CHAPTER 3

Access to Care for Persons with Disabilities

Key Points

Access to Care for Persons with Disabilities

- This chapter summarizes a literature review on access to care for non-institutionalized adults with disabilities under age 65 who are Medicaid-only enrollees, a group with a wide range of health care needs and functional limitations. We found little research directly examining access to acute care for our study population and therefore reviewed a wider range of studies based on large-scale population surveys, provider and stakeholder data, consumer interviews and other qualitative data, and state Medicaid program data.
- Access to health care among Medicaid-only enrollees with disabilities is comparable to that of other insured persons with disabilities, based on large-scale population survey data.
- Unmet need among Medicaid-only enrollees with disabilities is lower compared to individuals with disabilities covered by private insurance or Medicare-only, based on survey data. Preventive services are potentially underused among Medicaid enrollees with disabilities, though findings vary by service.
- Interviews with providers, plans, and other stakeholders share three areas of concern: 1) disability competency training in medical schools for non-pediatric specialists; 2) accessibility of equipment and services; and 3) access to dental services. However, studies specific to Medicaid are rare and leave an unclear picture of access for our study population.
- Several access barriers figure prominently in qualitative studies of adults with disabilities: 1) scheduling appointments and receiving timely primary care; 2) communication with providers and staff; 3) accessibility of health care facilities and services; 4) finding a doctor who understands their disability; and 5) transportation. However, these experiences may not be representative of experiences among Medicaid enrollees with disabilities.
- Studies using state Medicaid program data provide little information on access to care for Medicaid enrollees with disabilities. Studies do not have comparison groups with other forms of coverage and include no data on service use prior to enrollment.
- Further research is needed on: 1) the impact of enabling services on access to care; 2) disability competency and accessibility in Medicaid provider networks; and 3) evaluation and best practices in risk-based managed care. Additional areas of research are the role of non-physician practitioners in access to care for subpopulations with disabilities, and best practices in service delivery.

CHAPTER 3

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Medicaid enrollees under age 65 with disabilities are a heterogeneous population with a wide range of health care needs and functional limitations, including mobility and cognitive limitations, difficulty with self-care, and difficulty participating in everyday activities (KCMU 2011, Allen et al. 2000). They include persons with genetic disorders, such as Down syndrome; persons with traumatic brain injury and spinal cord injury; and persons with disabilities stemming from degenerative diseases, chronic diseases, and serious mental illnesses.

This chapter presents information from a literature review on access to care for adults with disabilities under age 65, with a specific focus on non-institutionalized individuals enrolled in Medicaid and not dually enrolled in Medicare. Medicaid-only enrollees constitute over 60 percent of individuals under age 65 who are eligible for Medicaid on the basis of disability (MACPAC 2012).[1]

Persons with disabilities require a wide range of services to address the underlying causes of disabilities as well as co-occurring conditions prevalent in this population, especially mental illness.[2] Nearly half of Medicaid-only enrollees qualifying on the basis of disability have a mental illness such as depression, schizophrenia, or bipolar disorder (Kronick et al. 2009). The prevalence of mental illness is even higher among enrollees with physical health conditions (Kronick et al. 2007). Among enrollees who have one of the five most common physical conditions, approximately two-thirds also have a mental illness (Boyd et al. 2010).[3]

Providing appropriate access to care for this population is relatively challenging because a broad range of services may be needed, and each provider must accommodate the unique needs related to an individual's disability and consider the cause and nature of the disability in treatment plans.

Scope of Literature Review

Study population. In our review, we found little research directly examining persons with disabilities enrolled only in Medicaid and therefore we reviewed a wider range of studies to learn about access in selected care settings or among persons with a common disability (e.g., intellectual disabilities). Throughout this chapter, we note which studies provide evidence specifically for our study population—persons with disabilities under age 65 enrolled in Medicaid only—and which provide evidence for a more general population.

Services. The health services we examined are broadly defined as acute care services and included acute care hospital services, physician and non-physician practitioner services (including primary care), dental services, prescription drugs, and imaging and laboratory testing. These acute care services accounted for 74 percent of Medicaid spending for this population in fiscal year 2008 (MACPAC 2012).

Persons with disabilities may also need other services not examined here in order to maintain function and independence. These services—referred to as long-term services and supports (LTSS)—usually include home health, durable medical equipment, personal attendant care, residential habilitation, minor home modifications, and other services. Average Medicaid spending on LTSS for Medicaid-only enrollees is relatively low compared to spending on acute care services (MACPAC 2012), and only a small share (16 percent) of the Medicaid-only population with disabilities uses Medicaid-covered LTSS (MACPAC 2013).

Sources. We reviewed published studies and critical reviews on access to care for adults with disabilities under age 65, drawing from quantitative and qualitative research. These sources included peer-reviewed journals, federal and state government sources, independent federal agencies or advisory bodies, and web-based published literature from universities and non-partisan independent research organizations and foundations.

A Framework for Examining Access to Health Care

The access framework previously developed by MACPAC informs this assessment of the literature on access. The framework recognizes three main elements of a health care coverage program as essential to examining access to care: (1) the unique characteristics of enrollees, (2) provider availability and other health care system arrangements, and (3) utilization or realized access, including enrollees' experiences with the health care system (MACPAC 2011). For the purposes of this review, we first briefly summarize the unique characteristics of the population of interest, and then look more systematically at the current knowledge and supporting evidence of the factors influencing provider availability and service use as they relate to enrollees with disabilities.

Characteristics of the Population

The health characteristics and health needs of persons with disabilities in Medicaid vary widely. Importantly, having a disability is not equivalent to ill-health or incapacity. Persons with disabilities can be both healthy and well (CDC 2005). Some persons with disabilities have a disability that is stable and unrelated to any chronic disease process (e.g., deafness present at birth) (CDC 2005). Other individuals are medically fragile or have a medically complex disease or disorder underlying the disability. In these cases, inattention to routine or minor medical problems can result in further functional decline or life-threatening infections and other complications (CDC 2005, Neri and Kroll 2003, Rimmer 1999).

