovascular care. Specific behavioral health measures that the state will use include: medication adherence to antipsychotics, antidepressants, and mood stabilizers; care coordination (e.g., percent of hospital-discharged members with whom the care manager made telephonic or face-to-face contact within two days of discharge and performed medication reconciliation with input from the primary care provider (PCP)); reduction in the proportion of adults (18 and older) reporting use of any illicit drug during the past 12 months; and reduction in the proportion of adults (18 and older) who drank excessively in the previous 12 months.

- ▶ Michigan received a design contract from CMS to develop new approaches to better coordinate care for persons dually eligible for Medicaid

and Medicare. As part of the planning process, stakeholders representing behavioral health, managed care plans, academic researchers, LTSS providers, and other interested parties were convened to consider performance measures and quality monitoring in an integrated, capitated system. The stakeholder group determined that an integrated system should report metrics more often than annually, and by population and geographic region. They recommended considering development of population-specific dashboards that combine a few selected measures applicable to the whole population and a few selected measures that apply to a subpopulation (e.g., persons with developmental disabilities or nursing home residents). Population-specific measures would be selected from among those currently used by the state's LTSS providers, managed care

plans, habilitation supports waiver, serious and persistent mental illness program, and developmental disability services program.

- ▶ Wisconsin developed a survey called the Personal Experience Outcomes Integrated Interview and Evaluation System for enrollees with developmental and physical disabilities and enrollees who utilize LTSS. The survey collects their perspectives on choice, personal experiences, and health and safety. Its goal is to help care managers and enrollees evaluate whether available services are supporting enrollees' most important needs.

Other Quality Measurement Initiatives

In addition to federal and state efforts in quality measurement for persons with disabilities, there are also initiatives being led by private organizations or in collaboration with government agencies that may be applicable to Medicaid enrollees with disabilities.

HEDIS measure development. HEDIS is a set of quality, access, and effectiveness-of-care measures for selected conditions that is often used by states to monitor the care delivered by managed care organizations to Medicaid enrollees.⁷ Many states require their participating plans to collect and report data on HEDIS measures. Measures address multiple areas such as effectiveness of care, access to and availability of care, experience of care, and utilization and relative resource use. Certain HEDIS disease-specific measures may be applicable to persons with complex health conditions, such as behavioral health measures and measures pertaining to adults age 65 and over. Efforts are currently underway to implement seven new HEDIS measures focused on schizophrenia

and bipolar disorder. The National Committee for Quality Assurance (NCQA) recently sought public comment on these measures for inclusion in the 2013 HEDIS measurement set (NCQA 2012). NCQA is also working to set quality measurement priorities for persons dually eligible for Medicaid and Medicare and to develop, evaluate, and test measures for this population (O'Kane 2011).

CAHPS. CAHPS is a set of consumer surveys designed for children and adults that addresses a range of topics, including enrollees' satisfaction with care, perceptions of access to care, and use of services.⁸ State Medicaid programs and managed care organizations use CAHPS to measure plan performance, determine where to focus improvement efforts, track performance improvement over time, and gauge member satisfaction. In addition to survey questions that are applicable to all Medicaid enrollees, there are supplemental question sets that gather the experiences and perceptions of subpopulations, such as children with chronic conditions.

The CAHPS survey for children with chronic conditions has 24 questions that inquire about the health care experiences of children and cover areas such as:

- ▶ access to prescription medications;
- ▶ access to specialized services;
- ▶ family-centered care; and
- ▶ coordination of care and services.

This survey identifies children with chronic conditions based on the use of or need for prescription medications; above-average use of or need for medical, mental health, or education services; functional limitations compared with other children of the same age; use of or need for specialized therapies; and treatment or counseling

⁷ HEDIS measures are maintained and updated annually by the National Committee for Quality Assurance.

⁸ AHRQ oversees the CAHPS program and surveys.

for emotional, behavioral, or developmental problems (AHRQ 2008).

An additional CAHPS survey tool collects data on persons with lower-limb mobility impairments. This 21-question set covers topics such as use of mobility equipment, ability to walk and/or difficulty in walking a quarter of a mile, obtaining a range of therapies (i.e., physical, occupational, and speech), and obtaining or replacing mobility equipment, among other issues. There are also three questions that can be used to identify adults with mobility impairments.⁹

Measure Applications Partnership (MAP).

