



Insights from Nonelderly Adults with Disabilities on Difficulties Obtaining Home- and Community-Based Services and Other Health Care

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Many people with disabilities¹ require home health care, personal assistance, physical or occupational therapy, medical equipment and supplies, and other home- and community-based services (HCBS) to live independently in their communities and meet complex medical needs.² Despite shifts in public funding for long-term services and supports (LTSS) toward home and community settings over time, barriers to accessing HCBS have not only persisted but also worsened dramatically in the wake of the COVID-19 pandemic (Chong et al. 2022; Goddard et al. 2022; Sage, Standley, and Ipsen 2022; Schwartz et al. 2021).³ These barriers intersect with and magnify other challenges people with disabilities face when navigating the health care system (Akobirshoev et al. 2022; Gonzalez et al. 2023; Kennedy, Geneva Wood, and Frieden 2017; NCD 2009). Understanding the experiences of disabled people who face difficulties obtaining needed services is critical for developing policies that equitably center people's needs, improve access to affordable care, and promote their health and well-being. However, national data on nonelderly disabled adults' experiences are limited.

In this brief, we use a mixed-methods approach to examine delayed and unmet needs for selected HCBS and other health care services among adults ages 18 to 64 with disabilities and members of their households. Our analysis draws on nationally representative data from the Urban Institute's December 2022 Well-Being and Basic Needs Survey, as well as in-depth, semistructured telephone interviews conducted in May and June 2023 with 25 respondents with self-identified disabilities who had reported delaying or forgoing needed services in the 12 months before the survey. The interviews explored the

types of services people had trouble getting, the reasons they had difficulty obtaining services, and how these difficulties affected their lives. Members of a community advisory board convened by the Urban Institute⁴ with lived experience with disabilities and professional experience as advocates for people with disabilities helped guide the research approach for both the survey and interviews, as well as an earlier survey study that informed the analysis (Karpman, Morriss, and Gonzalez 2024). Our key findings include the following:

- **Nonelderly adults with disabilities reported challenges getting a variety of services, equipment, and supplies.**
 - » In December 2022, many survey respondents with disabilities reported they delayed getting or did not get needed medical equipment or supplies (18 percent), physical therapy and other skilled therapy services (17 percent), home health care (6 percent), and personal assistance services (6 percent) in the past year.
 - » Adults who participated in the in-depth follow-up interviews also described difficulty accessing home adaptations (such as grab bars and wheelchair ramps) and transportation.
 - » Lack of access to transportation and personal assistance compounded problems getting other health care.

- **Insurance barriers were a common reason for delaying or forgoing needed services.**
 - » Uninsured interview participants reported especially severe challenges accessing care.
 - » Among those with health insurance coverage, interviewees were often told that the services or equipment they needed were not covered or only partially covered by their health plans. Many faced barriers related to prior authorization processes, claim denials, and delayed reimbursement for covered benefits.
 - » Narrow provider networks and transitions in coverage causing changes in those networks contributed to disruptions in care.
 - » Participants struggled to meet stringent eligibility criteria for LTSS in Medicaid as well as federal disability insurance programs that are often used to determine eligibility for public coverage.

- **People faced additional challenges interacting with health care providers, home care agencies, and medical equipment suppliers.**
 - » Several participants had problems getting providers to write prescriptions, provide documentation needed for insurance reimbursement, or take their concerns seriously.
 - » Provider shortages, supply chain issues, and equipment recalls presented additional access barriers.

- **Delayed and unmet service needs had harmful effects on the health and well-being of adults and their families.**
 - » Health impacts of going without needed supports included injuries, worsening physical conditions, chronic pain, and poor mental health.

- » A lack of personal assistance made it difficult or impossible for some people to carry out daily activities such as dressing, bathing, cleaning, and shopping.
- » Difficulty getting services also affected adults' ability to work and participate in social activities.
- » Lost work and out-of-pocket expenses strained household budgets, resulting in debt and trouble meeting basic needs.
- » Family caregivers who had limited support experienced increased stress and isolation, worse health, and job loss.

Though interview participants cited a wide range of challenges, they also shared some positive experiences and suggestions for facilitating access to services. Some highlighted the value of having a health care provider who advocated on their behalf, and most emphasized the critical need for insurance reforms to improve coverage and make the reimbursement process less burdensome. Engaging the voices of people with disabilities in shaping policy and practice changes will be essential for building more responsive and equitable health care and social service systems.

Background

What Are HCBS?

HCBS consist of a range of health and social services that assist people with daily activities and enable them to live independently in their communities (Colello 2022). Our survey analysis and interviews focused on a subset of these services: home health care (i.e., from a nurse or other health professional);⁵ personal assistance services that provide help with activities of daily living such as bathing, dressing, or eating and instrumental activities of daily living such as housework and shopping; physical, occupational, speech, and respiratory therapies (hereafter referred to as skilled therapies); and medical equipment and supplies. Examples of other HCBS that were not included in our survey are adult day health, case management, employment services, health promotion, home adaptations, home-delivered meals, legal and financial assistance, nonmedical transportation, and respite services for family caregivers (Colello 2022; Mitra et al. 2011; Peebles and Bohl 2014).

What Roles Do Medicaid and Other Sources of Insurance Play in Facilitating Access to HCBS for Nonelderly Adults with Disabilities?

Medicaid provides health insurance coverage to more than one-third of working-age adults with disabilities (Creedon et al. 2021). It is also the nation's largest source of funding for LTSS, an increasing share of which has shifted from nursing facilities and other institutional settings toward HCBS in recent decades (Murray et al. 2021).⁶ Several factors have driven this rebalancing trend, including the Supreme Court's 1999 *Olmstead* decision, which affirmed the rights of people with disabilities under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act to receive services in the most integrated setting appropriate to their needs (MACPAC 2019; Musumeci and Claypool 2014).⁷

Home health care is the only mandatory Medicaid HCBS state plan benefit and must include nursing services; home health aide services; and medical supplies, equipment, and appliances (Colello 2022).⁸ Other HCBS are optional, and states primarily offer them through waiver authorities allowing states to establish enrollment caps and waiting lists and target services toward specific groups of beneficiaries rather than all those who qualify on a statewide basis (O'Malley Watts, Musumeci, and Chidambaram 2020). Coverage of optional services and eligibility criteria vary widely across states and Medicaid authorities through which HCBS are offered (MACPAC 2023; Musumeci, O'Malley Watts, and Chidambaram 2020). In April 2023, the Centers for Medicare and Medicaid Services (CMS) proposed a rule intended to improve access to and quality of Medicaid HCBS, such as by standardizing state reporting requirements and enhancing direct care workers' wages (see the "Discussion" section for further detail).⁹

Not all adults with disabilities who need HCBS meet the stringent financial and functional criteria to access these services through Medicaid. Medicare and private insurance provide limited funding for LTSS and more restrictive coverage than Medicaid for certain services like home health and durable medical equipment.¹⁰ Some adults are dually eligible for Medicare and Medicaid, and these people often face confusion and difficulty when seeking reimbursement for services covered by both programs (MedPAC/MACPAC 2022; Verdier et al. 2014). In addition, nearly 1 in 5 nonelderly adults with disabilities lack health insurance for some or all months of the year (Creedon et al. 2021).