Health needs and risk factors

Persons with disabilities often have health and medical needs stemming from the disability itself, an underlying condition, or common risk factors and co-occurring conditions. Among Medicaid-only enrollees with disabilities, there is a high prevalence of cardiovascular and central nervous system diseases, in addition to mental and behavioral diagnoses (Kronick et al. 2009).

To address these health needs and risk factors appropriately, some patients may require special equipment or additional time with practitioners. For other patients, time and equipment may not be a factor. Instead, practitioners may need specialized training or need to tailor the clinical process or communication strategy to meet the patient's clinical needs.

Selected examples of the health needs and risk factors common to persons with specific disabilities include the following:

- Persons with intellectual disabilities have difficulty recognizing and communicating symptoms (DFCM 2011), are at increased risk of osteoporosis (Fisher and Kettl 2005, Center et al. 1998), and are highly susceptible to dental disease (Fisher 2012).
- Persons with neurodevelopmental disabilities such as cerebral palsy may be medically complex and require ongoing care from specialists, they may take medications that increase fall risk, and physicians may encounter challenges attributing symptoms to the disabling condition or another emerging condition (DFCM 2011).
- Individuals with spinal cord injury and those dependent on wheelchairs are at risk of osteoporosis, bowel dysfunction, and loss of muscle tone. An inability to feel pain (due to paralysis) places these individuals at risk of unknowingly injuring themselves and developing major infections (McColl et al. 2008, CDC 2005).

Prevention and wellness

Persons with disabilities have the same general need for health prevention and wellness services as persons without disabilities (McColl et al. 2008, CDC 2005). In addition, prevention of secondary conditions and the maintenance of functional independence are vitally important to the well-being of persons with disabilities. Health prevention services for adults and youth with disabilities may include prescribing exercise in a health care setting, and counseling and guidance to change eating habits or take measures to avoid injury (CDC 2005).[4]

Women with disabilities require the full spectrum of reproductive and family planning health care services, just as women without disabilities do. For older women, this would include information related to menopause, including osteoporosis and insomnia (NCD 2009, Wilkinson and Cerreto 2008).

Socioeconomic characteristics

Individuals with disabilities are more likely than non-disabled individuals to face socioeconomic disadvantages that create additional challenges to obtaining medical care, and this is true within the Medicaid population as well.

Income and education. Medicaid enrollees with disabilities are more likely than enrollees without disabilities to face economic and educational disadvantages. Adults receiving Supplemental Security Income (SSI) and enrolled in Medicaid are among the poorest Medicaid enrollees, and just over 40 percent have no high school degree.[5]

In addition, low health literacy and lack of English language proficiency are also challenges.

Health literacy. Health literacy—the ability to read and understand health care information—is reported to be a common challenge within disabled populations (NCD 2009). Low literacy may stem from difficulties with communication over a lifetime related to auditory processing disabilities, cognitive limitations, and neuromuscular limitations (NCD 2012).

People with specific disabilities that limit the ability to read (e.g., blindness, traumatic brain injury, stroke, Down syndrome, cerebral palsy) may have difficulty understanding written materials (NCD 2012). People who are deaf or hard-of-hearing may lack exposure to the popular media due to the auditory format, which limits the opportunity to learn about health promotion activities or health services (Steinberg et al. 1998).

Individuals with low health literacy are less likely to be responsive to health education, to use disease prevention services, and to successfully manage their chronic illnesses (Dewalt et al. 2004).

English proficiency. Lack of English proficiency can be an additional barrier for persons whose primary language is American Sign Language (ASL) or Braille. ASL and Braille are recognized as "succinct and separate from English under federal regulation and guidance."[6] ASL does not have a written form and does not have syntax equivalent to English syntax (NCD 2012). ASL does not have signs for many common medical terms like "cholesterol." Deaf individuals who use ASL as their primary language may lack English proficiency and have low health literacy as a result. A survey among deaf individuals in Chicago found that one-third could not define the word "cancer" (Margellos et al. 2004).

A Review of Research Findings on Access to Care

Information about access to care among persons with disabilities enrolled in Medicaid is based primarily on four kinds of data sources: (1) large-scale population surveys, (2) provider and stakeholder data, (3) consumer interviews and other qualitative data, and (4) state Medicaid program data. The summary of the research presented in this section is organized into four subsections based on each of these four types of data sources. Given that research studies from common types of sources often share the same limitations in the scope and generalizability of their findings, each subsection of this chapter concludes with a discussion about the strengths and limitations of the literature with respect to this chapter's objective.

Findings from large-scale population surveys

Several large-scale population surveys have supported general research on access to care for non-institutionalized individuals with disabilities. Two federal surveys permit comparisons between individuals covered by Medicaid and individuals with other forms of health coverage. The National Health Interview Survey (NHIS) can produce national and state-level estimates (NCHS 2010), while the Medical Expenditure Panel Survey (MEPS) is designed to be nationally representative (AHRQ 2009). The survey items on disability in the NHIS and in the household component of the MEPS allow a variety of definitions of disability with respect to degree of dependency, domains of disability, and source of disability (NCHS 2010).[7] The surveys collect data on respondents' limitations in activities of daily living (e.g., dressing) and functional activities (e.g., climbing a flight of stairs); impairments in mobility, cognition, vision, and hearing; as well as conditions that cause these limitations.

Although the NHIS and the MEPS differ somewhat in wording and scope of questions, both surveys ask about the respondent's experiences with regular providers and about barriers to care. Specifically, surveys collect self-reported data about characteristics of the respondent's usual place of care; reasons for not having one; problems experienced obtaining needed medical, mental health, dental, and prescription care; and reasons for not getting needed care, as examples. Both the NHIS and the MEPS also collect self-reported data on utilization of preventive visits and preventive care, doctor visits, emergency department visits, inpatient hospital stays, and contact with other providers (AHRQ 2011, NCHS 2010).

