



Barriers to Accessing Medical Equipment and Other Health Services and Supports within Households of Adults with Disabilities

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People with disabilities¹ face persistent inequities in access to high-quality, affordable health care. Studies have documented a range of barriers, including a lack of accessible doctors' offices and exam room equipment, biases and a lack of disability competency among health professionals and staff, limited availability of transportation to appointments, and inadequate health insurance coverage (Iezzoni et al. 2021; Lagu, Griffin, and Lindenauer 2015; Krahn, Klein-Walker, and Correa-De-Araujo 2015; MACPAC 2013; National Council on Disability 2009; Stillman et al. 2014). Access barriers often result in incomplete medical exams and lower rates of preventive screenings and recommended treatments for people with disabilities, as well as a greater likelihood of delaying or forgoing needed care, leading to worse health outcomes (Chong et al. 2022; Iezzoni et al. 2000; Kennedy, Wood, and Frieden 2017; Mitra et al. 2022).

Additional challenges stem from difficulty obtaining consistent access to medical equipment and supplies, home health care, personal assistance services,² and skilled therapy services³ that are critical for the health and well-being of many people with disabilities and their ability to live independently and participate in their communities. Supply chain and workforce shortages and other disruptions during the COVID-19 pandemic, many of which have persisted, have exacerbated problems with obtaining care (Akobirshoev et al. 2022; Kreider and Werner 2023; Lund and Ayers 2022; Monden et al. 2021; O'Malley Watts, Musumeci, and Ammula 2021; Sage, Standley, and Ipsen 2022).⁴ Though people with disabilities of all ages are affected by these gaps in the health care system, nationally representative

data on access to disability-related health services is limited for adults under age 65. Existing survey evidence from selected states and population groups, however, suggests that many nonelderly adults experienced unmet equipment and service needs prior to the pandemic (Chong et al. 2022; Henry et al. 2011; Mitra et al. 2011).

In this brief, we assess the extent to which nonelderly adults with disabilities and members of their households delayed getting or did not get medical equipment, supplies, and other vital services and supports between mid-2021 and mid-2022, the second year of the COVID-19 pandemic. We also focus on the types of equipment and supplies households had difficulty obtaining and the reasons for delayed or unmet needs. Our analysis draws on June 2022 data from the Urban Institute's Health Reform Monitoring Survey (HRMS), a nationally representative survey of adults ages 18 to 64 living in households. Our measure of disability status is based on current federal data collection standards and is defined as having vision, hearing, cognitive, ambulatory, self-care, or independent living difficulties (see the data and methods section in the appendix for more information). Survey questions on delayed and unmet needs were developed in collaboration with members of a Community Advisory Board who have lived experience with disability and who serve as advocates for people with disabilities. Key findings include the following:

- In June 2022, 15 percent of adults with disabilities reported that they or someone in their household delayed getting or did not get the medical equipment or supplies they needed in the past 12 months. Some adults with disabilities also reported that they or a household member experienced delayed or unmet needs for physical or occupational therapy (12 percent), home health care (5 percent), personal assistance services (4 percent), and speech therapy (3 percent).
 - » For each of these items and services, adults with disabilities were more likely than adults without disabilities to report delayed or unmet needs, both for themselves and for other people living in their households.
- Among households of adults with disabilities in which someone delayed getting or did not get needed medical equipment or supplies, the most common types of equipment and supplies that were delayed or not received included eyeglasses (40 percent), breathing equipment (34 percent), mobility equipment (29 percent), diabetes equipment and supplies (27 percent), and hearing aids (15 percent).
- The most frequently reported reasons for delayed or unmet medical equipment and supply needs among these households were related to difficulties using health insurance coverage (Box 1). These reasons included the equipment or supplies not being covered by the health plan (52 percent), difficulty securing health plan authorization (47 percent), and being unable to afford the cost sharing (47 percent). About 1 in 3 also reported difficulty obtaining a prescription from a provider (33 percent), more than 1 in 4 reported equipment or supplies being unavailable because of supply chain shortages (27 percent), and just over 1 in 5 reported a lack of health insurance (21 percent).

- Delayed and unmet needs for medical equipment and supplies, skilled therapy services, home health care, and personal assistance added to the broader range of health care access challenges facing adults with disabilities, including forgoing other types of needed health care in the past 12 months because of cost, difficulty using coverage, and difficulty finding or getting to health care providers.

Because the HRMS is an internet-based household survey, it underrepresents the disabled population, as we discuss in the section on data and methods. Moreover, the survey did not examine the full spectrum of home- and community-based services (HCBS) that assist people with disabilities with daily living activities (Peebles and Bohl 2014). The survey was also fielded during a period of significant turmoil in the health care system and policy responses to mitigate its consequences for patients. Despite these limitations, the findings from our analysis show that many adults with disabilities have difficulty getting vital medical equipment, supplies, and services for themselves and other members of their households and that policymakers will need to address insurance, provider access, and supply-related barriers to alleviate these challenges.

BOX 1

Health Insurance Coverage for Medical Equipment and Other Services and Supports for People with Disabilities

Access to medical equipment and supplies, home health care, personal assistance, skilled therapy services, and other HCBS is shaped in large part by the benefits and rules governing health insurance coverage plans and programs. In our sample, 43 percent of adults with disabilities were insured by Medicare (16 percent) or Medicaid (26 percent) at the time of the survey, including 9 percent reporting both Medicare and Medicaid coverage; 48 percent had commercial insurance through an employer (40 percent) or the nongroup market (7 percent) or reported an unspecified type of coverage; and 9 percent were uninsured (table A.1). Roughly twice that share (18 percent) were uninsured for some or all months of the year before the survey. Most adults with insurance at the time of the survey were insured with the same type of coverage all year. This section provides a brief background on insurance coverage for medical equipment and other services and supports that were the focus of our analysis.

- *Medicare:* Adults with disabilities under age 65 who receive Social Security Disability Insurance can receive Medicare after a two-year waiting period.⁵ Medicare covers home health services for beneficiaries who are considered homebound and in need of skilled care on a part-time or intermittent basis.⁶ Covered services include skilled nursing care; part-time or intermittent home health aide services; physical therapy, occupational therapy, and speech-language pathology; medical supplies; and medical social services.⁷ Home health benefits are generally of limited duration, given the program's emphasis on acute and post-acute care (Colello 2022b). Medicare does not cover 24-hour care, nor does it cover personal care services when this is the only type of care needed.⁸

Medicare also covers durable medical equipment (DME), prosthetics and orthotics, and disposable medical supplies used in connection with DME. Covered DME items must withstand repeated use; have an expected lifetime of at least three years; and be used primarily and customarily for medical purposes, generally not useful in the absence of illness or injury, and appropriate for use in the home (Mayhew, Kouzoukas, and Engelhardt 2019). Medicare covers 80 percent of the approved amount (after the Part B deductible is met) for medically necessary DME

prescribed by providers and furnished by suppliers enrolled in Medicare.⁹ Traditional fee-for-service Medicare requires covered suppliers in certain areas to participate in its competitive bidding program. Covered suppliers for Medicare Advantage plans vary based on the plans' provider networks. Many Medicare Advantage plans also cover vision and hearing benefits that are not covered under traditional fee-for-service Medicare.