MAP is a public-private partnership, led by the National Quality Forum (NQF), that advises the U.S. Department of Health and Human Services (HHS) on choosing performance measures for public reporting and performance-based payment programs. Four advisory workgroups, including one focused on persons dually eligible for Medicaid and Medicare, will provide input on performance measurement across various areas. While the Dual Eligible Beneficiaries workgroup is focused primarily on quality measurement for persons who are dually eligible, its work is applicable to Medicaid enrollees with disabilities as well, given that almost 38 percent of Medicaid enrollees under age 65 qualifying on the basis of a disability are dually eligible for Medicaid and Medicare. The workgroup also includes members representing persons with disabilities.¹⁰ The workgroup's initial report:

- ▶ highlights the unique characteristics of this population and deficits in quality measurement that address the complex problems faced by persons dually eligible for Medicaid and Medicare;
- ▶ outlines an approach to quality measurement that includes an overview of characteristics of persons dually eligible for Medicaid and Medicare (including high-need subgroups), goals for high-quality care, guiding measurement principles, and quality improvement opportunities; and
- ▶ characterizes appropriate measures for this population.

The group's final report, scheduled for submission to HHS in June 2012, will address gaps in available measures for persons dually eligible for Medicaid and Medicare and examine potential modifications to existing quality measures, as well as the need for new measures (NQF 2012).

⁹ During the AHRQ expert meeting in April 2010 on quality measures for persons with disabilities, some participants expressed concern about the lower-limb mobility impairments CAHPS survey. In developing the survey questions, researchers found they could not use the word "barrier" when asking about physical impediments that individuals encounter, and they were unable to find an alternative phrasing. Given this, AHRQ meeting participants thought this major area of concern for persons with disabilities was overlooked in this particular survey.

¹⁰ A list of workgroup members can be found in Appendix C of the Dual Eligible Beneficiaries workgroup's interim report (NQF 2011).

Commission Recommendation

Despite efforts at the federal and state levels and by other organizations to develop quality measures and improve quality of care for Medicaid enrollees, little is known about whether or not quality measures commonly used for the Medicaid population are sufficient for assessing the care provided to Medicaid enrollees with disabilities. More research is needed to determine if existing measures of quality are appropriate for this population, if adjustments to current measures are needed, or whether new measures should be developed to measure quality of care for enrollees with disabilities.

Recommendation 1.2

The Secretary, in partnership with the states, should update and improve quality assessment for Medicaid enrollees with disabilities. Quality measures should be specific, robust, and relevant for this population. Priority should be given to quality measures that assess the impact of current programs and new service delivery innovations on Medicaid enrollees with disabilities.

Rationale

Medicaid enrollees with disabilities are particularly vulnerable to poor quality care, yet little is known about the quality of care Medicaid enrollees with disabilities receive. Medicaid enrollees with disabilities have more complex health conditions and greater functional needs, and use many more medical and other health-related services than do other Medicaid enrollees. Despite this greater need and vulnerability, however, there are limitations in research and a lack of quality assessment

specifically designed to identify the particular needs of these individuals.

It is not clear whether or not commonly used quality measures can adequately assess the quality of care provided to Medicaid enrollees with disabilities. There are some standard measures for a limited number of common and potentially disabling conditions such as asthma, diabetes, and heart failure. However, new measures may be required or adjustments to the current measures may be needed to consider enrollee health conditions (e.g., dental measures adjusted to target enrollees with disabilities) and functional status.

Research and scientific evidence needed to inform the development of quality measures to address disability-related issues is limited.

The Commission encourages the development of new research to guide the development of new measures, and/or refinement of existing measures, applicable to these individuals. The improvement of quality measures for Medicaid enrollees with disabilities would provide federal and state governments with additional data and measurement tools to determine whether or not these individuals receive quality care.

Development of quality measures for Medicaid enrollees with disabilities provides states with measurement options to determine whether or not services provided are of high quality. The development of additional research to support outcomes data specific to Medicaid enrollees with disabilities is critical for supporting quality measures that are specific, robust, and appropriate for this population. This recommendation would provide federal and state governments with the additional measurement tools and data they need to help determine whether or not individuals receive quality care that is appropriate and cost-effective.

If new quality measures are developed for Medicaid enrollees with disabilities, other measures should be phased out. Phasing out some measures will be necessary to prevent data collection redundancies that impose unnecessary administrative burdens without improving the quality of care.

As the federal government and states develop innovative programs for this population, quality measurement should be continuously updated. The Commission recommends that research and evidence development on quality measurement should be sufficiently robust to fully assess the impact of these innovative programs on the coordination of physical, behavioral, and community support services. This would allow policymakers to assess health plan and provider performance and align payment approaches with quality improvement.

Implications

Federal spending: There is no immediate and direct impact on the federal budget.