The Behavioral Risk Factors Surveillance System (BRFSS) was established by the Centers for Disease Control and Prevention and is fielded on an ongoing basis by all 50 states, the District of Columbia, and the U.S. Territories. The BRFSS provides state estimates of basic access measures for individuals with activity limitations. It does not capture Medicaid coverage but allows comparison between individuals with public, private, and no coverage (CDC 2012). Three other national surveys are no longer fielded, but have supported analysis cited in this review (Box 3-1).

There are few studies that focus specifically on Medicaid enrollees with disabilities under age 65 that draw data from large-scale surveys. However, when complemented by additional studies of the broader population of adults with disabilities, survey analyses consistently draw the same conclusions about persons with disabilities enrolled in Medicaid. These conclusions are summarized below.

BOX 3-1. Other Large-Scale Surveys Supporting Analyses of Medicaid Enrollees with Disabilities Cited in This Chapter

National Survey of SSI Children and Families (NSCF). This nationally representative survey of current and former recipients of Supplemental Security Income (SSI) was last fielded from 2001 to 2002 (SSA 2012). The NSCF provided a rich source of information on health services use and access to care among children and young adults in the SSI program (and enrolled in Medicaid) and a comparison group of young adults who had recently exited the program (former Medicaid enrollees).

Henry J. Kaiser Family Foundation (KFF)/ICR 2003 Survey. This one-time national telephone survey of adults ages 18 through 64 with permanent physical and mental disabilities was fielded from 2002 to 2003 for the purpose of comparing access to care and unmet needs for persons with severe disabilities based on source of insurance coverage (KFF 2003).

National Survey of American Families (NSAF). This national survey was fielded in 1997, 1999, and 2003 by the Urban Institute as part of its Assessing the New Federalism project. The NSAF provided national and state-level estimates (for 13 states) of adults and children with different forms of health insurance coverage, including Medicaid. The NSAF captured disability through a question on work limitations and included a rich set of questions about access to care and service use, as well as other topics (Coughlin et al. 2005).

Access to health care among persons with disabilities enrolled in Medicaid is comparable to that of persons with other sources of coverage. The percentage of individuals reporting that they have a usual place to go when they need care or have a regular doctor are commonly cited measures of potential access to care. In a national survey of persons with severe and permanent disabilities, the percentage of persons who reported having no regular doctor was the same—15 percent—for persons with Medicaid-only coverage, persons with Medicare-only or private-only insurance, and those dually enrolled in Medicare and Medicaid (Hanson et al. 2003). Persons with Medicare and supplemental private insurance had the lowest percentage (7 percent) with no regular doctor. In contrast, 69 percent of uninsured persons with disabilities had no regular doctor.

Medicaid enrollees appear to face similar challenges as persons with Medicare and private coverage in finding a regular doctor whom they perceive as competent to treat them. In the same study, the percentage of Medicaid-only respondents who reported trouble finding a doctor who understood their disability (25 percent) was not significantly different from respondents with other forms of coverage (Hanson et al. 2003).

Studies also show that a greater or equal percentage of persons with disabilities report having a usual source of care relative to persons without disabilities but with similar incomes, education, and health conditions (NCHS 2008, Iezzoni and O'Day 2006). However, few studies have controlled adequately for age and insurance type (Coughlin et al. 2008, Parish and Ellison-Martin 2007).

For some persons with disabilities, the lack of a usual source of care may have serious health consequences. Young adults with developmental disabilities are an especially vulnerable population because they rely on an array of public programs and services, frequently face challenges being actively engaged as patients, and upon adulthood must leave specialized pediatric clinics familiar with their condition and find adult care physicians who can meet their unique care needs (DFCM 2009). For such vulnerable groups, having no established source of care might signal disruptions in care that could present particular risks.

Unmet need among persons with disabilities enrolled in Medicaid is lower compared to those with other sources of coverage. Studies comparing persons with disabilities covered by Medicaid to those covered by private insurance or Medicare, or who are uninsured show Medicaid reduces unmet need and unmet need due to cost. A national study of youth with disabilities transitioning into adulthood estimated that continuing Medicaid coverage after age 18 had a major impact on access to care (Hemmeter 2011). The study analyzed the experiences of SSI recipients after turning age 18 and found that, relative to youth who continued Medicaid insurance after age 18, the uninsured were 42 percentage points more likely to report an unmet medical need, 33 percentage points more likely to report an unmet dental need, and 27 percentage points more likely to report an unmet prescription drug need.

In another study of working-age persons with severe and permanent disabilities, those with Medicaid-only coverage were significantly less likely than those with either Medicare-only or private insurance to report postponing care or skimping on medications due to cost (Hanson et al. 2003). Medicare-only enrollees were more than 12 times as likely as Medicaid-only enrollees to postpone care due to cost, despite the fact that Medicaid-only enrollees in this sample were much poorer. Having unmet need has been linked to higher use of hospital care and emergency departments in the following year among disabled Medicaid enrollees (Long et al. 2005).

Unmet need among persons with disabilities enrolled in Medicaid is higher than among Medicaid enrollees without disabilities. In a national sample of working-age women from the 1999 National Survey of American Families, women with work limitations who were covered by Medicaid reported lower rates of receiving medical care and medications when needed, were less likely to have cervical cancer screenings, and were less satisfied with their care than were other women covered by Medicaid, controlling for the usual type of care reported (Parish and Ellison-Martin 2007).

In a 2003 national telephone survey of working-age adults with severe and permanent disabilities, one-fourth of adults covered by Medicaid reported having postponed care, 40 percent had gone without needed equipment, and 28 percent had skipped doses of their medications (Hanson et al. 2003). Studies have also identified disparities in access between Medicare enrollees with and without disabilities (Iezzoni et al. 2003) and among the uninsured with and without disabilities (Sommers 2006). Among persons with disabilities, those with greater impairment report more unmet need and difficulty accessing care than do those with less impairment (Sommers 2006, Long et al. 2002).