- **Medicaid:** Medicaid is the nation's primary source of funding for long-term services and supports,¹⁰ with a majority of that spending dedicated to HCBS (Colello 2022a; O'Malley Watts, Musumeci, and Chidambaram 2020). Home health services are the only mandatory HCBS state plan benefit and include part-time or intermittent nursing services; home health aide services; and medical supplies, equipment, and appliances (Colello 2022a; MACPAC 2019; O'Malley Watts, Musumeci, and Chidambaram et al. 2020).¹¹ Most HCBS are provided at state option, with a majority of funding through Section 1915(c) HCBS waivers or Section 1115 demonstration waivers allowing states to target services to specific groups of beneficiaries who meet the state's financial and level-of-care criteria (O'Malley Watts, Musumeci, and Chidambaram 2020).

People enrolled simultaneously in Medicare and Medicaid can face unique challenges receiving home health services and medical equipment and supplies. Though Medicare is the primary payer for services covered by both programs, Medicaid coverage is generally broader. For instance, Medicaid may cover medically necessary DME for use in the home or the community. But providers must often seek and fail to receive Medicare reimbursement before submitting a claim to Medicaid (Mayhew, Kouzoukas, and Engelhardt 2019; Verdier et al. 2014). Because Medicare typically processes claims after equipment has been delivered, uncertainty over the source of payment can lead to confusion and delay. Integrated care programs seek to improve coordination and access for people with dual coverage (MACPAC 2020). Similar challenges may arise for other people with multiple sources of coverage, including those enrolled in both private insurance and Medicaid.

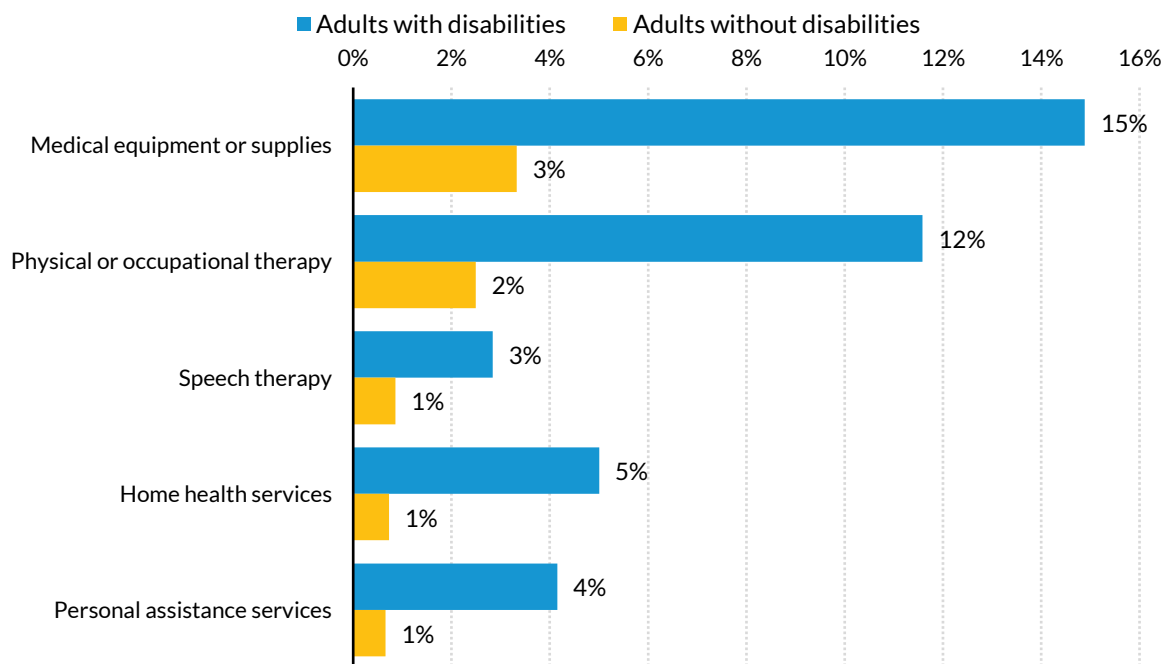
- **Private insurance:** The Affordable Care Act requires individual market and fully insured small group plans to cover essential health benefits, including rehabilitation and habilitation services and devices, such as medical equipment, physical therapy, occupational therapy, and speech therapy.¹² Commercial health plans may offer varying coverage of these services (e.g., in terms of number of covered visits). Coverage requirements for Health Insurance Marketplace health plans also vary across states, depending on the essential health benefits benchmark plan,¹³ and plans may have different benefits with respect to coverage limits; covered suppliers; and rental, purchase, and repair of DME (National Council on Disability 2016).¹⁴ Private health insurance coverage is limited for long-term services and supports, and private long-term care insurance is often unaffordable, contributing to the current state of affairs in which unpaid family caregivers provide the majority of these services (Colello 2022b; Reaves and Musumeci 2015).

Results

In June 2022, 15 percent of adults with disabilities reported that they or someone in their household delayed getting or did not obtain medical equipment or supplies they needed in the past 12 months. Some adults with disabilities also reported that they or a household member experienced difficulties obtaining home health care, personal assistance, and skilled therapy services.

Overall, 18 percent of adults in our sample reported one or more types of disabilities (table A.2).¹⁵ Figure 1 shows that adults with disabilities were about five times as likely as nondisabled adults to report delayed or unmet needs for medical equipment and supplies for themselves or a member of their household in the past 12 months (15 percent versus 3 percent). Some adults with disabilities also reported that they or someone living with them experienced delayed or unmet needs for physical or occupational therapy (12 percent), speech therapy (3 percent), home health care (5 percent), and personal assistance services (4 percent).

FIGURE 1
Share of Adults Ages 18 to 64 Reporting Delayed or Unmet Medical Equipment and Service Needs in the Past 12 Months for Themselves or Other Household Members, June 2022



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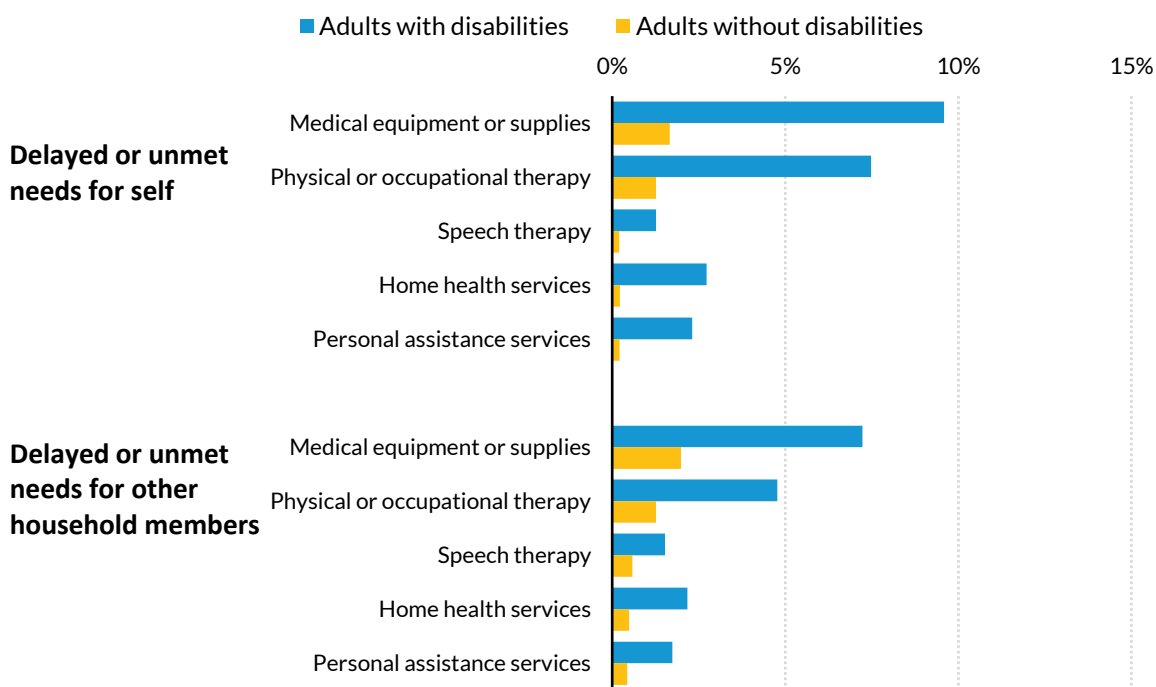
Source: Health Reform Monitoring Survey, June 2022.