How Do Federal Disability Insurance and Medicaid Program Rules Affect Access to Coverage and Care?

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are federal programs that provide cash assistance to people with limited ability to work because of their disabilities and serve as key pathways to public health insurance coverage. For both programs, adults must be unable to engage in "substantial gainful activity" (i.e., earnings exceeding about \$1,470 per month in 2023) because of a chronic health condition and must navigate complex disability determination processes to qualify for benefits (Smalligan and Boyens 2019).¹¹ SSI has a maximum monthly benefit of about 74 percent of the federal poverty level for an individual (82 percent for a married couple) and an asset limit of \$2,000 for an individual (\$3,000 for a couple; Colello and Morton 2019).

Disabled adults who qualify for SSDI can receive Medicare after a two-year waiting period.¹² SSI recipients automatically qualify for Medicaid in most states, with eight states using more restrictive eligibility criteria that were in place at the time the SSI program was created (MACPAC 2023).¹³ These SSI-related pathways are the only mandatory pathways for categorical eligibility for Medicaid based on disability status. States have also adopted various optional eligibility pathways that allow for higher income or asset limits for people with disabilities, including those seeking LTSS through Medicaid (MACPAC 2023).¹⁴ In addition to meeting financial criteria under each eligibility pathway, enrollees must further meet state-defined level-of-care criteria to qualify for Medicaid LTSS (Colello and Morton 2019).

What Do We Know about Nonelderly Adults' Unmet Needs for HCBS?

Though federal surveys have documented access barriers for HCBS among older adults (Casado, van Vulpen, and Davis 2011; Fabius et al. 2021; Freedman and Spillman 2014), nationally representative data for adults with disabilities under age 65 have been limited (Chong et al. 2022; Mitra et al. 2011).¹⁵ The Urban Institute's June 2022 Health Reform Monitoring Survey found greater levels of delayed or unmet needs for medical equipment and other health services and supports within households of adults ages 18 to 64 with disabilities compared with households of adults without disabilities (Karpman, Morriss, and Gonzalez 2024). Other recent surveys have found more than half of disabled adults of all ages needing personal assistance delayed or went without these services during the first year of the COVID-19 pandemic, and many reported unmet needs before the pandemic (Goddard, Hall, and Kurth 2022; Sage, Standley, and Ipsen 2022). Earlier federal survey research, surveys of adults with disabilities in selected states and/or Medicaid programs, and qualitative studies have found HCBS access barriers are associated with negative outcomes related to employment, physical and mental health, personal care, and participation in community life (Chong et al. 2022; Henry et al. 2011; Kaye, Harrington, and LaPlante 2010; LaPlante et al. 2004; Mitra et al. 2011; Sage, Standley, and Ipsen 2022).¹⁶

Our study builds on this research by providing timely national estimates of delayed and unmet needs for selected HCBS among a representative household sample of disabled adults ages 18 to 64, complemented by qualitative data from in-depth follow-up interviews. The data and methods are described in this brief's appendix.

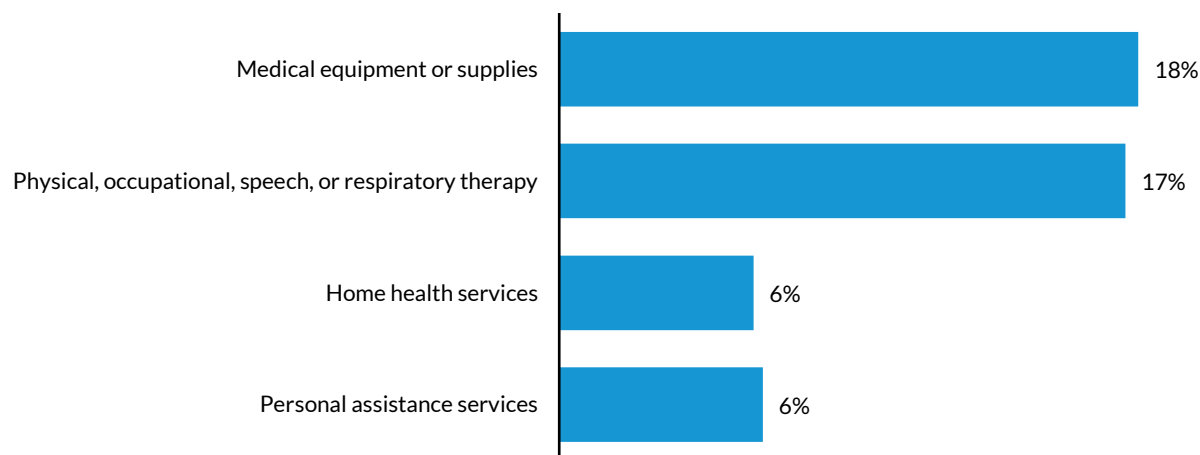
Findings

What Types of Services Did Adults with Disabilities Have Difficulty Getting?

In December 2022, nearly 1 in 5 nonelderly adults with disabilities (18 percent) reported that they delayed getting or did not get medical equipment or disposable medical supplies they needed in the past 12 months (figure 1). A similar share (17 percent) reported difficulty getting one or more of the skilled therapy services examined in the survey. Six percent reported delayed or unmet needs for home health care, and 6 percent reported problems getting personal assistance services, such as help with bathing, dressing, eating, or shopping.¹⁷

FIGURE 1

Share of Adults Ages 18 to 64 with Disabilities Reporting Delayed or Unmet Needs for Selected Services in the Past 12 Months, December 2022



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Source: Well-Being and Basic Needs Survey, December 2022.

Notes: "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.

Adults with self-care difficulties (i.e., difficulty dressing or bathing) were most likely to report delayed or unmet needs: 40 percent of these adults had problems getting medical equipment or supplies, 36 percent had problems getting skilled therapy services, and more than 1 in 5 had delayed or unmet needs for home health care (22 percent) or personal assistance (26 percent; data not shown).

MEDICAL EQUIPMENT AND SUPPLIES

In follow-up interviews with disabled adults who had reported delaying or forgoing needed services, nearly all interviewees said they or their family members had difficulty obtaining, repairing, or replacing medical equipment or getting medical supplies. They mentioned a broad range of items that included mobility equipment such as canes, walkers, scooters, and wheelchairs; diabetes equipment and supplies; knee and back braces; CPAP (continuous positive airway pressure) machines and other breathing equipment; tracheostomy supplies; nebulizers; hearing aids; leg compression pumps; and enteral feeding supplies. Some interviewees described having to rely on equipment that did not fully meet their needs, including a woman who was unable to get coverage for a walker without wheels that would have helped her posture after she was told it would not be covered because she requested it within five years of getting reimbursed for a rolling walker. Others described potentially life-threatening delays. For instance, one woman described a frightening experience getting tracheostomy supplies for her husband during a period when both of them were uninsured:

The suction tube—we had to wait. It was just a couple of weeks that we had to wait for it...That was just very scary. It actually caused him to have to go to the emergency room. He almost lost his life on what they call a mucus plug because of...the lack of suction.