Use of many health services among persons with disabilities enrolled in Medicaid is high compared to service use among those without disabilities. A recent national study of working-age adults with disabilities found that having a disability is associated with more difficulty accessing needed care, higher emergency department use, and higher hospitalization rates than having multiple conditions but no disability (Gully et al. 2011). According to these data, persons with disabilities also reported more chronic and acute conditions, obesity, physical inactivity, and smoking when compared to persons without disabilities. The same study found substantially higher ambulatory health care visits to a wider array of physicians and other providers among persons with disabilities than among those with no disability but similar health conditions. This pattern of high physician contact and high unmet need among persons with disabilities is documented in other surveys as well (Gully and Altman 2008).

Studies have also reported higher hospital readmission rates among Medicaid and other insured beneficiaries with disabilities relative to their counterparts without disabilities (Sommers and Cunningham 2011, Gilmer and Hamblin 2010). Lack of engagement among patients and their community providers may contribute to high hospitalization rates. Both readmission studies found that a significant share of Medicaid patients did not have a physician visit within 30 days after discharge.

Other research has estimated that the independent effect of disability doubles the risk of high use of services, after accounting for chronic conditions and disease severity (McColl and Shortt 2006). The authors attribute the higher consumption of services to needs directly related to the disability, as well as conditions exacerbated by social factors.

Preventive services are potentially underused among Medicaid enrollees with disabilities, though findings vary by service. The possible exception to the pattern of high use documented above is preventive services. In the few surveys that support comparisons in preventive screenings, women with disabilities have consistently reported lower rates of routine screening for breast cancer and cervical cancer than have women without disabilities (Armour et al. 2009, Parish and Ellison-Martin 2007, Smeltzer 2006, Wei et al. 2006, Ramirez et al. 2005). A similar pattern is apparent with respect to PSA tests for prostate cancer among men with and without disabilities (Ramirez et al. 2005). Only one of these studies tested and found statistically significant disparities among Medicaid enrollees (Parish and Ellison-Martin 2007). In one national study, women with disabilities were more likely than those without disabilities to receive influenza immunizations, cholesterol screenings, and colorectal screenings after controlling for insurance status (Wei et al. 2006). None of these studies directly compared the experiences of persons with disabilities enrolled in Medicaid to similarly disabled individuals with private insurance.

Findings are inconclusive regarding the effect of Medicaid managed care on access to care among persons with disabilities. Most states have only recently begun to transition a large share of adults with disabilities into partial or full-risk managed care (MACPAC 2011, Gifford and Paradise 2011). The only two national studies that have examined the experiences of persons with disabilities in managed care report conflicting results. Using survey data from 1996 to 2004, Burns (2009) found that adults with disabilities in counties with mandatory Medicaid managed care were more likely to wait over 30 minutes to see a provider or report a problem accessing a specialist, and less likely to receive a flu shot, relative to adults with disabilities living in counties with voluntary managed care or fee for service (FFS).

Using other survey data from the same time period, Coughlin and colleagues (2008) found that adult Medicaid enrollees with disabilities living in urban counties with Medicaid managed care reported better access to care than their FFS counterparts on three measures: (1) having a usual source of preventive care, (2) contact with a general medical doctor or specialist, and (3) receipt of flu shots. The study found no improvement in the use of other preventive services, and no gains in access in rural managed care counties. Neither study could capture enrollment in managed care at the individual level and instead used county-level managed care status as a proxy for individual experience. In one study of California's voluntary Medicaid managed care program in which individual enrollment was observed, there were no differences in any measures of access to care or quality of care for Medicaid enrollees who enrolled voluntarily into managed care compared to those who remained in FFS (Graham et al. 2011).

Limitations of large-scale population surveys

Population surveys typically used in national studies of access to health care are limited in their ability to explain why individuals experience barriers to care because these sources do not measure such details as the percentage of individuals who delayed care or reported unmet need due to lack of accommodation for a disability.

With respect to the performance of managed care plans, research based on population surveys can provide only the broadest picture of the access experience and does not identify plan-level factors that could drive results (e.g., member services such as case management or transportation, and enrollee use of these services). In summary, national studies to date on access to care among persons with disabilities have consistently identified overall patterns that would benefit from further investigation into the factors driving them. These patterns include: (1) high unmet need, (2) high utilization rates, and (3) low preventive care use.

Findings from provider and stakeholder data

A small number of statewide provider surveys have captured providers' perceptions of access to medical facilities and clinical practices for persons with disabilities. Other studies have drawn on in-depth interviews with primary care physicians (McColl et al. 2008) and other key informants—such as subject matter experts, non-physician providers, health plans, program managers, and agency directors—to identify critical barriers to access and quality of care for persons with disabilities (Engquist et al. 2012, NCD 2009, Harder and Company 2008). These stakeholders share three areas of concern summarized below.

Disability competency training in medical schools for non-pediatric specialties. Disability competency in the medical setting refers to several aspects of care, including how to perform basic procedures; disability-specific clinical training, such as awareness of atypical risk factors; cultural competency in the treatment of persons with disabilities; and gaining experience in the diagnosis and treatment of persons with a variety of disabilities.

In its 2009 report, the National Council on Disability concluded: "The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent persons with disabilities from receiving appropriate and effective health care" (NCD 2009). This conclusion was based on a literature review and interviews with subject matter experts, including federal agency officials and health care practitioners. A workgroup of California stakeholders, including representatives from county health departments, health plans, clinicians, and community-based organizations drew similar conclusions (Harder and Company 2008).