Note: “Medical equipment or supplies” refers to medical equipment, devices, or aids and disposable medical supplies. “Home health services” refers to care at home from a nurse or other health professional. Examples of personal assistance services include help with bathing, dressing, eating, or shopping. All differences between adults with and without disabilities are statistically significant at the 0.01 level, using two-tailed tests.

Adults with disabilities were more likely than adults without disabilities to report delayed or unmet medical equipment and service needs, not only for themselves but also for other household members (figure 2). For instance, adults with disabilities were five times as likely as nondisabled adults to report delayed or unmet medical equipment or supply needs for themselves (10 percent versus 2 percent). Disabled adults were also more than three times as likely as nondisabled adults to report challenges

acquiring medical equipment and supplies for another person who was living in their household (7 percent versus 2 percent). This may partially reflect the greater likelihood that adults with disabilities live with another disabled household member,¹⁶ as well as their lower average household incomes and higher average out-of-pocket health care costs (Kennedy, Wood, and Frieden 2017; Vallas et al. 2022). Few nondisabled adults reported that they personally experienced challenges obtaining home health care, personal assistance services, and the skilled therapy services included in the survey (0 to 1 percent).

FIGURE 2
Share of Adults Ages 18 to 64 Reporting Delayed or Unmet Medical Equipment and Service Needs in the Past 12 Months for Themselves and for Other Household Members, June 2022



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Source: Health Reform Monitoring Survey, June 2022.

Note: “Medical equipment or supplies” refers to medical equipment, devices, or aids and disposable medical supplies. “Home health services” refers to care at home from a nurse or other health professional. Examples of personal assistance services include help with bathing, dressing, eating, or shopping. All differences between adults with and without disabilities are statistically significant at the 0.01 level, using two-tailed tests.

Table 1 shows that delayed and unmet needs were most common for adults with ambulatory, self-care, and independent living difficulties, and the groups in this table are not mutually exclusive (because people could report more than one type of disability). For instance, 25 percent of adults with self-care difficulties (e.g., difficulty dressing or bathing) reported challenges getting medical equipment or supplies for themselves, 11 percent had problems getting home health services, and 10 percent had problems getting personal assistance services.

TABLE 1

Share of Adults Ages 18 to 64 with Disabilities Reporting Delayed or Unmet Medical Equipment and Service Needs in the Past 12 Months for Themselves, by Type of Disability, June 2022

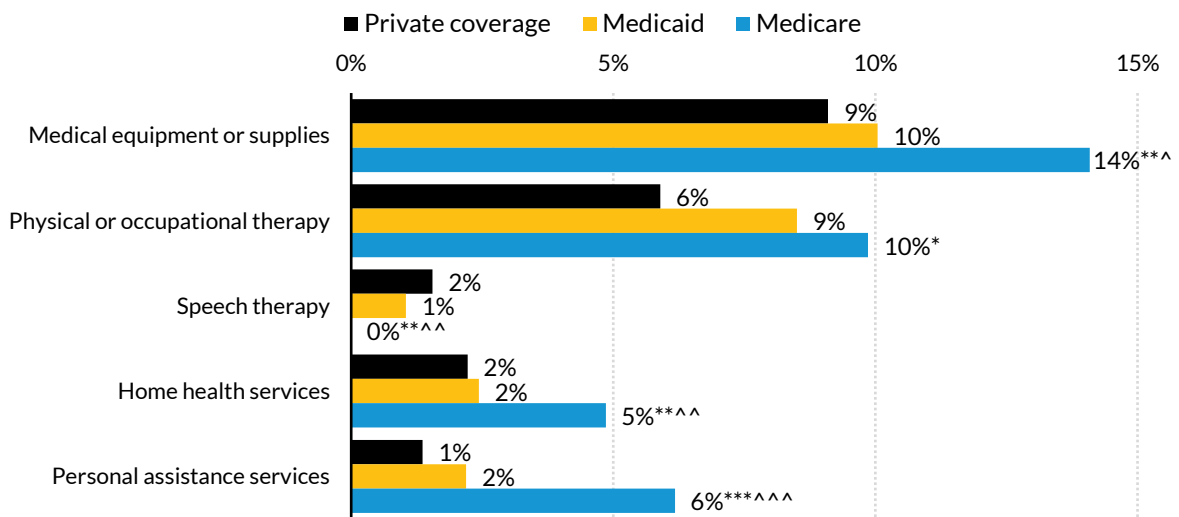
	Type of Disability						
	All adults with disabilities	Hearing difficulty	Vision difficulty	Cognitive difficulty	Ambulatory difficulty	Self-care difficulty	Independent living difficulty
Medical equipment or supplies	10%	13%	13%	10%	16%	25%	16%
Physical or occupational therapy	7%	8%	7%	9%	10%	17%	11%
Speech therapy	1%	1%	1%	2%	2%	3%	2%
Home health services	3%	3%	4%	3%	5%	11%	5%
Personal assistance services	2%	2%	4%	3%	5%	10%	5%
Sample size	1,963	350	319	1,043	915	339	711

Source: Health Reform Monitoring Survey, June 2022.

Note: Respondents could report more than one type of disability, and the categories shown in the table are not mutually exclusive. Types of disability are described in the appendix. “Medical equipment or supplies” refers to medical equipment, devices, or aids and disposable medical supplies. “Home health services” refers to care at home from a nurse or other health professional. Examples of personal assistance services include help with bathing, dressing, eating, or shopping.

These problems also varied by the types of health insurance coverage held by the respondent (figure 3). Disabled adults who were insured with Medicare for all months of the previous year (including those reporting both Medicare and Medicaid) were more likely to report delayed or unmet needs for medical equipment and supplies for themselves than those with private insurance (14 percent versus 9 percent) and more likely to report problems obtaining home health care and personal assistance services than those with Medicaid only or with private insurance. However, we cannot determine the extent to which variation by coverage type in these experiences reflects differences in the characteristics of the populations covered by each type of insurance or differences in the coverage itself. For instance, Medicare covers adults with disabilities under age 65 who are generally unable to work and have greater-than-average health care needs and access challenges (Cubanski, Neuman, and Damico 2016). We were also unable to provide estimates for adults with disabilities who were uninsured all year because of sample size limitations, though previous studies have found that lack of coverage is associated with a greater likelihood of disabled adults experiencing unmet health care needs (Sommers 2006).