HOME HEALTH CARE AND PERSONAL ASSISTANCE SERVICES

Some interview participants relayed how greater access to care at home from a nurse or home health aide would reduce caregiving demands for family members. Additionally, nearly half described unmet needs for help with daily activities such as bathing, dressing, preparing meals, cleaning, doing laundry, and running errands. In several cases, people were told they did not qualify for assistance under their insurance coverage, but adults with Medicaid who were eligible for assistance also faced hurdles. Several interview participants were unsure whether they qualified for assistance. One woman who lived alone described the challenges she faced during a period when she needed in-home help:

For two months, I wasn't able to clean my apartment or do anything that I was supposed to. Every little thing that I would do was really, really hard. I ended up losing my apartment...I needed somebody in there with me that could monitor and see what I was going through.

SKILLED THERAPIES

Several interview participants mentioned problems getting physical therapy or other skilled therapy services, citing costs and coverage limits. For instance, one interviewee could not afford speech therapy services for a condition that causes difficulty swallowing and breathing. She said that each session would have cost her \$100, and “there’s no way somebody with my condition, living on a fixed income, could afford that.” Another woman who was caring for her disabled husband said he could not get speech therapy and therapy for lymphedema “without paying an ungodly amount of money that we can’t afford.”

HOME MODIFICATIONS

In addition to the types of services included in the survey (shown in figure 1), a few interview participants cited unmet needs for home modifications that would have made their homes safer and improved their ability to care for themselves. Examples included grab bars and other items that would prevent additional injuries caused by falls. A woman with mobility difficulties described facing an extended wait for Medicaid authorization as she tried to prove it was necessary to have a ramp to her home installed.

TRANSPORTATION

One of the most common problems interview participants discussed was finding transportation to medical appointments and pharmacies. Almost half reported having limited access to transportation, which compounded other difficulties they faced in getting needed health care. For instance, one woman who did not drive explained that lack of transportation limited her choice of local pharmacies and ability to get a blood glucose meter, which her nearest pharmacy did not have in stock. Interviewees discussed frustrating experiences using transportation services covered by Medicaid, even though nonemergency medical transportation is a mandatory benefit for those with full Medicaid coverage (MACPAC 2021). Several people recounted problems coordinating with paratransit and ride-sharing services, brokers, and their insurance plans. For instance, a man who was insured with Medicare and Medicaid was unable to see a dentist because of problems using transportation benefits:

I scheduled several different rides, and nobody ever showed up...they couldn't get anybody scheduled to come out here to get me. I tried half a dozen times. Finally, I had to drop that option because I knew nobody's going to come get me.

This person experienced significant hassle because of the intermediary role his insurance provider played in the process of scheduling rides. He recounted having to provide the same information multiple times to different representatives of his insurer and the transportation company and that “by the time you get it done, you’ve spent 45 minutes on the phone trying to set up an appointment for a ride.”

A few participants had to ensure home health aides were available to accompany them or their disabled family members to appointments and that appropriate transportation was available, such as vehicles that could transport a wheelchair. Interviewees also faced limited choice of providers because of covered mileage limits.

PRESCRIPTION DRUGS AND OTHER HEALTH CARE

More than half of interviewees reported problems getting other types of care, including prescription drugs, lab tests, or specialist visits. Many of them went without medications they needed because of out-of-pocket costs, step therapy requirements,¹⁸ insurance denials, and difficulty getting prescriptions from doctors. Participants were also unable to find specialists in their insurance plans’ provider networks, resulting in unmet needs for medications.

What Were the Reasons for Delayed and Unmet Service Needs?

The most commonly reported reasons for difficulty getting services and health care were related to issues using health insurance. This finding was consistent with findings from a previous analysis showing that problems getting medical equipment and supplies were most often related to insurance barriers (Karpman, Morriss, and Gonzalez 2024). Moreover, interview participants who were uninsured faced some of the most severe challenges getting services and care.

LACK OF HEALTH INSURANCE

Though most interview participants reported that they had public or private health insurance, those who were uninsured faced some of the greatest difficulty obtaining services. Some of these adults had recently lost employer-sponsored insurance, in one case because they had to stop working to take care of disabled parents. Interviewees or their family members went without coverage while waiting for a SSI, SSDI, Medicare, or Medicaid application to be approved. Without protection against high medical bills, these families faced prohibitive out-of-pocket costs for critical diagnostic tests, therapies, medical supplies, home health services, and other care. “If you can’t afford insurance, you die,” said one woman whose husband was unable to afford an imaging test that they were told would cost \$15,000 out of pocket. “Health insurance needs to come down, so people like us can afford it to get help.”

DIFFICULTIES WITH COVERAGE LIMITS AND PRIOR AUTHORIZATION

Among interviewees with health insurance, more than half encountered at least one problem when requesting reimbursement or authorization for care. These adults were often told that the services they

needed were not covered by their insurance plan or were subject to coverage limits, particularly with respect to medical equipment, supplies, and medications. One man was unable to get his Medicaid plan to pay for a continuous blood glucose monitor unless he first used lower-cost tests that had caused problems for him in the past. He also experienced periodic denials for a diabetes medication that previously had been approved: “It seems like every six months when it comes up for renewal, they just flat deny it right off the bat. I’m like, ‘I’ve been on this medication for two years. How is this still a problem?’”

Other interview participants expressed similar frustration when their plans denied requests for prior authorization or other claims for equipment, services, or medication they thought would be covered. Typically, their insurance plans stated that it was not medically necessary or required them to use a lower-cost alternative that did not always meet their needs. A respondent who had difficulty getting mobility equipment and home modifications reported that his insurance plan repeatedly rejected his requests:

My insurance company sent denial after denial after denial. The medical equipment store said my insurance company denied it due to it not being considered a medical device that’s needed for me, even though all my medical records are saying that I need it and that my injury is never going to get any better...I’ve had medication denied...I can’t get a specialist. I can’t get a pain management doctor.

Other interview participants noted that they “are just so used to getting turned down for everything,” that their insurers “denied every claim and left me in debt,” and that “just because you’ve got insurance doesn’t mean they’re going to cover you.” Repeated denials discouraged one woman from applying for transportation services.

Even when services and medication were covered, some respondents with Medicare or private insurance reported that they had trouble affording the deductibles and other out-of-pocket costs. As one Medicare beneficiary recounted, “I have drug insurance, but it doesn’t cover anything. They’re basically for catastrophic.”