Surveys of practicing physicians provide additional support for closer attention to disability competency in medical school curriculum; however, none of the data gathered pertains specifically to Medicaid providers. A 2003 survey of primary care physicians in California found that, among those interacting with persons with physical disabilities, 68 percent had not received education or training on physical disability issues (McNeal et al. 2002). A 2004 survey of primary care physicians in Connecticut found that 91 percent of physicians treating adults with intellectual disabilities had no formal training in the care of this population (Kerins et al. 2004).

A 2001 survey of diverse health care delivery sites across Massachusetts provides a somewhat different picture (Bachman et al. 2006). The large majority of responding sites served persons with disabilities on a daily or weekly basis. Three-quarters of the responding providers reported they had received training in disability-related issues over the previous year, including cognitive impairments, severe psychiatric impairments, and communication impairments.

Accessibility of medical equipment and service delivery processes. Provider surveys that have collected information on providers' perceptions of the accessibility of facilities indicate that medical equipment and delivery processes that are not disability-compliant continue to persist as barriers to care (NCD 2009, Harder and Company 2008, McNeal et al. 2002). Three 2006 case studies of tertiary care hospitals found a range of deficiencies related to accessibility, including lack of accessible call systems, diagnostic equipment, and examination tables (Kirschner et al. 2007). This finding is consistent with qualitative interviews with consumers reporting a lack of accommodation in medical settings (Wilkinson et al. 2011, Scheer et al. 2003).

In a recently published "secret shopper" survey of 256 subspecialty practices in four U.S. cities, only 9 percent of practices reported the ability to use a height-adjustable table or mechanical lift to accommodate a patient in a wheelchair unable to self-transfer (Lagu et al. 2013). Another 40 percent could schedule appointments with such patients, but reported the patient would be transferred manually to a standard table, and 29 percent offered to examine the patient without transfer.[8, 9] The remaining 22 percent of the practices reported they would not schedule appointments with such patients, explaining that they could not accommodate patients in wheelchairs unable to self-transfer or that the building was inaccessible.[10]

Access to dental services. The oral health needs among persons with disabilities is high. Research documents a combination of high incidence of oral disease, poor oral hygiene, and greater treatment needs in this population (HRSA 2001).

Quantitative data documenting access to dental services nationwide for adults with disabilities enrolled in Medicaid is scant (Stiefel 2002) due in part to the limited scope of adult dental benefits in most state Medicaid programs (Wall 2012, McGinn-Shapiro 2008). Specialty care dentists and other provider advocates have raised concern that access to dental services is poor for adults with disabilities (Waldman and Perlman 2012), and unmet need for dental care is high (Fisher 2012).

Studies of broader populations inclusive of the study population are consistent with this assertion but do not directly answer this question. In one qualitative study, persons with disabilities generally reported difficulty finding a dentist willing to treat them (Drainoni et al. 2006). In a national analysis of outpatient visit data, a significant number of individuals in the United States, including those covered by private insurance and Medicaid, were found to have sought care for avoidable dental problems in hospital emergency rooms (Elangovan et al. 2011, Nalliah et al. 2010). In another nationwide study comparing Medicaid-covered adults to low-income privately insured adults, Medicaid-covered adults reported poorer access to dental services (Coughlin et al. 2005). Neither study was specific to persons with disabilities covered by Medicaid.

Poor access is generally attributed to: documented evidence of the small number of dentists who are trained to provide specialty care dentistry to persons with developmental disabilities (Waldman and Perlman 2012); inadequate training in general dentistry education on treating persons with special health care needs (Davis 2009); and the small share of dentists who participate in Medicaid (GAO 2010).

Limitations of provider and stakeholder data

Data from physicians, other providers, and stakeholders complement data collected from consumers on access issues and help form a clearer picture of delivery- and program-level barriers to receiving appropriate, quality care, as well as interventions that have facilitated access to care. Provider studies specific to the Medicaid program, however, are sparse and other studies are dated, leaving an unclear picture of the current state of access to care for persons with disabilities enrolled in Medicaid. Another limitation of provider surveys is that person-level estimates cannot be derived. Thus, the proportion of Medicaid enrollees who are served by physicians with disability competency (or other characteristics) cannot be estimated from them.

Findings from consumer interviews

Qualitative studies using in-depth interviews and focus groups of consumers with disabilities provide insights into the barriers that individuals confront, and the mechanisms by which individuals' disability characteristics and related factors (e.g., poverty) compound the daily challenges they face in meeting their health and medical needs (Drainoni et al. 2006, Iezzoni and O'Day 2006, Iezzoni et al. 2006, Iezzoni et al. 2003, Neri and Kroll 2003, Scheer et al. 2003). Participants were usually recruited on a voluntary basis from multiple sites in a selected community to seek a diversity of perspectives. Study participants were also recruited based on characteristics such as their disability attributes, income, insurance status, age, race, managed care enrollment, or geography to represent individuals with different experiences with the health system. Almost all of these studies include individuals with a mix of sources of insurance coverage and little ability to stratify by source, and thus do not allow detailed analysis of the experiences of those with Medicaid coverage.

Several access barriers figure prominently in qualitative studies of adults with disabilities and are summarized below. However, most findings on this topic do not establish the barriers most common to Medicaid enrollees with disabilities. Moreover, qualitative studies are not designed to assess the relative importance of these barriers. As a result, these studies simply identify barriers that need to be investigated further to establish their importance for Medicaid program management.

Scheduling appointments and receiving timely primary care. In several qualitative studies, some persons with disabilities describe multiple barriers when scheduling appointments, including problems finding a doctor who accepts Medicaid and difficulties getting an appointment in a timely manner (Drainoni et al. 2006, Scheer et al. 2003). Difficulty getting an appointment can be related to the challenge of finding a facility that can provide physical access for a procedure or test, with one study pointing to the accessibility of dental services as a significant challenge (Drainoni et al. 2006).