State spending: There is no immediate and direct impact on state budgets.

Beneficiaries: Development of measures to monitor the quality of care delivered to Medicaid enrollees with disabilities may assist with improving enrollees' overall health outcomes and the quality of care they receive.

Providers: There is no anticipated provider impact given that the development of new quality measures for Medicaid enrollees with disabilities should allow for the phasing out of existing measures which may become redundant.

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Chapter 1c Annex 1

TABLE 1c-A1. HHS Initial Core Set of Children’s Quality Measures for Medicaid and CHIP

| Measure | |
|---------|---|
| 1 | Frequency of ongoing prenatal care |
| 2 | Timeliness of prenatal care – the percentage of deliveries that received a prenatal care visit as a member of the organization in the first trimester or within 42 days of enrollment in the organization |
| 3 | Percent of live births weighing less than 2,500 grams |
| 4 | Cesarean rate for low-risk first birth women [NQF #0471] |
| 5 | Childhood immunization status [NQF #0038] |
| 6 | Immunizations for adolescents |
| 7 | BMI documentation for ages 2 to 18 [NQF #0024] |
| 8 | Screening using standardized screening tools for potential delays in social and emotional development – Assuring Better Child Health and Development (ABCD) initiative measures |
| 9 | Chlamydia screening for women [NQF #0033] |
| 10 | Well-child visits in the first 15 months of life |
| 11 | Well-child visits in the third, fourth, fifth, and sixth years of life |
| 12 | Well-child visits for 12 to 21 years of age – with PCP or OB-GYN |
| 13 | Total eligibles receiving preventive dental services (EPSDT measure, Line 12B) |
| 14 | Appropriate testing for children with pharyngitis [NQF #0002] |
| 15 | Otitis media with effusion – avoidance of inappropriate use of systemic antimicrobials – ages 2 to 12 |
| 16 | Total EPSDT eligibles who received dental treatment services (EPSDT CMS Form 416, line 12C) |
| 17 | Emergency department (ED) utilization – average number of ED visits per member per reporting period |
| 18 | Pediatric catheter-associated blood stream infection rates (PICU and NICU) [NQF #0139] |
| 19 | Annual number of asthma patients (≥ 1 year-old) with ≥ 1 asthma-related ER visit (S/AL Medicaid Program) |
| 20 | Follow-up care for children prescribed attention-deficit/hyperactivity disorder (ADHD) medication (Continuation and Maintenance Phase) [NQF #108] |
| 21 | Follow-up after hospitalization for mental illness |
| 22 | Annual hemoglobin A1c testing (all children and adolescents diagnosed with diabetes) |
| 23 | CAHPS® Health Plan Survey 4.0, Child Version including Medicaid and Children with Chronic Conditions supplemental items |
| 24 | Children’s and adolescents’ access to primary care practitioners (PCPs), by age and total |

Note: Measures that have received National Quality Forum (NQF) endorsement are indicated with the relevant number.

Source: Department of Health and Human Services. 2009. Medicaid and CHIP programs: Initial core set of children’s health care quality measures for voluntary use by Medicaid and CHIP programs. Notice with comment period. *Federal Register* 74, no. 248 (December 29): 68846–6884

Chapter 1c Annex 2

TABLE 1c-A2. HHS Initial Core Set of Adult Quality Measures for Medicaid

| Measure | |
|---------|--|
| 1 | Flu shots for adults ages 50 to 64 (collected as part of HEDIS CAHPS Supplemental Survey) |
| 2 | Adult BMI assessment |
| 3 | Breast cancer screening |
| 4 | Cervical cancer screening |
| 5 | Medical assistance with smoking and tobacco use cessation (collected as part of HEDIS CAHPS Supplemental Survey) |
| 6 | Screening for clinical depression and follow-up plan |
| 7 | Plan all-cause readmission |
| 8 | Diabetes, short-term complications admission rate |
| 9 | Chronic obstructive pulmonary disease (COPD) admission rate |
| 10 | Congestive heart failure admission rate |
| 11 | Adult asthma admission rate |
| 12 | Chlamydia screening in women ages 21 to 24 (same as CHIPRA core measure, however, the State would report on the adult age group) |
| 13 | Follow-up after hospitalization for mental illness |
| 14 | Elective delivery |
| 15 | Antenatal steroids |
| 16 | Annual HIV/AIDS medical visit |
| 17 | Controlling high blood pressure |
| 18 | Comprehensive diabetes care: LDL-C screening |
| 19 | Comprehensive diabetes care: Hemoglobin A1c testing |
| 20 | Antidepressant medication management |
| 21 | Adherence to antipsychotics for individuals with schizophrenia |
| 22 | Annual monitoring for patients on persistent medications |
| 23 | CAHPS Health Plan Survey v 4.0 – Adult Questionnaire with CAHPS Health Plan Survey v. 4.0H – NCQA Supplemental |
| 24 | Care transition – transition record transmitted to health care professional |
| 25 | Initiation and engagement of alcohol and other drug dependence treatment |
| 26 | Prenatal and postpartum care: postpartum care rate (second component to CHIPRA core measure “timeliness of prenatal care;” State would now report 2/2 components instead of 1) |