NARROW PROVIDER NETWORKS AND INSURANCE TRANSITIONS

Narrow provider networks and transitions in insurance coverage that led to changes in those networks also contributed to unmet care needs or disruptions in care for several respondents. This issue was a particular challenge for getting specialist care, for getting dental care and other services not typically covered by public and private health insurance, and for people living in rural areas or lacking reliable transportation. A respondent with Medicaid who needed to see an oral surgeon observed that an in-network provider could be more than 40 miles away. Another man experienced problems getting medications after enrolling in Medicaid because he was unable to find certain specialists. He reported having limited access to a neurologist and cardiologist because the ones who would accept Medicaid were located several hours away. One woman reported the state unexpectedly and involuntarily transferred her from a Marketplace health plan to Medicaid during her pregnancy, resulting in her psychiatrist no longer being in network:

My current physicians were not covered with the new plan. In order just due to, I don't know what, I guess supply and demand, to get an appointment with a covered doctor in the area took over a year to get in...It was not covered, so therefore, it was prohibitively expensive to continue to see my current provider...I didn't have psychiatric care. I was about 18 months between doctors.

DIFFICULTY APPLYING FOR DISABILITY BENEFITS AND MEDICAID LTSS

Several interview participants struggled to meet the stringent eligibility criteria and complete burdensome application processes for federal disability benefits or Medicaid LTSS. Most interviewees who applied for SSI or SSDI, either successfully or unsuccessfully, indicated the disability determination process was complicated, prolonged, and costly, with applications only approved after multiple attempts. In several instances, these difficulties with the SSI or SSDI application process delayed coverage under Medicaid or Medicare, respectively. For instance, one person could not get insurance to cover a wheelchair while his SSI and Medicaid applications were pending. Another respondent described how his family provided critical support while his application for SSI took years to complete:

They had to get a lawyer for the second or third one denied—you had to go to the court case next. Then you took a big 20 percent bite of the back pay. It was quite a long, arduous process. People without a support mechanism like a family are going to have extreme issues trying to get on SSI or disability.

A woman whose application for SSDI was being processed for three years noted that Social Security Administration office closures during the COVID-19 pandemic had made wait times to speak to a representative “almost insurmountable.”

Some individuals whose disabilities partially limited their ability to work were unable to qualify for Social Security benefits. Interviewees also discussed how SSI financial eligibility rules presented them with a choice between depleting their savings to access benefits and services or trying to maintain their current standard of living without those services. A disabled man raising children with disabilities faced this dilemma and said, “It just feels like to me that social services or Social Security—they feel as if your family has to be destitute....Social Security is nowhere to be found in this entire process. I'm doing this all on my own.”

Respondents also reported nonfinancial barriers to qualifying for Medicaid LTSS. For instance, one woman was told she did not meet the functional criteria used to determine eligibility for coverage of personal assistance services at home from a paid professional:

[The service provider] decided, you don't need help because you don't qualify to be an inpatient in the nursing home. I'm like, okay, well, how do people get at-home care? Not everybody qualifies...If I met the criteria to be in a nursing home, I would be in the nursing home.

UNFAIR TREATMENT FROM PROVIDERS

Not all access barriers were related to health insurance. Several participants faced problems interacting with health care providers who would not write prescriptions or provide other documentation needed to get services or equipment. In some cases, adults with disabilities felt that their providers dismissed

their concerns or treated them differently because of their health conditions, race, gender, sexual orientation, or type of health insurance coverage. Examples included the following:

- A man was told by a specialist that he did not need a hearing aid despite his significant difficulty hearing.
- A woman said, “[My doctor] was telling me that there was nothing really wrong with me,” and did not get medical equipment and prescriptions she needed because the doctor did not follow up to get her medical records.
- A man said he “always sensed a different type of treatment in a doctor’s office” until he saw a doctor of the same race who took his pain seriously and prescribed new medication. “For a minute, it felt like I was a normal human being,” he said.
- A man said his doctor resisted helping him navigate Medicaid prior authorization processes for medical equipment because “he doesn’t like my insurance.”

Another man who lost his job and employer-based coverage after having a stroke described how his primary care provider treated him unfairly during a follow-up visit to discuss lab results because he had Medicaid:

[My primary care physician] keeps it very short, minimal, and then ushers me out the door because I’m on Medicaid. She tells me that their contract only pays her \$12 for my visit with her...That’s just another reason why I don’t mind skipping the appointment because I’m going to get ridiculed for being on Medicaid... When I walked in there with [private insurance], it’s like they rolled out the red carpet. They offered every treatment, every service, every preventive thing that they could offer.

WORKFORCE SHORTAGES

Many participants reported facing long waits for appointments with providers, particularly for behavioral health and other specialty care. Several respondents reported that the shortage of direct care workers, and high turnover among those workers, led to significant disruptions for families in need of personal assistance services. A woman described how problems finding consistent home health care for her disabled mother left her with greater caregiving responsibilities at a time when she was struggling with her own health issues:

People have proven unreliable. They just don’t show up...and so I wound up doing everything for her when I was having difficulty even walking...From my experience with my mother with three different agencies, it was always hit and miss. It’s expensive. She depleted her savings because I couldn’t possibly care for her 24/7 and still take care of what she and I needed.

A man with dual coverage through Medicare and Medicaid who needed help with housecleaning only received services for a short period. “They did eventually find somebody,” he said. “She was out here maybe five times, and then she quit her job. Then they weren’t able to find somebody to take her place.”

Though consumer-directed care options allow people to hire their own care providers, including family members, not all state Medicaid programs allow spouses or other legally responsible relatives to fulfill this role (Musumeci, O'Malley Watts, and Chidambaram 2020). One man explained how his state's Medicaid rules on paying family caregivers led to a transition in his care:

They [Medicaid] allow family members, but not my wife...She used to be my health care aide and then I married her. At that point, I lost my home health care aide and waited a year and three months or four months before a new one was given to me.

This man's stepson currently receives state compensation to help him with tasks such as cleaning, meal preparation, shopping, and transportation to appointments. However, his managed care organization recently denied a request for additional paid hours per week based on a determination that it was not medically necessary.

SUPPLY CHAIN ISSUES

The COVID-19 pandemic exacerbated challenges obtaining medical equipment and supplies that were affected by supply chain disruptions. These disruptions caused a man who was insured with Medicare to wait eight months for a wheelchair. Others faced supply challenges that were unrelated to the pandemic, such as equipment recalls. A man whose CPAP machine was recalled had to pay for a new one out of pocket because of delays with his insurance. A woman described the challenges she faced in getting enteral feeding supplies for her disabled husband:

He has to have...a special feeding liquid that I have to insert into his stomach...They don't always have it, so if they don't have it, then I've got to go through another company, which I have to search for...It can be very difficult and very expensive...The syringe that it takes to put the food into his stomach feeding tube, \$6 for a syringe. I go through them about every three days. The supplies [are] very hard to find.

What Were the Consequences of Delayed and Unmet Service Needs?

Respondents reported that the delayed and unmet service needs they and their family members experienced had harmful effects on their health and well-being, social participation, employment, and finances. These consequences not only affected those with disabilities but also their family members who struggled to balance caregiving and work responsibilities with limited support.