FIGURE 3
Share of Adults Ages 18 to 64 with Disabilities Reporting Delayed or Unmet Medical Equipment and Service Needs in the Past 12 Months for Themselves, by Type of Health Insurance Coverage in the Past 12 Months, June 2022



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Source: Health Reform Monitoring Survey, June 2022.

Note: Coverage categories indicate the type of coverage held at the time of the survey among adults who reported that they were insured for all 12 months of the past year and had the same type of coverage all year. Adults with Medicare include those reporting both Medicare and Medicaid coverage. Adults with Medicaid exclude those who also had Medicare coverage. Estimates are not shown for adults who were uninsured because of sample size limitations (n = 111). “Medical equipment or supplies” refers to medical equipment, devices, or aids and disposable medical supplies. “Home health services” refers to care at home from a nurse or other health professional. Examples of personal assistance services include help with bathing, dressing, eating, or shopping.

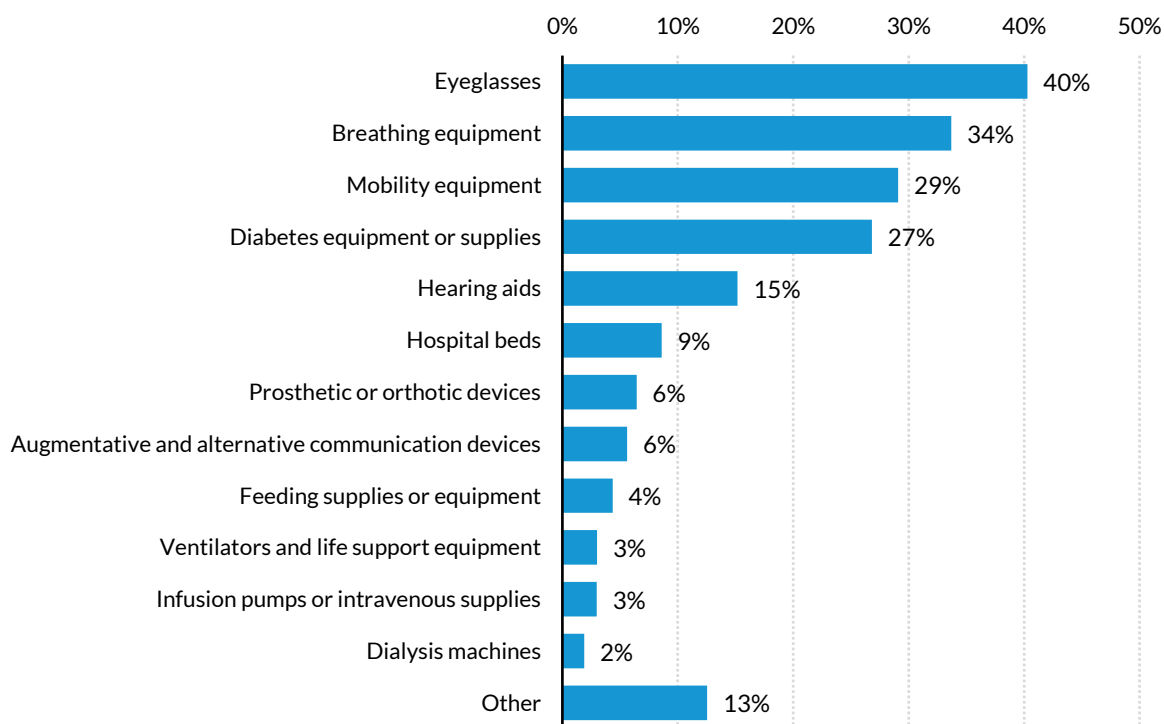
/ Estimate differs significantly from adults with private coverage at the 0.10/0.05/0.01 level, using two-tailed tests.

^^/^^/^^^ Estimate differs significantly from adults with Medicaid coverage at the 0.10/0.05/0.01 level, using two-tailed tests.

Among adults whose households delayed getting or did not get needed medical equipment or supplies, the most common types of equipment and supplies they had difficulty getting included breathing equipment, eyeglasses, diabetes equipment and supplies, mobility equipment, and hearing aids.

Figure 4 shows the types of medical equipment and supplies that adults with disabilities reported difficulty obtaining for themselves and for members of their households. Among households with delayed or unmet needs, more than one-third reported difficulty getting eyeglasses (40 percent) and breathing equipment such as nebulizers, continuous positive airway pressure devices, or oxygen equipment (34 percent). Nearly 3 in 10 reported problems getting mobility equipment (29 percent) and diabetes equipment and supplies (27 percent), and about 1 in 7 had problems getting hearing aids (15 percent).

FIGURE 4
Types of Medical Equipment and Supplies That Adults Ages 18 to 64 with Disabilities or Members of Their Households Delayed Getting or Did Not Get in the Past 12 Months, June 2022



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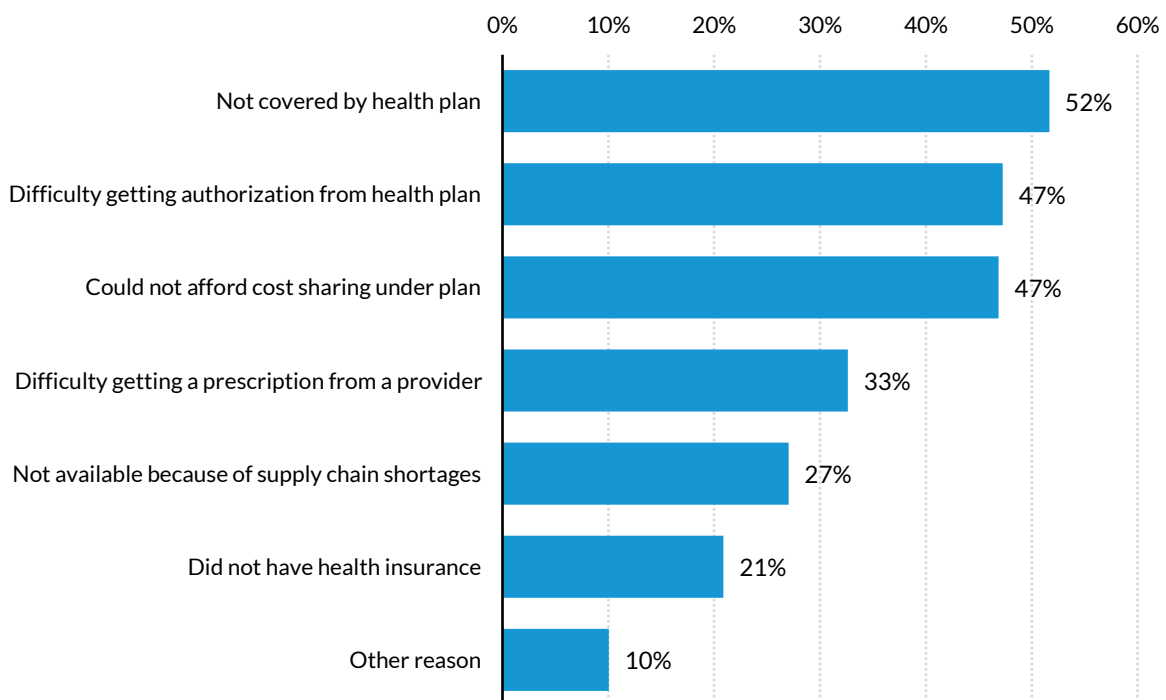
Source: Health Reform Monitoring Survey, June 2022.