Source: Department of Health and Human Services. 2012. Medicaid program: Initial core set of health care quality measures for Medicaid-eligible adults. Final notice. *Federal Register* 77, no. 2 (January 4): 286–290

Chapter 1c Annex 3

Quality Measures Relevant to High-Need, High-Cost Populations, Reported by State Medicaid Programs, 2010

Several states have initiated efforts to develop measures to monitor and evaluate high-need, high-cost enrollees' care and experiences accessing the health care system. MACPAC identified quality measures that are being used by at least one state, are not existing HEDIS measures, and may be relevant to Medicaid enrollees with disabilities and persons dually eligible for Medicaid and Medicare. The clinical quality and access measures were self-reported by states as part of the 50-state survey of Medicaid managed care programs conducted by Health Management Associates for the Kaiser Commission on Medicaid and the Uninsured. These measures fall into the following categories: hospitalizations/emergency room (ER) visits; mental health/substance abuse; chronic care; access, utilization, and costs; care coordination; satisfaction and quality of life; and additional measures.

TABLE 1c-A3. Quality Measures Reported by State Medicaid Programs, 2010

| Measure | Total States Reporting | State/Program |
|--|------------------------|---------------------------------------|
| Hospitalizations/ER Visits | | |
| Inpatient visit for ambulatory care-sensitive conditions | 2 | IL (PCCM); TX (PCCM) |
| Avoidable hospitalization rate | 2 | ME (PCCM); MO (MCO for children only) |
| Emergency department diversion | 1 | OH (MCO) |
| Hospital readmission (within 72 hours with same complaint) | 1 | NE (PCCM) |
| Follow-up within 30 days of hospital discharge | 1 | PA (PCCM) |
| Mental Health/Substance Abuse | | |
| Coordination of behavioral health and medical care | 1 | AZ (PHP) |
| Timeliness of first service for children with special health care needs (CSHCN) through the Children's Rehabilitative Services Program | 1 | AZ (PHP) |
| Access to care/appointment availability for routine behavioral health services | 1 | AZ (PHP) |
| Mental health admission to inpatient hospitals | 1 | CA (reported by one specialty plan) |

TABLE 1c-A3, Continued

| Measure | Total States Reporting | State/Program |
|--|-------------------------------|--|
| Discharges to out-of-home placements | 1 | CA (reported by one specialty plan) |
| Mental health readmission rate | 5 | FL (MCO); IA (PHP); NC (PHP); PA (PHP for inpatient psychiatric admissions); TX (PCCM) |
| Average time between mental health hospitalizations | 1 | IA (PHP) |
| Follow-up after hospitalization for substance abuse treatment | 2 | IA (PHP); PA (PHP) |
| Follow-up after hospitalization for the dually diagnosed (mental health and substance abuse) | 1 | IA (PHP) |
| Implementation of mental health inpatient discharge plans | 1 | IA (PHP) |
| Outcome measurement for Medicaid children and adolescents, improvement in the psychosocial domain | 1 | IA (PHP) |
| Documentation of mental health discharge plan | 1 | IA (PHP) |
| Rate of discharge to homeless or emergency shelter | 1 | IA (PHP) |
| Inpatient concordance rate – percentage of requests for mental health inpatient treatment that the plan authorizes for a 24-hour level of care | 1 | IA (PHP) |
| Percent of involuntary hospitalizations | 1 | IA (PHP) |
| Readmission for non-inpatient services | 1 | IA (PHP) |
| Frequency with which network providers communicate with PCPs | 1 | IA (PHP) |
| Number of adult and child enrollees receiving integrated services, rehabilitation, or support services | 1 | IA (PHP) |
| Documentation of substance abuse treatment discharge plans | 1 | IA (PHP) |
| Rate of substance abuse treatment readmission | 1 | IA (PHP) |
| Psychotropic medication screening | 1 | IA (PHP) |
| Return to the community for children in psychiatric medical institutes | 1 | IA (PHP) |
| Improvement in emotional health – Medicaid adults and older adolescents | 1 | IA (PHP) |
| Percentage of enrollees receiving services annually | 1 | IA (PHP) |
| Expenditures for integrated services and supports | 1 | IA (PHP) |
| Substance abuse days and discharges, partial hospitalization days and discharges, and alternative services | 1 | MO (MCO) |