EFFECTS ON PHYSICAL AND MENTAL HEALTH

Most interview participants described harmful health impacts that resulted from going without needed services and supports, including injuries, worsening physical health conditions, chronic pain, poor mental health, and feelings of low self-worth. One respondent said that the problems she had finding consistent and high-quality home health care for her mother ultimately resulted in her mother's early death because of medical errors made by poorly trained staff.

Several people explained how delayed and unmet needs led to falls and other injuries. For instance, difficulty getting mobility equipment and home modifications resulted in emergency room visits for a man with brain and spinal injuries. Two participants with difficulty getting diabetes equipment said they

had more difficulty managing their conditions. One experienced chest pains that prompted a hospital visit. Another had stopped regularly monitoring his blood glucose levels for the past year. For one woman, delays in getting high-quality care led to permanent nerve damage in her arm.

Unmet needs often resulted in increased stress and worse mental health. One woman described the toll of being confined to her home when she was unable to get a wheelchair for six months: “I was stressed out all the time, having panic attacks when I was not able to pay the bills. Everything had kicked into overdrive.” Another respondent explained how he was adversely affected by a transition in health insurance:

I don't have coping skills really because of the mental problems, and that was one thing that I was working on when I did have quality health insurance...cognitive behavioral therapy and rehab to learn how to cope and learn how to function with diminished mental capacity and the memory loss.

EFFECTS ON DAILY ACTIVITIES, SOCIAL PARTICIPATION, AND EMPLOYMENT

Difficulty getting services affected adults' ability to perform self-care tasks, clean their homes, work, and participate in social activities. “Sometimes I have difficulty where I'm just in so much pain, I can even hardly do for myself,” said one woman. “It's real hard on an employer to allow me to work because I'd be calling in sick.” Other interviewees went without care that would interfere with their work. A man with diabetes who was unable to get a continuous glucose monitoring device explained that using lancets would interfere with his employment and other activities:

Anything I do for work involves my fingertips. I transcribe stuff for people...I also play saxophone and clarinet and I need my fingertips....I've tried other testing sites and none of them work for me. Only my fingertips will work...Testing four, five, six, seven times a day...would seriously interfere with what little work I do and actually the music that I play as part of a community ensemble.

Some interview participants were unable to get around in the community or inside their homes. A man with mobility difficulties mentioned that he did not go out frequently for reasons other than medical appointments and trips to the grocery store because of a lack of transportation. Another man said that he stayed in bed most of the time for about a month when faced with problems getting mobility equipment. One woman explained how her seizures intersected with transportation barriers to prevent her from getting health care:

When I have a seizure, down here in [my state], the law says, when you have a seizure, you can't drive for six months. Now I have to find somebody to take me to doctors, grocery stores, etc. Now, I can't go to the doctor.

EFFECTS ON HOUSEHOLD FINANCES AND BASIC NEEDS

Most interview participants faced adverse financial consequences because of challenges obtaining services or getting insurance to pay for them. Lost work and expenses for equipment and services that were not covered or only partially covered by insurance strained household budgets. This situation often resulted in difficulty paying for food and other basic needs. One respondent said he had to cut

back on essential expenses to pay out of pocket for a wheelchair while he was waiting for it to be approved by Medicaid:

I had to pay—I think it was about \$380 with the shipping included, and of course that means, okay, I have to take money from somewhere else because I'm disabled. I don't have an income. My SSI is \$103 a month, so that means I have to cut back on food. I have to cut back on, you know, anything that I have, even if it's just electricity is all that I have, that just has to be it.

Other adults ran through savings or incurred additional debt. One woman who depleted her 401(k) plan after losing her job because of her disability paid most of her \$300 monthly prescription costs with a credit card while she waited for her SSDI application to be approved.

EFFECTS ON FAMILY CAREGIVERS

Stress and isolation, worsening health, and loss of employment not only affected those who faced barriers to accessing services, but also their family members who stepped in to provide care. A woman who stopped working for this reason described the effects on her own health and well-being:

There was a point where we were not living in the same place, and I basically slept on her couch...it was probably eight months out of the year in her living room—no privacy. It did nothing for my health. It took me down. Everything that I just didn't take care of myself because I was taking care of her.

Another woman described how her worsening mental health created stress for her and her family during a period when she had difficulty getting a wheelchair and transportation to a mental health clinic. "They had to do a lot for me...due to me having the loud outbursts and everything else," she said.

COPING STRATEGIES

Adults with disabilities reported employing various coping strategies when faced with unmet needs for equipment, services, and health care, including increased reliance on family and friends for financial and caregiving support, receiving charitable assistance (e.g., financial help or donated equipment), or using suboptimal equipment or medications. For instance, some people could only get their insurance plans to pay for medications that were less effective or had worse side effects than the medications they would have preferred. One woman with psychiatric disabilities said "there's something that will work and would be less hard on my body, but it costs too much. You have to go with this [medication] that causes horrible side effects because it costs less." Among adults who needed or provided personal assistance, those who had limited financial and social support from family, friends, and social service organizations tended to report the greatest levels of stress and feelings of isolation.

POSITIVE EXPERIENCES

Though interview participants faced challenges getting a wide range of services, they also highlighted factors that improved their experiences. Several people benefited from having doctors who listened carefully, treated them with respect, and were strong advocates for them when navigating prior authorization and insurance claims processes. Others reported positive experiences with their health plans, including during times when their interactions with health care providers were difficult or confusing. One man who was insured with Medicaid received frequent assistance from a care

coordinator to get the medical tests, treatments, and equipment he needed. Medicaid enrollees also valued the low out-of-pocket costs for medications and other care, as well as programs that addressed social determinants of health such as nutrition and physical activity.

Discussion

Overall, survey respondents with disabilities and those who participated in follow-up interviews described an array of barriers to accessing needed services. Interviewees shared that these challenges often had negative consequences for their health and well-being. Insurance authorization processes were particularly burdensome, but respondents also faced difficulties interacting with providers and medical suppliers. In addition, problems getting one type of service often exacerbated barriers to another—for example, lack of transportation or assistance to get to a doctor’s appointment or difficulty getting a prescription or other documentation needed to obtain medical equipment.