Note: “Medical equipment and supplies” refers to medical equipment, devices, or aids and disposable medical supplies. Examples of breathing equipment that were listed in the survey questionnaire include nebulizers, continuous positive airway pressure devices, or oxygen equipment (other than ventilators). Examples of mobility equipment include wheelchairs, scooters, walkers, crutches, or canes. Examples of diabetes equipment or supplies include blood sugar monitors, lancets, test strips, diabetic shoes, or insulin pumps. Examples of feeding supplies or equipment include feeding tubes, formula, or total parenteral nutrition. Examples of ventilators and life support equipment include tracheostomy tubes, ventilator circuits, suction equipment, and other related supplies.

The most frequently reported reasons for delayed or unmet medical equipment and supply needs were related to difficulties using health insurance coverage.

Among adults with disabilities reporting that they or someone in their household delayed getting or did not get needed medical equipment and supplies, about half reported that the reasons for these difficulties were because their health plan did not cover the equipment or supplies (52 percent), they had difficulty getting authorization from their health plan (47 percent), or they could not afford the deductibles and other cost-sharing requirements under their plan (47 percent) (figure 5). About one-third reported difficulties obtaining a prescription from a health care provider, which could reflect either difficulty seeing a provider or providers' unwillingness to write a prescription (33 percent). More than 1 in 4 (27 percent) cited supply chain shortages, likely reflecting the disruptions caused or exacerbated by the COVID-19 pandemic. About 1 in 5 (21 percent) indicated that lack of health insurance was the reason they or someone living with them delayed getting or did not get equipment or supplies. This result suggests that for respondents or their household members who had periods without coverage in the previous year, lack of coverage remained a significant barrier to accessing needed medical equipment and supplies, especially considering that 82 and 84 percent of adults with and without disabilities had health insurance all year.

FIGURE 5
Reasons for Delayed and Unmet Needs for Medical Equipment and Supplies among Adults Ages 18 to 64 with Disabilities and Their Households in the Past 12 Months, June 2022



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Source: Health Reform Monitoring Survey, June 2022.

Note: "Medical equipment and supplies" refers to medical equipment, devices, or aids and disposable medical supplies. "Cost sharing" refers to deductibles, copayments, or coinsurance.

Delayed and unmet needs for medical equipment and supplies, skilled therapy services, home health care, and personal assistance added to a broader range of health care access challenges facing adults with disabilities.

In addition to challenges obtaining the medical equipment, supplies, and services described above, many adults with disabilities also reported forgoing other types of health care for themselves in the past year because of costs. Table 2 shows that many adults with disabilities had cost-related unmet needs for dental care (31 percent); prescription drugs (24 percent); specialist (21 percent) or primary care visits (16 percent); tests, treatment, or follow-up care (20 percent); mental health care or counseling (17 percent); and substance use treatment or counseling (4 percent), typically at more than twice the rate of nondisabled adults. Nearly half of adults with disabilities (46 percent) reported unmet needs for at least one of these services because of costs in the past year. Additional factors that caused unmet health care needs included difficulty getting health plan authorization for care, finding doctors accepting new patients or the person’s coverage type, and finding transportation. Adults with disabilities were more than twice as likely as nondisabled adults to have had problems paying family medical bills in the past year and to have past-due medical debt.

TABLE 2
Health Care Access and Affordability Challenges among Adults Ages 18 to 64, by Disability Status, June 2022

	Adults with disabilities	Adults without disabilities
Unmet needs for health care in the past 12 months because of costs	46%	22%
Dental care	31%	15%
Prescription drugs	24%	8%
Specialist visit	21%	8%
Tests, treatment, or follow-up care	20%	8%
General doctor visit	16%	8%
Mental health care or counseling	17%	5%
Treatment or counseling for alcohol or drug use	4%	1%
Unmet needs for health care in the past 12 months because of difficulties with a health plan, if ever insured	35%	14%
Getting authorization for care or prescription drugs	24%	8%
Finding a doctor accepting coverage type	21%	8%
Getting information from plan on providers in network, covered services, or cost of care	19%	7%
Unmet needs for health care in the past 12 months because of difficulties finding and getting to a provider	42%	18%
Getting an appointment as soon as needed	27%	12%
Finding a doctor accepting new patients	22%	9%
Finding transportation	17%	2%
Getting to a doctor’s office or clinic when it was open	15%	5%
Getting a telehealth visit	11%	3%
Problems paying family medical bills in the past 12 months	32%	13%
Family has past-due medical debt	29%	12%
Sample size	1,963	7,531

Source: Health Reform Monitoring Survey, June 2022.

Note: All differences between adults with and without disabilities are statistically significant at the 0.01 level, using two-tailed tests.

Discussion and Policy Implications

This brief finds that many adults with disabilities under age 65 reported that they or a member of their household experienced delayed or unmet needs for medical equipment and supplies, home health care, personal assistance services, or selected skilled therapy services between June 2021 and June 2022. Previous surveys of people with disabilities have found that unmet needs for these and other HCBS are associated with lower rates of employment, increased emergency room visits and hospitalizations, worse community living outcomes, injuries, medication mistakes, and going without groceries and personal items (Chong et al. 2022; Henry et al. 2011; Kietzman and Chen 2022; LaPlante et al. 2004; Mitra et al. 2011).

The diverse barriers experienced by adults with disabilities and members of their households suggest that increasing access to key services will require a multifaceted policy response that addresses gaps in health insurance coverage and improves patients' interactions with insurers, health care providers, and medical equipment suppliers. The following section, though not exhaustive, highlights selected policy implications of our findings.

Coverage Gaps

The most common reasons given for difficulty obtaining medical equipment and supplies were related to problems using health insurance, which reflects the fact that most people with disabilities were continuously insured throughout the year. However, lack of health insurance was nevertheless cited as a reason by 1 in 5 adults with disabilities whose households experienced delayed or unmet equipment or supply needs, suggesting that those who have intermittent or prolonged periods without coverage face significant access barriers.

The expiration of the Medicaid continuous coverage requirement that was in place during the COVID-19 public health emergency and the resumption of Medicaid renewal processes that were phased in beginning in April 2023 are expected to increase the number of people who are uninsured, including among those with disabilities (Buettgens and Green 2022). Already, state Medicaid agencies have disenrolled more than 15 million adults and children, a majority of whom lost coverage for procedural reasons (e.g., paperwork issues) rather than determinations of ineligibility.¹⁷ Increased outreach and assistance to reenroll people who were wrongfully terminated and help Medicaid-ineligible people enroll in insurance plans from other sources could mitigate the adverse impacts of eligibility redetermination processes on health care access. The authorization of other temporary flexibilities during the public health emergency, such as state actions to suspend premiums for Medicaid programs serving people with disabilities, can inform future efforts to reduce coverage gaps.¹⁸

Coverage Limits and Cost-Sharing Requirements

Limits on covered services and problems meeting cost-sharing requirements were among the most common challenges encountered by people with insurance. Health plan benefits vary widely across different types of insurance. For instance, Medicare offers more restrictive coverage for medical

equipment and home health services than Medicaid and requires deductibles and coinsurance for medical equipment, while traditional fee-for-service Medicare does not cover most vision and hearing services. Private insurance plans also have varying coverage limits and cost-sharing requirements for home health services, habilitative and rehabilitative therapies, and medical equipment and supplies. Increasing minimum coverage standards across insurance types (e.g., by updating essential health benefits in the individual and small group markets and requiring Medicare to cover medical equipment used outside the home), limiting cost-sharing requirements, and exempting selected services from those requirements could reduce affordability barriers for insured people with disabilities.