Factors reportedly contributing to delays in getting timely care have been fear or distrust of one's physician based on prior negative encounters, or known problems with an inaccessible provider office, leading patients to avoid seeking needed medical care in the first place (Drainoni et al. 2006, Neri and Kroll 2003). Other factors relate to process or practice at the provider's office, including staff untrained in the use of text telephone (TTY), telephone menu options that do not accommodate a relay service, and lack of same-day appointments (Drainoni et al. 2006, Neri and Kroll 2003).[11]

The same studies have also documented serious health consequences that some persons with disabilities have suffered when small issues were not addressed in a timely manner, leading to unnecessary hospitalizations, avoidable surgeries, and permanent losses of function in some cases (Drainoni et al. 2006, Neri and Kroll 2003), with the frequency of these consequences unknown.

Communication with providers and support staff. Communication difficulties may complicate the scheduling of appointments, completing a visit with a provider, and obtaining appropriate care during a visit or procedure. Persons with disabilities have described communication barriers with staff and practitioners due to the lack of auxiliary aids, lack of interpreters, and staff untrained in the use of TTY phone systems for the deaf or hearing-impaired (Drainoni et al. 2006, Iezzoni et al. 2004). Rushed physicians or short appointment slots can also be barriers to obtaining appropriate care for persons with other disabilities, simply due to the complexity of their health care needs and the additional time needed to address all of their concerns (McColl et al. 2008, Drainoni et al. 2006).[12]

Communication difficulties can pose challenges for individuals whose primary language is ASL or Braille; persons who are hard-of-hearing; and persons with cognitive impairment, neuromuscular disorders, or voice and speech disorders (e.g., traumatic brain injury, stroke, cerebral palsy) who depend on alternative methods and devices to communicate.[13] To effectively communicate with these patients, providers may need to modify their own speech, written materials may need to be adapted to accessible formats, and alternative modalities such as video, photos, or demonstration may need to be used to relay important health information (NCD 2012).

For persons who are deaf or hard-of-hearing, repeated communication difficulties can lead to fear and mistrust of practitioners in general (Steinberg et al. 2006). Lack of adequate communication assistance has been documented by consumers in specific cases to have led to allergic reactions, fear for safety and confusion during and after procedures, and medication errors (Drainoni et al. 2006).

Physical accessibility of health care facilities and services. Persons with disabilities, without respect to insurance status and source of coverage, describe physical barriers to accessing medical facilities (Iezzoni et al. 2006). Persons with mobility impairments report additional barriers once inside provider offices due to the physical layout of the facility, inaccessible equipment, and lack of adaptive devices. Examples include exam rooms that are too small to accommodate a wheelchair, exam tables and diagnostic equipment that are not height-adjustable (Iezzoni and O'Day 2006), weight scales that do not accommodate a wheelchair (Iezzoni et al. 2010), and lack of nurse call bells or bed adjustment controls (Drainoni et al. 2006). Patients report fears of being injured when being lifted from a wheelchair if they cannot transfer themselves (Iezzoni et al. 2010).

Inaccessible equipment in office-based practices is one reason cited by physicians for refusing to schedule appointments for persons with disabilities, and thus may contribute to patients' difficulties in finding a doctor (Lagu et al. 2013). Mammography and other x-ray machines that do not accommodate persons with a range of mobility impairments and the absence of height-adjustable exam tables are described by women with disabilities as a barrier to obtaining screenings for breast and cervical cancer (Wilkinson et al. 2011, Mele et al. 2005), and as a barrier to obtaining treatment for breast cancer (Iezzoni et al. 2010).

Finding a doctor who understands their disability. Physicians' understanding of patients' disabilities encompasses several aspects of care, including how to perform basic procedures, knowledge of each patient's unique medical history, and disability-specific clinical training, such as cultural competence and experience distinguishing symptoms directly related to the underlying disability from those related to an emerging medical problem.

Persons with disabilities interviewed in depth describe difficulties finding physicians who understand their disabilities (Iezzoni et al. 2006). They also describe physicians' misconceptions about persons with disabilities and their health needs (Wilkinson and Cerreto 2008, Drainoni et al. 2006), and in specific cases, health problems that have gone undetected due to lack of training or clinical experience (Scheer et al. 2003).

Transportation to provider settings. Some persons with disabilities identify transportation as an issue in accessing primary and specialty care practices (Scheer et al. 2003). Transportation is reported to be a challenge for individuals with different kinds of disabilities across regions, especially for persons with mobility impairments (Iezzoni and O'Day 2006) and persons with intellectual disabilities (Havercamp et al. 2004).

As rural communities often lack extensive public transportation, persons with disabilities living in these areas may be more dependent on family or friends to drive them. Individuals living in rural areas have also reported difficulty gaining access to medical facilities in older buildings (Iezzoni et al. 2006).

Limitations of consumer interview data

In general, qualitative studies using voluntary methods of recruitment are subject to participant bias, in which those choosing to participate may place higher value on the subject matter of the study or offer perspectives different in scope or intensity from those of people who could have been chosen randomly from the wider population. Studies advertised as an opportunity to discuss problems with access to care may attract individuals with a poor history of access.

In many cases, qualitative studies provide the only information about certain barriers to care. Surveys do not collect the same details about barriers (e.g., the percentage of persons who missed an appointment due to unreliable transportation services). Without such representative data, it is not possible to draw conclusions as to how common these barriers are for persons with disabilities (e.g., what percentage of individuals confront inaccessible facilities or equipment when seeking appointments, what percentage of individuals delay care due to provider difficulty scheduling a certified interpreter). Finally, little is known about the extent to which individuals successfully overcome these barriers and obtain needed care.

State Medicaid program data

Studies using Medicaid program data usually examine the experience of program enrollees in one state or locale (Blecker et al. 2010, Allen et al. 2009, Banta et al. 2009, Long et al. 2005, Mitchell et al. 2004, Long et al. 2002), a subpopulation eligible for certain services or waiver programs (Chalmers et al. 2011, Bershadsky and Kane 2010, Hall et al. 2007, Krahn et al. 2007, Krahn et al. 2006), or enrollees eligible for managed care (Graham et al. 2011, Burns 2009, Coughlin et al. 2008). These studies draw from medical claims and encounters or other program data to describe participation, service levels, or referral rates, and some include interviews with participating enrollees or providers about access experiences with the program.