When asked what would have ameliorated the problems they had experienced, interview participants shared a range of ideas:

- **Increasing access to health insurance.** Interviewees emphasized the urgent need for affordable coverage. This challenge is likely to have become more pronounced following the April 2023 resumption of Medicaid renewal processes, which had been suspended for three years during the COVID-19 public health emergency. As of February 2024, more than 16 million people have been disenrolled from Medicaid, most commonly for procedural reasons (e.g., paperwork issues) rather than determinations of ineligibility.¹⁹ People with disabilities may need assistance reenrolling in Medicaid if their coverage was wrongfully terminated or finding alternative sources of coverage if they are no longer eligible for Medicaid.
- **Providing information and helping people navigate application processes and use of available benefits.** Interview participants wanted informational assistance that would reduce the amount of time spent learning what forms of help were available, suggesting the need for proactive outreach and enrollment support from insurance navigators and information and referral programs. Several people indicated that help navigating disability determination or functional assessment processes would make it easier to get needed benefits and coverage. For instance, one respondent mentioned that the clinic from which he receives care had a program that proactively assists patients applying for federal disability benefits, suggesting the need for additional similar supports. Interviewees also shared challenges with using their coverage to access services, raising the need for advocacy and assistance navigating complex systems.
- **Improving health insurance coverage quality, affordability, and efficiency.** Insured respondents wanted to reduce the burden of getting reimbursed for covered benefits, make premium and out-of-pocket health care costs more affordable, and ensure benefits and provider networks are adequate. In particular, they pointed to the complexity of prior authorization and claims processes, including unclear criteria for determining medical necessity as well as the frequency of denials. Their experiences underscored the need for greater

transparency and accountability in insurance reimbursement processes. A CMS final rule issued in January 2024 takes a step toward this objective by establishing prior authorization standards and reporting requirements in Medicaid, Medicare Advantage, and health plans sold through the federal health insurance Marketplace.²⁰

- **Addressing direct care worker shortages.** Respondents who received personal assistance services or provided such assistance to a family member recommended more flexibility for family members to serve as paid caregivers, increased pay and training for personal care aides and home health aides, and efforts to ensure continuity of care when a worker is unavailable or quits their job. Ensuring adequate wages for direct care workers would likely help address worker shortages and turnover in HCBS (Haley et al. 2023).
- **Streamlining transportation services.** Users of Medicaid-funded transportation benefits wanted to streamline the process for scheduling rides and have more direct communication with transportation providers to alleviate the problems they faced coordinating with insurance companies and brokers. Interviewees also recommended greater flexibility in using ride-sharing services such as Uber or Lyft and strengthening incentives for other transportation providers to improve customer service. Some respondents noted that easing local provider shortages and expanding access to health services at home would mitigate their transportation-related barriers to care.
- **Increasing financial support.** Interview participants who were unable to work and/or received SSI said that additional financial resources, in general, would have made it easier to get needed health services. Reducing application burdens for federal disability programs and increasing benefits would have helped limit the trade-offs between food, medicine, and other basic needs they were forced to make when trying to get insurance to cover vital health services and supports.
- **Supporting family caregivers.** In addition to informational assistance and compensation, the experiences of family caregivers we interviewed suggested the need for additional help such as respite care, counseling, and peer support.²¹

Policy proposals currently under consideration seek to address some of these objectives. For instance, in April 2023, the Biden administration issued a proposed rule to improve access to Medicaid services. Several provisions of the rule are designed to expand access to and quality of HCBS by establishing national standards and promoting greater transparency.²² These changes would require states to do the following:

- Ensure at least 80 percent of Medicaid payments for home health aide, personal care, and homemaker services are spent on compensation for direct care workers.
- Report the average amount of time Medicaid beneficiaries wait to receive these services after they are initially approved.
- Report the average hourly pay of direct care workers.

- Report on a new set of national HCBS quality measures and set performance targets and improvement strategies.
- Publish information about waiting lists in HCBS waiver programs, including how the lists are maintained, the number of people waiting for services, and average wait times.
- Reassess functional needs and update person-centered service plans annually for at least 90 percent of participants in HCBS programs.

This rule and a separate rule focused on Medicaid managed care include additional provisions to improve access to other Medicaid services.²³ For instance, the new regulations would promote transparency of provider payment rates and network adequacy.

States are also continuing some policies to expand HCBS that were implemented through temporary flexibilities and funding during the COVID-19 public health emergency. These policies include allowing virtual evaluations of eligibility and care needs, increasing provider payment rates, adding waiver slots, easing utilization limits, and expanding support for paid family caregivers (Burns, Mohamed, and O'Malley Watts 2023; Burns, Mohamed, and Rudowitz 2023).

Additional strategies for expanding access to HCBS and other health care for people with disabilities are highlighted in a related brief (Karpman, Morriss, and Gonzalez 2024). Some of these policy changes, such as efforts to substantially increase funding for HCBS and make them a mandatory Medicaid benefit, would require federal legislation. As the nation struggles to meet rising demand for HCBS (Kreider and Werner 2023), future research and policy initiatives must engage the voices of people with disabilities in identifying health care and social service reforms to better meet people's needs.

Appendix: Data and Methods

Survey Data Collection

The Well-Being and Basic Needs Survey (WBNS) is a nationally representative, internet-based, annual survey of adults ages 18 to 64 designed to monitor changes in individual and family well-being as policymakers consider changes to federal safety net programs (Karpman, Zuckerman, and Gonzalez 2018).²⁴ The survey sample is drawn from the KnowledgePanel, a probability-based internet panel maintained by Ipsos that includes households with and without internet access. Participants can complete the survey in English or Spanish. The core sample for the December 2022 round of the survey included 7,881 adults, including 2,194 who reported having a disability. We measured presence of a disability based on six questions used in the American Community Survey (ACS) that conform to minimum data collection standards established by the US Department of Health and Human Services and a seventh question on communication difficulties that we adapted from the Washington Group Short Set on Functioning.²⁵ Participants were identified as having a disability if they answered yes to any of the following questions about difficulties 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?
- Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?

The survey included the following question to collect information about delayed or unmet needs for selected services: In the past 12 months, was there a time when you delayed getting or did not get any of the following types of equipment, supplies, or services you needed?

- medical equipment, devices, or aids (including getting new equipment, devices, or aids or repairing existing equipment, devices, or aids)
- disposable medical supplies
- physical therapy, occupational therapy, speech therapy, or respiratory therapy
- care at home from a nurse or other health professional
- personal assistance services (such as help with bathing, dressing, eating, or shopping)

One in five adults (20 percent) reported having at least one type of disability examined in the survey. Table 1 shows the characteristics of these adults. More than half (54 percent) reported more than one type of disability, with the most common types including difficulty concentrating, remembering, or making decisions, independent living difficulty (e.g., doing errands alone), and mobility difficulty (e.g., walking or climbing stairs). Adults with disabilities were more likely than nondisabled adults to be ages 50 to 64 or female, to be unemployed or out of the labor force, and to have multiple chronic health conditions, family incomes below the federal poverty level, and insurance coverage through Medicaid and/or Medicare. More than 4 in 10 adults with disabilities lived with another disabled household member, including 38 percent who lived with another disabled adult ages 19 or older and 10 percent who lived with a disabled child under age 19 (data not shown).