Insurance-Related Administrative Burdens

The administrative burden of getting insurance to pay for covered services affects people with all types of coverage and can be especially difficult to navigate for people with disabilities (Kyle and Frakt 2021). A recent study of a selected group of Medicaid managed care organizations found that they denied 1 in 8 prior authorization requests in 2019, often with limited state oversight, and some organizations denied more than 25 percent of requests (Grimm 2023). Similar concerns have been raised about denial of prior authorization requests in Medicare Advantage (Grimm 2022). Other analyses have found high levels of claim denials and/or processing delays in Medicaid and in health plans sold through the Health Insurance Marketplace (Gottlieb, Shapiro, and Dunn 2018; Pollitz, Lo, et al. 2023), and surveys have found that adults with private insurance are more likely than those with public coverage to report having had claims denied (Pollitz, Pestaina, et al. 2023).

Insurers may use narrow definitions of medical necessity or reject claims for DME, complex rehabilitation technology, and other services because of insufficient documentation submitted by providers (Lunsford et al. 2019). Approved coverage limits may not fully meet a beneficiary's needs. And extended delays in securing approval for new medical equipment or replacing or repairing existing equipment, as well as other services, can have significant adverse consequences for patients' health and well-being.

Recent federal efforts have sought to increase transparency and standards for prior authorization processes. For instance, in December 2022, the Centers for Medicare and Medicaid Services proposed a rule that would require insurers to report prior authorization metrics, include specific reasons for denials, and streamline the process and time frame for authorization decisions.¹⁹ Similarly, a final rule issued in April 2023 seeks to improve oversight of utilization management practices in Medicare Advantage.²⁰ These proposals recognize the importance of strengthening systems for monitoring access as a key step in driving program improvements in Medicaid and other federal health programs (MACPAC 2022a).

Coordination between Medicare and Medicaid for People with Dual Coverage

Navigating insurance coverage can be especially complex for people enrolled in multiple health plans, including those with dual coverage under Medicare and Medicaid. For instance, as the payer of last resort, Medicaid will typically only determine medical necessity and pay claims for DME after Medicare

has denied coverage. But because Medicare only processes claims for DME after equipment has been delivered, suppliers may be reluctant to furnish items until they have assurance that one of the programs will pay (Mayhew, Kouzoukas, and Engelhardt 2019; Montebello 2018). In response to this dilemma, state Medicaid programs have developed provisional prior authorization procedures, and the Centers for Medicare and Medicaid Services has issued guidance on how states can develop lists of items not covered by Medicare for which claims can be submitted directly to Medicaid without first obtaining a Medicare denial (Mayhew, Kouzoukas, and Engelhardt 2019). Advancing integrated care initiatives for people with dual coverage can further improve coordination for home health services and medical equipment covered by both programs (Verdier et al. 2014).²¹

Availability of and Access to Direct Care Workers and Other Providers

Even when services are covered, provider shortages and inadequate provider networks pose additional access barriers (Candon et al. 2018; MACPAC 2021; Rosenbaum 2014). In our survey, adults with disabilities were more than twice as likely as nondisabled adults to have unmet health care needs because of difficulties finding providers who accepted their health insurance coverage or who were accepting new patients (table 2). These challenges may partially explain reported instances of unmet needs for medical equipment and supplies because of difficulties obtaining a prescription from a provider. Moreover, the worsening shortage of direct care workers during the COVID-19 pandemic may have contributed to the difficulties experienced by respondents and their households in receiving home health and personal assistance services (Chidambaram and Burns 2022; Kreider and Werner 2023). Noncompetitive pay and benefits, difficult working conditions, and rising demand are among the factors contributing to shortages of home health aides, personal care aides, and other direct care workers (Kreider and Werner 2023; MACPAC 2022b).

A rule proposed in April 2023 seeks to increase the transparency of provider payment rates to assess their effects on access in Medicaid and the Children’s Health Insurance Program, establish standards for certain appointment wait times, disclose pay rates for direct care workers providing certain HCBS, and assess the quality and timeliness of access to HCBS.²² In an effort to address the direct care worker shortage, the proposed rule would also require at least 80 percent of Medicaid payments for home health and personal care services to be spent on compensation for those workers. The efficacy of this provision may depend on whether it is tied to a broader standard ensuring that direct care workers earn a living wage (Haley et al. 2023).

Insurance Coverage for Long-Term Services and Supports

Medicaid offers long-term services and supports that are generally not available through Medicare or private insurance. Access may vary, however, based on the types of services needed and state program rules. People seeking personal assistance services and other HCBS through Medicaid must meet functional criteria (often requiring an institutional level of care) as well as income and asset limits that may require spending down savings or applying income toward the cost of care (Colello and Morton 2019; Musumeci, Chidambaram, and O’Malley Watts 2019).²³ In addition, because most HCBS are

covered at state option, eligibility criteria and covered benefits vary across states, and states provide most HCBS through waiver authorities that allow them to offer services to specific populations, cap enrollment, and establish waiting lists (Musumeci, O'Malley Watts, and Chidambaram 2020).

Temporary authorities during the public health emergency and funding from the American Rescue Plan Act enabled states to expand eligibility and covered services, add waiver slots or reduce waiting lists, remove prior authorization requirements, increase payment rates to direct care workers, and allow family members to be paid providers (Burns, Mohamed, and Rudowitz 2023; Sullivan 2021). States are discontinuing some of these changes following the expiration of the public health emergency authorities (Burns, Mohamed, and O'Malley Watts 2023). Going forward, policies to increase funding and make HCBS a mandatory Medicaid benefit could help overcome the program's institutional bias (in which nursing home care is mandatory, but most HCBS are optional) and reduce gaps in access under the current patchwork of state policies (Haley et al. 2023; Musumeci 2021; O'Malley Watts, Musumeci, and Chidambaram 2021). Adding HCBS benefits to Medicare would extend services to people who do not meet the stringent financial criteria for Medicaid (Mitra et al. 2022).