Studies of state Medicaid programs provide little information on access to care for Medicaid enrollees with disabilities. Study populations and access measures have varied widely, and rarely include comparison groups. Selected examples include the following:

- In a Florida home and community-based services (HCBS) waiver program for adults with intellectual and developmental disabilities (I/DD), 40 percent of the adults enrolled did not see a primary care provider between 1999 and 2003 (Hall et al. 2007). The study did not report on use of specialists.
- In Iowa, among adults under age 65 with I/DD either enrolled in a Medicaid HCBS waiver or receiving case management services, over 80 percent received a preventive dental visit in 2005 (Chalmers et al. 2011).
- In New York City during 1999 and 2000, among SSI beneficiaries under age 65 in FFS Medicaid, 25 percent of adults with mental illness had no outpatient mental health visits (Long et al. 2002). The study did not report comparable estimates for adults with other forms of coverage.
- In rural counties of Kentucky with only FFS Medicaid, more than 95 percent of SSI recipients had a usual source of primary care in 1999. Among persons with mental illness, 60 percent had a usual source of mental health care (Mitchell et al. 2004).
- Two studies that include multistate comparisons among persons with disabilities documented wide variations in Medicaid-covered maternity care across states in terms of access and service use (Gavin et al. 2006) and in diabetes care among persons

taking antipsychotic medications (Morrato et al. 2008).

Well-designed evaluations in the published literature are rare. In one comprehensive evaluation of substance abuse treatment services for Medicaid-eligible adults in Oregon, adults eligible on the basis of disability accessed treatment services at about half the rates of two other Medicaid comparison groups (Krahn et al. 2007). Interviews with participants, providers, and agency staff identified multiple patient-, provider-, and program-level barriers to participation for persons with disabilities, including family support for treatment, staff training about disability, and route of referrals (Krahn et al. 2006).

One nationwide effort to collect access measures for a portion of our study population is the National Core Indicators Project (NCI). To our knowledge, NCI supports the only ongoing, large-scale, multi-state comparison on acute care access for Medicaid enrollees with disabilities at the subpopulation level. NCI reports underscore the variability in access experiences reported in other state program data (HSRI 2013). Because the sample represents the most severely disabled persons with developmental disabilities who receive long-term care services and case management, a small portion of all persons enrolled in Medicaid on the basis of disability, we do not report on those findings here.[14]

Limitations of program studies

The overall quality, depth, and scope of studies using state program data are generally poor and the most recent data on some topics are over 10 years old. Virtually no studies assess the relationship between state program elements and access to care. Typically, studies provide descriptive information about service use without investigating the factors contributing to utilization or describing the characteristics of persons who did not receive services. Studies do not have comparison groups of similarly situated persons with other forms of coverage and include no data on service use among Medicaid enrollees prior to enrollment. Thus, they do not allow conclusions as to whether access levels are due to community factors that would affect all individuals with disabilities or to program factors that affect only Medicaid enrollees. Moreover, without comparison groups, it is unclear whether to interpret access levels as "low," "improved," or "high." Finally, these studies are not representative of Medicaid programs or enrollee experiences nationally.

Further Research Needed

This review serves to inform the Commission's future activities in its examination of access to appropriate care. Major gaps are evident in the research and evidence base about access to care for persons with disabilities, in part because there are too few studies posing access questions about Medicaid enrollees with disabilities to assess which barriers are significant problems for this population. Additionally, access issues especially important to this population have not been explored.

Enabling services. Various studies identify lack of non-emergency transportation and difficulty obtaining sign and oral interpretation services as barriers for persons with disabilities generally. State Medicaid programs offer these enabling services to specifically address these barriers. While the utilization of some enabling services financed by Medicaid and consumer satisfaction with these services has been documented in state reports, the focus of these evaluations is on cost and service process, not the effect of the service on medical care.[15]

Federal Medicaid rules require that states "ensure necessary transportation for recipients to and from providers."[16] States have several options through which to provide transportation services, and this choice determines the federal matching rate for these services and the amount of flexibility a state has in the provision of services. In addition, states may choose to carve-in or carve-out transportation from managed care contracts (Hilltop Institute 2008).

With respect to translation and interpretation services, states face similar choices in service provision and payment. State Medicaid agencies and their subcontractors are required to "take reasonable steps to provide meaningful access to Limited English Proficient (LEP) persons," including individuals with impaired hearing, vision, or speech.[17, 18, 19] The Children's Health Insurance Program Reauthorization Act allowed the costs incurred by state Medicaid programs for translation and interpretation services for LEP persons—including persons whose primary or spoken language is ASL or Braille—to be matched at the enhanced State Children's Health Insurance Program (CHIP) federal medical assistance percentage (FMAP) (CMS 2010).[20] CMS guidance further clarified that the enhanced match was available to assist CHIP and adult Medicaid enrollees to "access covered services" (CMS 2010).

These major design elements—payment, carve-out contracts, capitation, and waiver design—would affect plan and provider incentives for delivering enabling services and are expected to affect access. The impact of enabling services on improved access to medical care has not been independently evaluated to our knowledge.

Medicaid provider networks. A small number of physicians participating in Medicaid serve a disproportionately large share of Medicaid enrollees, relative to physicians participating in Medicare or commercial markets (Cunningham and May 2006). Further research is needed on the disability competency of the clinicians serving the largest share of Medicaid enrollees with disabilities, on the accessibility of diagnostic equipment, and on clinical and staff practices in these settings.