TABLE 1

Selected Characteristics of Adults Ages 18 to 64 with and without Disabilities, December 2022

	Adults with disabilities	Adults without disabilities	
Type of disability			
Hearing difficulty	14%	--	
Vision difficulty	14%	--	
Cognitive difficulty	57%	--	
Ambulatory difficulty	39%	--	
Self-care difficulty	16%	--	
Independent living difficulty	41%	--	
Communication difficulty	17%	--	
More than one type of disability	54%	--	
Ages			
18-34	37%	35%	
35-49	26%	33%	***
50-64	37%	32%	***
Sex			
Female	55%	50%	***
Race/ethnicity			
Asian, non-Hispanic/Latinx	3%	7%	**
Black, non-Hispanic/Latinx	14%	13%	
Hispanic/Latinx	20%	19%	
White, non-Hispanic/Latinx	58%	59%	
Additional races, non-Hispanic/Latinx	5%	2%	**
Employment			
Working	44%	76%	***
Unemployed	9%	4%	***
Not in the labor force	47%	20%	***
Family income			
Below 100% of FPL	33%	11%	***
Between 100-200% of FPL	17%	11%	***
Between 200-400% of FPL	27%	26%	
At or above 400% of FPL	23%	51%	***
Chronic conditions			
Has one chronic condition	27%	23%	***
Has multiple chronic conditions	57%	16%	***
Health insurance			
Employer-sponsored insurance	39%	67%	***
Medicare	16%	2%	***
Medicaid	26%	9%	***
Both Medicare and Medicaid	8%	1%	***
Private nongroup coverage or unspecified coverage	9%	10%	
Uninsured	11%	11%	
Sample size	2,194	5,687	

Source: Well-Being and Basic Needs Survey, December 2022.

Notes: Additional races include people who are American Indian/Alaska Native, Native Hawaiian or Other Pacific Islander, another race, or more than one race. FPL is the federal poverty level. Unemployed includes people actively looking for work or on temporary layoff. Health insurance is based on coverage reported at the time of the survey. Respondents who reported more than one coverage type were assigned to mutually exclusive categories based on the following hierarchy of responses so that coverage estimates sum to 100 percent: employer-sponsored insurance (including military); Medicare; Medicaid (including the Children's Health Insurance Program); and private nongroup or unspecified coverage.

//*** Estimates for adults with and without disabilities differ significantly at the 0.10/0.05/0.01 levels, using two-tailed tests.

INTERVIEW DATA COLLECTION

Recruitment for the follow-up interviews focused on survey participants with disabilities who reported any delayed or unmet needs for services and who granted permission to be contacted about the interviews. We prioritized recruitment of adults with long-term disabilities by focusing on those who reported disabilities in both the December 2022 WBNS and the June 2022 round of the Urban Institute's Health Reform Monitoring Survey, which draws its sample from the same internet panel (and therefore has partial overlap across survey samples) and which included the six ACS questions on disability status. We sought to interview a diverse group of adults by setting minimum recruitment targets based on the types of services people had trouble getting; types of disabilities; race and ethnicity; presence of another disabled adult or child in the household; and type of health insurance coverage.

Based on these criteria, Ipsos contacted survey respondents by phone and/or email to invite them to participate in a phone interview and coordinated scheduling; recruitment emails asked whether respondents could participate by Zoom if they were unable to participate by phone and to indicate any accommodations required. Of the 115 people contacted, 25 were successfully reached and interviewed. Urban Institute researchers conducted all 25 interviews by phone in May and June 2023. Informed consent was obtained in both recruitment emails and at the beginning of each interview, and interviews were audio recorded with participants' permission. Recruited respondents received an incentive to participate equivalent to \$25.²⁶

We conducted semistructured interviews lasting up to 30 minutes using an interview protocol that included questions on household composition; the nature of respondents' and their household members' disabilities; health insurance coverage; difficulty getting medical equipment and supplies, home health care or personal assistance, and other HCBS or health care including skilled therapy services, transportation, and prescription drugs (for the respondent or for a household member); reasons for and consequences of delayed and unmet needs for services; coping strategies; and suggested changes that would have improved their experiences.

Audio recordings were professionally transcribed. Three members of the research team independently reviewed transcripts to develop a coding structure and document key themes using an inductive thematic analysis approach. The researchers met to discuss and consolidate themes, which one of the researchers later organized based on the discussion to create a working thematic analytical framework relevant to all interviews.

Members of a community advisory board with lived experience with disabilities and professional experience as disability advocates informed each stage of the research process, including identifying the research questions, developing the survey questionnaire and interview protocol, interpreting the survey results, and providing feedback on themes that emerged from the interviews. One of these community advisory board members was also part of the research team and helped refine the interview protocol after observing three of the initial interviews. All survey and interview procedures were approved by the Urban Institute's Institutional Review Board.

Table 2 shows the demographic characteristics of interview participants, who were about evenly split by sex (12 female, 13 male) and who were primarily older in age (2 ages 18 to 34, 12 ages 35 to 49, and 11 ages 50 to 64). Four participants were Hispanic/Latinx. Of those who were non-Hispanic/Latinx, 11 were white; 5 were Black; and 5 were Asian, American Indian/Alaska Native, some other race, or more than one race. A majority of interview participants reported Medicaid, either as their sole source of coverage (10) or dual Medicaid and Medicare (5), and others had Medicare only (3), private insurance (5), or were uninsured (2).

Interviewees had various physical, sensory, psychiatric, and cognitive disabilities, some of which were present since birth or childhood and others that developed later in life as a result of chronic health conditions, workplace injuries, or other factors. Most interviewees had more than one type of disability, including multiple physical conditions and/or physical and mental health conditions that were often interrelated. Several of the disabled adults interviewed were also providing care for another disabled family member, including children, spouses, or parents.

TABLE 2
Interview Participants’ Selected Characteristics

	Number of participants
Ages	
18–34	2
35–49	12
50–64	11
Sex	
Female	12
Male	13
Race/ethnicity	
Black, non-Hispanic/Latinx	5
Hispanic/Latinx	4
White, non-Hispanic/Latinx	11
Asian or additional races, non-Hispanic/Latinx	5
Health insurance	
Private insurance	5
Medicare only	3
Medicaid only	10
Medicare and Medicaid	5
Uninsured	2
Sample size	25

Source: Well-Being and Basic Needs Survey, December 2022.

LIMITATIONS

The WBNS has several limitations, including coverage and nonresponse error, that are only partially mitigated by survey weighting procedures. The underlying panel from which the sample is drawn is composed of people living in households who can complete online surveys in English or Spanish. It therefore excludes people with disabilities who live in institutional settings, are homeless, have low literacy levels, or only speak other languages. The survey sample only focused on adults under age 65.

The internet-based survey mode may also pose greater accessibility challenges for people with certain types of disabilities, such as visual, cognitive, or physical limitations. And the questions used to measure disability status have been found to exclude some people with disabilities, including those related to mental health conditions (Hall et al. 2022). Therefore, survey estimates should not be interpreted as representative of the full population of adults with disabilities.

The survey examined only a subset of HCBS, including home health care, personal assistance, selected skilled therapies, and medical equipment and supplies. Some of these services may have been needed on a short-term basis. During the follow-up interviews, some people discussed unmet needs for other types of HCBS that were not covered by the survey.

Though interviewees were recruited by phone and email and offered a choice of interview modes and accommodations, all interviews were ultimately conducted by phone. Because of this, the interviews do not capture the experiences of people with disabilities who have difficulty communicating by phone, further limiting the generalizability of the qualitative findings. Because the interviews were only conducted in English, the qualitative findings may not represent unique challenges faced by disabled adults who primarily speak other languages.