Additional Policies

The health insurance reforms described above would address many apparent access barriers, but other policies would be needed to fully address these barriers for people with disabilities. For instance, the pandemic raised awareness of the need to address vulnerabilities in the supply chain for medical equipment and supplies and the inequities that left disabled people without medical supplies for home use because they were prioritized for hospitals (Lund and Ayers 2022; Monden et al. 2021). Efforts to reduce instances of unfair treatment in health care settings, improve the accessibility of medical offices, and increase transportation availability are also important strategies for improving access (Gonzalez et al. 2023; Lagu et al. 2022; Smith et al. 2023). Further research is needed to assess the nature of the barriers that people with disabilities experience and determine which have the greatest impact on their ability to receive needed equipment, supplies, and services. The recent National Institutes of Health designation of people with disabilities as a health disparities population could help advance this research objective.²⁴

Appendix: Data and Methods

Survey Data

This analysis draws on data from the June 2022 round of the Urban Institute's Health Reform Monitoring Survey (HRMS), a nationally representative internet-based survey of adults ages 18 to 64 that provides timely information on health insurance coverage, health care access and affordability, and other health topics. For each round of the HRMS, a stratified random sample of nonelderly adults is drawn from the Ipsos KnowledgePanel, the nation's largest probability-based online research panel. Members of the panel are recruited from an address-based sampling frame covering approximately 97

percent of US households, including those without internet access. If needed, panel members are given internet access and web-enabled devices to facilitate their participation.

The June 2022 round of the HRMS had a sample size of 9,494 adults, including oversamples of adults in low- and moderate-income households, nonwhite and Hispanic/Latinx adults, and young adults. Survey weights adjust for unequal selection probabilities and are poststratified to the characteristics of the national nonelderly adult population based on benchmarks from the Current Population Survey and the American Community Survey (ACS). Participants can take the survey in English or Spanish, and the survey takes a median of 15 minutes to complete. The margin of sampling error, including the design effect, for the full sample of adults in the 2022 survey is plus or minus 1.2 percentage points for a 50 percent statistic at the 95 percent confidence level.

Key Measures and Analysis

We assessed disability status using six questions that are based on data collection standards established by the US Department of Health and Human Services.²⁵ These questions are used in the ACS and several other federal surveys asking about disability. Participants were asked the following questions about difficulties they may have doing certain activities because of a health problem:

- Are you deaf or do you have serious difficulty hearing?
- Are you blind or do you have serious difficulty seeing, even when wearing glasses?
- Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
- Do you have serious difficulty walking or climbing stairs?
- Do you have difficulty dressing or bathing?
- Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

Adults responding yes to one or more questions were identified as having a disability.

Questions on delayed and unmet service needs were developed in collaboration with members of a Community Advisory Board who provided diverse perspectives based on their lived experience as people with disabilities, caregivers of people with disabilities, and disability advocates. All survey respondents were asked the following question:

- In the past 12 months, was there a time when you or someone living with you delayed getting or did not get any of the following types of equipment, supplies, or services you or they needed?
 - » Medical equipment, devices, or aids (including getting new equipment, devices, or aids or repairing existing equipment, devices, or aids)
 - » Disposable medical supplies
 - » Physical or occupational therapy

- » Speech therapy
- » Care at home from a nurse or other health professional
- » Personal assistance services (such as help with bathing, dressing, eating or shopping)

For some of these categories, we drew on wording used in previous federal surveys, such as the Consumer Assessments of Healthcare Providers and Systems (CAHPS) Mobility Impairments Supplement and the National Health Interview Survey. Respondents who reported that they or a household member delayed or did not get needed medical equipment, supplies, or services were asked follow-up questions about who in the household delayed getting or was unable to get each service, the types of medical equipment or supplies they had difficulty getting, and the reasons for those difficulties. The full questionnaire is available on the Urban Institute website.²⁶

We compared the prevalence of delayed or unmet needs among adults with and without disabilities. When examining differences in delayed or unmet needs by type of disability and health insurance coverage, we focus only on the type of disability and health insurance coverage of the respondent since we do not know the disability or health insurance status of other household members.

Limitations

Like all surveys, the HRMS has limitations, including those related to coverage and nonresponse error. Though the survey weights mitigate nonresponse bias, the sampling and survey design excludes or underrepresents certain groups of adults, including people with disabilities. For instance, the panel does not include adults with disabilities living in institutional settings, and our sample includes only adults under age 65, though respondents may be living with adults ages 65 and older or children under 18. In addition, given the internet-based survey mode, people with certain visual, cognitive, and physical disabilities may be underrepresented. The HRMS questions on disability status, which draw on US Department of Health and Human Services data collection standards, also do not fully capture the population of adults with disabilities, such as those related to difficulties with communication and mental health (Hall et al. 2022). We also did not collect information on the disabilities and health insurance coverage of other members of the respondents' households, limiting our ability to examine differences in delayed and unmet needs by disability status and coverage status. Finally, the June 2022 HRMS was fielded during a period of unprecedented disruption to the health care system, as well as emergency policy responses to protect access to coverage and health care. We, therefore, do not know the extent to which our findings can be generalized to a less volatile economic and policy environment.

TABLE A.1

Health Insurance Coverage among Adults Ages 18 to 64, by Disability Status, June 2022

	Adults with disabilities	Adults without disabilities	
Health insurance coverage at time of survey			
Medicare	16%	2%	***
Medicaid/CHIP	26%	10%	***
Medicare and Medicaid	9%	1%	***
Employer-sponsored coverage	40%	67%	***
Private nongroup coverage	7%	8%	**
Unspecified coverage	1%	2%	
Uninsured	9%	11%	
Health insurance coverage in past year			
Insured all months of the year	82%	84%	
Insured with the same type of coverage all year	76%	78%	
Uninsured some months but not every month	12%	7%	***
Uninsured all months of the year	6%	8%	*
Sample size	1,963	7,531	

Source: Health Reform Monitoring Survey, June 2022.

Note: CHIP is the Children's Health Insurance Program. Because respondents could report more than one type of health insurance coverage at the time of the survey, we use the following hierarchy of responses to assign respondents to mutually exclusive coverage-type categories: employer-sponsored coverage; Medicare; Medicaid; private nongroup coverage; unspecified coverage; uninsured.

*/**/** Estimate differs significantly from adults with disabilities at the 0.10/0.05/0.01 level, using two-tailed tests.

TABLE A.2

Share of Adults Ages 18 to 64 Reporting a Disability in the June 2022 Health Reform Monitoring Survey and 2021 American Community Survey

	Among all adults		Among adults with disabilities	
	2022 HRMS	2021 ACS	2022 HRMS	2021 ACS
Any type of disability	18%	11%	100%	100%
Hearing difficulty	3%	2%	19%	17%
Vision difficulty	3%	2%	20%	17%
Cognitive difficulty	10%	5%	45%	56%
Ambulatory difficulty	7%	4%	42%	38%
Self-care difficulty	2%	2%	15%	14%
Independent living difficulty	6%	4%	35%	36%
Sample size	9,494	1,790,396	1,963	194,110

Source: Health Reform Monitoring Survey, June 2022, and American Community Survey, 2021.