A study using a nationally representative sample of practicing physicians confirmed that the small percentage of primary care physicians serving Medicaid patients differs in many respects from physicians disproportionately serving privately insured patients or accepting few or no Medicaid patients (Sommers et al. 2011).[21] Physicians serving Medicaid patients more frequently reported having an interpreter available at their main practice, and that the settings in which they work are community health clinics and hospital-based practices, or practices owned in part by a hospital.[22] These entities generally have other incentives to comply with federal laws requiring physical accommodation for persons with disabilities.

Medicaid managed care. With a few exceptions, states have only recently begun to enroll a larger number of persons with disabilities into full- and partial-risk Medicaid managed care (MACPAC 2011, Gifford and Paradise 2011). Therefore, states' experiences with setting capitation rates and managed care plans' corresponding experiences serving high-cost, high-need populations vary considerably. Best practices and evaluations of risk-based managed care could help states improve managed care contracting practices and potentially improve oversight of risk-based managed care programs as they expand to serve these populations.

Additional areas of research that would be especially critical for building an evidence base to support Medicaid policy include:

- the role of non-physician practitioners in access to appropriate care for subpopulations with disabilities, and capacity to draw state comparisons using standard measures;

- studies evaluating the effects of program changes on access to care and service use;
- studies exploring the links between barriers to care, service use, and the appropriateness of care, cost, and efficiency of care delivery; and
- evidence from best practices in service delivery for persons with disabilities to produce access, quality, and health outcomes.

Access to care for children with special health care needs falls outside the scope of this chapter. Nonetheless, the program's performance in meeting the needs of these children also deserves attention.

Endnotes

[1] MACPAC analysis of Medicaid Statistical Information System annual person summary data and CMS-64 Financial Management Report net expenditure data, as shown in Figure 1b-2 on p. 45 of MACPAC's March 2012 report to the Congress.

[2] Box 1a-1 of MACPAC's March 2012 report to the Congress (p. 19) provides examples of Medicaid enrollees with disabilities.

[3] The five most common physical conditions are asthma/chronic obstructive pulmonary disease, congestive heart failure, coronary heart disease, diabetes, and hypertension.

[4] Exercise prescription refers to an individualized plan for fitness-related activities designed for a specific purpose, often developed by a fitness or rehabilitation specialist for a patient with chronic illness or disability. This prescription looks much like a drug prescription, indicating the type of activity, duration, frequency, intensity, and precautions (Suleman et al. 2012, HHS 2008, Moore 2004).

[5] MACPAC calculations based on the 2009–2011 NHIS.

[6] Subregulatory guidance defines a "limited English proficient individual" (LEP individual) (HHS 2003). Individuals whose primary language is ASL or Braille are identified as LEP individuals by CMS guidance (CMS 2010).

[7] For a description of questionnaire items in the MEPS, see the Medical Expenditure Panel Survey, Questionnaire Section: Health Status (AHRQ 2011).

[8] Manual transfer of a person with a disability by medical staff places the patient at risk of being dropped or hurt in the process (DOJ 2010). Lifting and transferring patients is a major risk factor for back injury among nurses and health aides (Hedge 2009).

[9] Guidance from the U.S. Department of Justice states that "examining a patient in their wheelchair usually is less thorough than on the exam table, and does not provide the patient equal medical services" (DOJ 2010).

[10] In accordance with federal laws, physicians cannot deny service to a patient who they would otherwise serve because the patient has a disability (DOJ 2010).

[11] A TTY, also known as a telecommunication device for the deaf, is a device that could be used by people who are deaf, hard-of-hearing, or speech-impaired. The telephone handset allows people to communicate over a telephone line by typing messages instead of speaking. A TTY is required at both ends in order to communicate. An alternative to TTY is the Telephone Relay Service, which requires a special operator. See http://www.abouttty.com for more information.

[12] For a more detailed discussion, see pp. 57–66 (Iezzoni and O'Day 2006).

[13] For a description of many of the devices used for augmentative and alternative communication, see the Assistech article on deaf communication (Assistech 2013).

[14] The NCI is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) and supports the quality management systems for 36 participating states and 22 subs-state regions or counties. More information about NCI can be found at http://www.nationalcoreindicators.org/about. The NCI Adult Consumer Survey interviews persons with developmental disabilities receiving publicly funded and case management services. In 2011-2012, a total of 19 states and one sub-state region participated in this survey. These data are limited for our purposes because states do not report the insurance status of respondents, although about 70 percent of respondents participate in an HCBS waiver program. The generalizability of report findings to non-participating states and to other persons with disabilities has not been established.

[15] See, as an example, a review of state reports on Medicaid non-emergency transportation by The Hilltop Institute (Hilltop Institute 2008).

[16] 45 CFR 1902(a)(70).

[17] State Medicaid agencies and their subcontractors are required to take these steps as recipients of federal financial assistance from the U.S. Department of Health and Human Services (HHS) under Title VI and HHS regulations, 45 CFR 80.3(b)(2).

[18] According to the Office of Civil Rights, recipients of federal financial assistance may include hospitals, nursing homes, home health agencies, managed care organizations, state Medicaid agencies, physicians, and other entities (OCR 2013).

[19] The accessibility of health care facilities is further mandated for people with disabilities under Section 504 of the Rehabilitation Act, which prohibits programs that receive federal financial assistance, as well as federally conducted programs and activities, from discriminating against individuals with disabilities; and Titles II and III of the Americans with Disabilities Act of 1990, which prohibits disability discrimination and requires health care providers to be physically and programmatically accessible to people with disabilities.

[20] Section 201(b) of the Children's Health Insurance Program Reauthorization Act of 2009, Pub. L. No. 111-3, enacted February 4, 2009.

[21] The study analyzed data from the 2008 Center for Studying Health System Change Health Tracking Physician Survey, which includes 1,460 primary care physicians (internists, family practice physicians, and general practitioners) who treat adults in outpatient settings.

[22] Authors found similar results for non-pediatric specialists in unpublished analysis.

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