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 Home- and community-based services (HCBS) include a range of health and social services that assist people with daily activities and enable them to live independently in their communities (Colello 2022). Though most HCBS are provided through Medicaid state plan or waiver authorities, our study was not limited to people who have been determined eligible for Medicaid long-term services and supports. In addition, our survey and interviews focused on services covered by other types of insurance, including on a short-term basis (e.g., home health care), as well as long-term care services other types of insurance generally do not cover (e.g., personal assistance). The survey and interviews did not ask about the full range of HCBS that may be available through Medicaid, such as adult day services, supported employment, or respite care.
- ³ Alice Burns, Maiss Mohamed, and Molly O’Malley Watts, “A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023,” KFF, November 29, 2023, <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023/>; John Beer, “For Wheelchair Users, Finding Attendants Has Gone from Crisis to Catastrophe,” *New Mobility*, May 1, 2023, <https://newmobility.com/a-rolling-crisis/>; Meghan Smith, “‘We’re in a Crisis’: PCA Shortage Is a Matter of Life and Death for People with Disabilities,” *GBH News*, May 30, 2023, <https://www.wgbh.org/news/local/2023-05-30/were-in-a-crisis-pca-shortage-is-a-matter-of-life-and-death-for-people-with-disabilities>; 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/>.
- ⁴ “Health Equity Community Advisory Board,” Urban Institute, accessed January 29, 2024, <https://www.urban.org/projects/health-equity-community-advisory-board>.
- ⁵ 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.

- ⁶ Kirsten J. Colello and Isobel Sorenson, “Who Pays for Long-Term Services and Supports?,” Congressional Research Service, September 19, 2023, <https://crsreports.congress.gov/product/pdf/IF/IF10343>.
- ⁷ “Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead,” US Department of Health and Human Services, last updated July 31, 2023, <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>.
- ⁸ States also have the option to include physical therapy, occupational therapy, and speech pathology and audiology services in the Medicaid home health services benefit. See Home Health Services, 42 CFR § 440.70 (2024).
- ⁹ “Ensuring Access to Medicaid Services (CMS 2442-P) Notice of Proposed Rulemaking,” Centers for Medicare and Medicaid Services (CMS), April 27, 2023, <https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicare-services-cms-2442-p-notice-proposed-rulemaking>.
- ¹⁰ “Medicare and Home Health Care,” CMS, March 2023, <https://www.medicare.gov/publications/10969-medicare-and-home-health-care.pdf>; “Medicare Coverage of Durable Medical Equipment & Other Devices,” CMS, August 2021, <https://www.medicare.gov/media/publication/11045-medicare-coverage-of-dme-and-other-devices.pdf>; Colello and Sorenson, “Who Pays for Long-Term Services and Supports?”
- ¹¹ “Substantial Gainful Activity,” Social Security Administration, accessed December 4, 2023, <https://www.ssa.gov/oact/cola/sga.html>.
- ¹² The two-year waiting period for Medicare is in addition to the five-month waiting period for receiving SSDI payments after being approved for SSDI.
- ¹³ “People with Disabilities,” Medicaid and CHIP Payment and Access Commission (MACPAC), accessed December 7, 2023, <https://www.macpac.gov/subtopic/people-with-disabilities/>.
- ¹⁴ Most nonelderly adults with disabilities who are enrolled in Medicaid do not receive SSI and have qualified for Medicaid through other eligibility pathways, such as the ACA Medicaid expansion, categorical eligibility for parents of dependent children based on income, or optional disability-related pathways. See MaryBeth Musumeci and Kendal Orgera, “People with Disabilities Are At Risk of Losing Medicaid Coverage Without the ACA Expansion,” KFF, November 2, 2020, <https://www.kff.org/medicaid/issue-brief/people-with-disabilities-are-at-risk-of-losing-medicare-coverage-without-the-aca-expansion/>.
- ¹⁵ Corinne Lewis and Christina Wu, “A Call for Improved Data Collection on the Long-Term Services and Supports Needs of Working-Age Adults with Disabilities,” *Health Affairs Forefront*, August 12, 2021, <https://www.healthaffairs.org/content/forefront/call-improved-data-collection-long-term-services-and-supports-needs-working-age-adults>.
- ¹⁶ Kathryn G. Kietzman and Lei Chen, “Unmet Needs for Help at Home: How Older Adults and Adults with Disabilities Are Faring in California,” UCLA Center for Health Policy Research, August 2022, <https://healthpolicy.ucla.edu/publications/Documents/PDF/2022/Unmet-Needs-for-Help-at-Home-factsheet-aug2022.pdf>.
- ¹⁷ These estimates were somewhat higher than estimates from a recent Urban Institute survey conducted in June 2022, likely in part because of differences in survey question wording (Karpman, Morriss, and Gonzalez 2024). The June 2022 round of the Urban Institute’s Health Reform Monitoring Survey first asked respondents whether they or someone living with them delayed or did not get services in the past 12 months. If respondents answered yes, they were asked who in the household delayed or did not get services. In contrast, the December 2022 Well-Being and Basic Needs Survey first asked whether the respondent delayed or did not get services before asking about others in the household.

- ¹⁸ Step therapy (also known as fail first) refers to a utilization management practice in which an insurer requires that plan members first try a lower-cost prescription medication before it will agree to cover a similar, higher-cost medication (Sachs and Kyle 2022).
- ¹⁹ “Medicaid Enrollment and Unwinding Tracker,” KFF, last updated February 1, 2024, accessed February 12, 2024, <https://www.kff.org/report-section/medicaid-enrollment-and-unwinding-tracker-overview/>.
- ²⁰ “CMS Interoperability and Prior Authorization Final Rule CMS-0057-F,” CMS, January 17, 2024, <https://www.cms.gov/newsroom/fact-sheets/cms-interoperability-and-prior-authorization-final-rule-cms-0057-f>.
- ²¹ “2022 National Strategy to Support Family Caregivers,” Administration for Community Living, last updated January 5, 2024, accessed February 12, 2024, <https://acl.gov/CaregiverStrategy>.
- ²² “Ensuring Access to Medicaid Services (CMS 2442-P) Notice of Proposed Rulemaking,” CMS, April 27, 2023, <https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-cms-2442-p-notice-proposed-rulemaking>.
- ²³ “The Biden-Harris Administration Proposes New Standards to Help Ensure Access to Quality Health Care in Medicaid and CHIP,” press release, CMS, April 27, 2023, <https://www.cms.gov/newsroom/press-releases/biden-harris-administration-proposes-new-standards-help-ensure-access-quality-health-care-medicaid>.
- ²⁴ The WBNS survey instrument for December 2022 is available at <https://www.urban.org/policy-centers/health-policy-center/projects/well-being-and-basic-needs-survey> (accessed February 22, 2024).
- 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>. “Washington Group Short Set on Functioning (WG-SS),” Washington Group on Disability Statistics, accessed August 22, 2023, <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>.
- ²⁶ Ipsos has an incentive system that allows KnowledgePanel members to accrue points based on the number of surveys they complete. Members can be entered into sweepstakes or raffles or redeem points for cash or other prizes.

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