Notes

- ¹ People have different preferences when referring to their disabilities. Some see their disability as an essential part of who they are and prefer to be identified with their disability first—called identity-first language—but others prefer person-first language. In recognition of the variation in preferences, for this study, we use “people with disabilities” and “disabled people” interchangeably.
- ² In this brief, we use the term “home health care” primarily in reference to skilled health care services (consistent with our survey question asking about “care at home from a nurse or other health professional”) and the term “personal assistance services” in reference to help with personal care and household tasks such as bathing, dressing, eating, or shopping. Home health may include services such as skilled nursing care and home health aide services, though the latter may also provide some personal assistance services. In addition, Medicare and other federal programs use the term “home health” to refer to a broader set of benefits provided in the home, including medical equipment and supplies and skilled therapy services. Survey responses may therefore reflect overlap in how these terms are interpreted.
- ³ In this brief, “skilled therapy services” refers to services such as physical therapy, occupational therapy, and speech language pathology that were included in the survey. However, the survey did not include the full spectrum of skilled therapy services, such as respiratory therapy.
- ⁴ Suzanne Schwartz and Tammy R. Beckham, “A Key Step to Build Resilience in the Medical Device Supply Chain,” *Health Affairs Forefront*, May 22, 2023, <https://www.healthaffairs.org/content/forefront/key-step-build-resilience-medical-device-supply-chain>. Katie Shepherd, “The Pandemic Threatens Their Lives, Even Though They Don’t Have Covid,” *Washington Post*, March 29, 2022, <https://www.washingtonpost.com/health/2022/03/29/pandemic-chronically-ill-disabled-supply-shortage/>. JonChristopher Collins, “For the Disabled Community, the Pandemic Has Had Hidden Costs,” *Huffington Post*, March 4, 2022, https://www.huffpost.com/entry/disability-supply-chain-pandemic_n_6219514ee4b0afc668c04e8c. Kate Ruder, “Refurbished Walkers and Wheelchairs Fill Gaps Created by Supply Chain Problems,” *KFF Health News*, April 11, 2022, <https://kffhealthnews.org/news/article/loan-closets-medical-equipment-shortage-supply-chain-problem/>.
- ⁵ Nonelderly adults with end-stage renal disease or amyotrophic lateral sclerosis can also qualify for Medicare without the two-year waiting period. Social Security Disability Insurance participants may continue receiving Medicare benefits during and after a trial work period. See “Medicare Coverage for People with Disabilities,” Center for Medicare Advocacy, accessed November 20, 2023, <https://medicareadvocacy.org/medicare-info/medicare-coverage-for-people-with-disabilities/>.
- ⁶ “Home Health Services,” Centers for Medicare and Medicaid Services, accessed August 1, 2023, <https://www.medicare.gov/coverage/home-health-services>.
- ⁷ “Medicare and Home Health Care,” Centers for Medicare and Medicaid Services, accessed August 1, 2023.
- ⁸ “Medicare and Home Health Care,” Centers for Medicare and Medicaid Services.
- ⁹ “Medicare Coverage of Durable Medical Equipment and Other Devices,” Centers for Medicare and Medicaid Services, August 2021.
- ¹⁰ “Long-term services and supports” refers to “a broad range of health and health-related services and supports needed by individuals who lack the capacity for self-care due to a physical, cognitive, or mental disability or condition” (Colello 2021, 1). These services may be provided in institutional settings or in home- and community-based settings for an extended period of time. Long-term services and supports provide assistance to people who require help with activities of daily living such as eating, bathing, dressing, using the toilet, or getting out of bed or a chair, as well as instrumental activities of daily living such as cleaning, preparing meals, shopping, or managing money.
- ¹¹ Home health services are a mandatory benefit for categorically eligible individuals ages 21 and older who are entitled to nursing facility coverage under a state’s Medicaid plan, and for categorically eligible individuals under 21 if the state plan provides nursing facility services to that group. Unlike under Medicare, these services are not contingent on the need for skilled care or limited to people who are considered homebound (Colello 2022a).

- ¹² “Fact Sheet #10: Medical Supplies Benefits,” National Disability Navigator Resource Collaborative, 2014.
- ¹³ For instance, all state essential health benefits benchmark plans cover home health care, but these benchmark plans do not have uniform coverage limits and exclusions (Uberoi 2015).
- ¹⁴ Elissa Suh, “Will My Insurance Cover Durable Medical Equipment (DME)?” Policygenius, September 11, 2019, <https://www.policygenius.com/health-insurance/dme-durable-medical-equipment/>.
- ¹⁵ The share of HRMS respondents reporting disabilities is higher than the share reported in the 2021 American Community Survey (ACS) for a comparable sample (18 percent versus 11 percent; table A.2), with the largest difference found in the share reporting a cognitive difficulty (i.e., serious difficulty concentrating, remembering, or making decisions). This could partially reflect the effects of long COVID, as reported cognitive impairments have increased during the COVID-19 pandemic. See Brendan M. Price, “Long COVID, Cognitive Impairment, and the Stalled Decline in Disability Rates,” *FEDS Notes*, August 5, 2022, <https://www.federalreserve.gov/econres/notes/feds-notes/long-covid-cognitive-impairment-and-the-stalled-decline-in-disability-rates-20220805.html>. In addition, estimates of the prevalence of disability vary across surveys, which may be related to differences in sampling design and survey administration (Gettens, Lei, and Henry 2015; Mitra et al. 2022). Overall, patterns in the types of disabilities reported among adults with any disability are consistent between the HRMS and ACS.
- ¹⁶ According to our analysis of public use microdata from the 2021 ACS, 36 percent of nonelderly adults with disabilities live with one or more disabled household members, compared with 15 percent for people without disabilities (among adults not living in group quarters).
- ¹⁷ “Medicaid Unwinding and Enrollment Tracker,” KFF, accessed January 23, 2024, <https://www.kff.org/report-section/medicaid-enrollment-and-unwinding-tracker-overview/>.
- ¹⁸ “Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19,” KFF, July 1, 2021, accessed January 23, 2024, <https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>.
- ¹⁹ “CMS Proposes Rule to Expand Access to Health Information and Improve the Prior Authorization Process,” press release, Centers for Medicare and Medicaid Services, December 6, 2022, <https://www.cms.gov/newsroom/press-releases/cms-proposes-rule-expand-access-health-information-and-improve-prior-authorization-process>.
- ²⁰ “2024 Medicare Advantage and Part D Final Rule (CMS-4201-F),” Centers for Medicare and Medicaid Services, April 5, 2023, <https://www.cms.gov/newsroom/fact-sheets/2024-medicare-advantage-and-part-d-final-rule-cms-4201-f>.
- ²¹ Ann Hwang and Laura M. Keohane, “From Natural Disasters to Bureaucratic Ordeals, Dual-Eligible Beneficiaries Face Hurdles in Accessing Durable Medical Equipment,” *Health Affairs Forefront*, September 27, 2023, <https://www.healthaffairs.org/content/forefront/natural-disasters-bureaucratic-ordeals-dual-eligible-beneficiaries-face-hurdles>.
- ²² “The Biden-Harris Administration Proposes New Standards to Help Ensure Access to Quality Health Care in Medicaid and CHIP,” press release, Centers for Medicare and Medicaid Services, April 27, 2023, <https://www.cms.gov/newsroom/press-releases/biden-harris-administration-proposes-new-standards-help-ensure-access-quality-health-care-medicaid>.
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- ²⁴ “NIH Designates People with Disabilities as a Population with Health Disparities,” press release, National Institutes of Health, September 26, 2023, <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>.
- ²⁵ “HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status,” Office of the Assistant Secretary for Planning and Evaluation, October 30, 2011, <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>.
- ²⁶ “Health Reform Monitoring Survey,” Urban Institute, accessed August 1, 2023, <https://www.urban.org/policy-centers/health-policy-center/projects/health-reform-monitoring-survey>.

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