TABLE 1c-A3, Continued

| Measure | Total States Reporting | State/Program |
|---|-------------------------------|---|
| Percentage of adults receiving services who have serious mental illness and no co-occurring substance abuse diagnosis | 1 | PA (PHP) |
| Percentage of adults receiving mental health services; substance abuse services | 1 | PA (PHP) |
| Chronic Care | | |
| Asthma-related ER visits | 4 | AL (PCCM, FFS); GA (MCO, FFS); MO (MCO for children); PA (MCO for children) |
| Asthma admission rate | 1 | GA (MCO, FFS); TX (PCCM, PHP, FFS) |
| Preventable asthma-related ER visits | 1 | MO (MCO for children) |
| Appropriate asthma medication: three or more controller dispensing events | 1 | NY (MCO) |
| Frequency of HIV disease monitoring lab tests | 1 | FL (MCO) |
| Highly active anti-retroviral treatment | 1 | FL (MCO) |
| HIV-related outpatient medical visits | 1 | FL (MCO) |
| HIV/AIDS comprehensive care: engaged in care, viral load monitoring, syphilis testing | 1 | NY (MCO) |
| Cervical cancer screenings in women who are HIV-positive | 1 | PA (MCO) |
| Admission rates – diabetes short- and long-term complications, uncontrolled diabetes, COPD, HTN, CHF, dehydration | 1 | TX (PCCM, PHP, FFS) |
| Diabetes – rate of lower extremity amputation | 1 | TX (PCCM) |
| Managing sickle cell anemia | 1 | AK (PCCM) |
| Hepatitis C treatment effectiveness | 1 | AK (PCCM, FFS) |
| Inpatient discharges for chronic conditions | 1 | OH (MCO) |
| Inpatient readmissions for chronic conditions | 1 | OH (MCO) |
| ER visits for chronic conditions | 1 | OH (MCO) |
| Access, Utilization, and Costs | | |
| 24/7 access to PCP coverage | 1 | AK (PCCM) |
| Outpatient drug utilization – average cost and number of prescriptions per member per month (PMPM) | 1 | GA (MCO, FFS) |
| Access – unduplicated Medicaid members served | 1 | ME (PCCM) |
| Medicaid costs ¹ | 1 | ME (PCCM) |

¹ No additional details on specific Medicaid costs were provided by Maine in the survey.

TABLE 1c-A3, Continued

| Measure | Total States Reporting | State/Program |
|---|-------------------------------|---|
| Care Coordination | | |
| Care management rate of all members | 1 | OH (MCO) |
| Care management rate of high-risk members | 1 | OH (MCO) |
| Satisfaction and Quality of Life | | |
| Days of work or school lost due to patient’s health condition | 1 | NE (PCCM) |
| Self-reported health status | 1 | NE (PCCM) |
| SF-12 and SF-10 functional status surveys | 1 | TX (PCCM, PHP, FFS) |
| Disease Management Association of America (DMAA) client satisfaction survey | 1 | TX (PCCM, PHP, FFS) |
| Additional Measures | | |
| Inpatient preoperative antibiotics | 1 | AK (PCCM, FFS) |
| Prevalence of pressure ulcers | 1 | AZ (elderly and disabled long term care population) |
| Transport timeliness | 1 | FL (MCO) |
| Transport availability | 1 | FL (MCO) |
| Generic medications as a percent of all prescription fills | 1 | NC (PCCM for Medicaid non-duals only) |
| Adolescent preventive care measures – assessment or counseling for risk behaviors, depression, tobacco use, and alcohol/substance use | 1 | NY (MCO) |
| Annual dental visits for members with developmental disabilities | 1 | PA (MCO) |

Note: Several measures in the table could apply to the general population, but given service use patterns for Medicaid enrollees with disabilities and persons dually eligible for Medicaid and Medicare, certain overall population measures such as avoidable hospitalization rate, hospital readmissions, ER diversion, etc., may be particularly relevant for these more complex populations. PCCM is primary care case management; PHP is non-comprehensive prepaid health plan (a prepaid plan that provides, arranges for, or otherwise has responsibility for a defined set of services, such as only behavioral health or dental services); MCO is managed care organization.

Source: Gifford et al. 2011