

Rationing Rights: Administrative Burden in Medicaid Long-Term Care Programs

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Abstract

Context: States use Medicaid waivers to provide supports for disabled people in communities rather than in institutions. Because waivers are not entitlements, those deemed eligible are not guaranteed these supports. How do states, *in practice*, use bureaucratic procedures to ration this “conditional” right?

Methods: Drawing on primary and secondary data, the authors analyze waiver programs and document state administrative procedures that indirectly and directly ration access.

Findings: Burdens indirectly limit disabled people’s access to Medicaid home- and community-based services via a complex array of waiver programs that exacerbate costs associated with gaining eligibility. In addition, burdens directly limit access via wait lists and prioritization among the eligible. There is also evidence that states strategically deploy opacity to provide political cover for unpopular wait lists. The overall process is opaque, confusing, and time intensive, with burdens falling hardest on marginalized groups.

Conclusions: Administrative burdens impede disabled people’s efforts to exercise their right to live in the community as afforded to them under the American with Disabilities Act. The opacity and associated burdens with waiver programs are a way to conceal these burdens, thereby demonstrating how burdens “neatly carry out the ‘how’ in the production of inequality, while concealing . . . the why” (Ray, Herd, and Moynihan 2023: 139).

Keywords Medicaid, long-term care, disability, inequality

There is growing evidence on how administrative burdens, or negative encounters with government, impede the exercise of basic rights, including access to benefits and services (for a review, see Herd et al. 2023). Burdens include learning costs, such as finding needed services; compliance costs,

such as complicated paperwork and time spent completing administrative processes; and psychological costs, such as stress and anxiety (Herd and Moynihan 2018). There is abundant evidence that burdens explain why so many individuals eligible for social welfare benefits do not receive them.

Attention to burdens in Medicaid and most other social welfare programs has focused on entitlement programs for low-income populations, such as children and pregnant women (Michener 2018). Here, research attends to how burdens indirectly (or *de facto*) ration access to benefits. Burdens, such as confusing eligibility processes, indirectly ration access to benefits or can constitute policy making by other means (Herd and Moynihan 2018). While policy makers may deliberately design confusing processes with the implicit intention of rationing, ultimately individuals are entitled. They can access benefits to which they have a right if they can navigate burdensome eligibility processes (Herd et al. 2023).

However, little attention has been paid to burdens in nonentitlement programs, including community-based long-term care. Home- and community-based services (HCBS) are mostly provided under Medicaid waivers, where states can “waive” rules stipulating that benefits cover all eligible participants statewide (Beauregard and Miller 2020). States can, for example, directly ration by limiting access to individuals deemed eligible. Unlike entitlements, such rights are “conditional” rights. Medicaid-funded institutional care, in contrast, is an entitlement.

These waivers facilitate two goals. One, originating from the 1981 Omnibus Budget Reconciliation Act that created waivers, is to constrain rapidly growing long-term care costs by shifting services from expensive institutions to the community (Ryan and Edwards 2015). Another goal, rooted in a mix of cultural changes (e.g., objections to disabled people living in institutions) and legal changes (e.g., the Americans with Disabilities Act), is to ensure that disabled individuals can live in the community instead of in institutions. Medicaid has significantly changed, with HCBS costs rising from less than 10% percent of overall long-term care spending in the early 1980s to 59% in 2019 (KFF 2023).

How do states ration access to nonentitlement HCBS? Rather than focusing on policy design, or who is eligible and what benefits are covered, we focus on the role of administrative processes and procedures—specifically administrative burdens—in rationing access. The choice to provide long-term care supports in the community through waivers, or as a nonentitlement, combined with cost-savings goals, meant that states were going to need to ration. The right to live in the community would be conditional. Yet, while there is robust attention to how states alter eligibility criteria and covered services to control costs, or ration access,

there is little examination of how states use administrative burdens to directly ration—despite the wide array of programs, from housing supports to traditional welfare, that are nonentitlements.

Consequently, we examine how administrative burdens in the Medicaid HCBS waiver programs ration access. We first provide background on the relationship between administrative burdens and rationing more broadly as well as the specific changes in how Medicaid funds and provides long-term care through waiver nonentitlement programs. We then draw on a mixture of primary and secondary sources to detail the role that burdens play in Medicaid HCBS waiver programs. We document both learning and compliance costs generated by rationing, but we also detail the particular role opaqueness plays in generating burdens. We conclude by pointing to the ways that burdens, especially opaqueness, help manage the political conflict between cost savings and disabled peoples' right to live in the community.

Background

How States Ration Access to Rights

There is increasing interest in why basic rights embedded in policy design—including access to health care—are not fulfilled in practice (Barnes 2020; Michener 2018; Zhang and Johnson 2023). In particular, a common explanation is administrative burden, which are the frictions the public experiences when interacting with public services (Herd and Moynihan 2018). While such burdens are easily recognizable, we often underestimate “their scale and invasiveness, and the way they affect marginalized groups” (Herd and Moynihan 2024: 2).

Burdens comprise three subcategories: learning costs include things such as finding out whether one is eligible for a program, what forms need to be filled out, or how to apply for and stay on public programs; compliance costs include things such as filling out forms, providing documentation, or waiting; and psychological costs include stress, frustration, stigma, or loss of autonomy, which arise from difficult experiences had while attempting to access benefits and services.

Burdens in entitlement programs, where those deemed eligible are guaranteed benefits, have received the most attention. Here, they indirectly ration (Barnes 2021; Herd et al. 2013; Ray et al. 2023). While burdens are sometimes attributable to bureaucratic dysfunction or limited capacity, they are often policy making by other means, undermining the exercise of

basic rights. For example, voter ID laws, or limited numbers of polling venues, are designed to increase learning and compliance costs and to make it harder to vote (Herd and Moynihan 2018).

There is robust evidence on burdens in entitlement Medicaid programs, where they indirectly ration. Indeed, burdens help explain why up to 40% of those eligible for Medicaid do not receive benefits (Arbogast, Chorniy, and Currie 2022; Fox et al. 2020; Herd et al. 2013; Lopoo, Heflin, and Boskovski 2020). Most striking is recent research documenting that “procedural” reasons, such as missing paperwork, explained 70% of coverage loss in Medicaid last year (Herd and Moynihan 2018). These burdens are an indirect mechanism limiting benefit receipt rather than a direct one.

Less well understood, however, is how administrative burdens may directly ration access to benefits and services prior to or regardless of eligibility (for exceptions, see Bouek 2023; Zhang and Johnson 2023). This is especially true in Medicaid (for notable exceptions, see KFF 2022; Burns, Mohamed, and O’Malley Watts 2023). Yet many social welfare programs, from child care subsidies to housing vouchers—and increasingly programs within Medicaid—are nonentitlements. They have fixed capacity. Those deemed eligible are not guaranteed access to benefits or services. Nonentitlements are a conditional right. How do states ration access to benefits when capacity is capped? In particular, what kinds of administrative procedures and practices do states employ?

Growth in Nonentitlement Medicaid Spending

Medicaid provides a useful lens to examine these questions because it includes both entitlement and nonentitlement programs. Medicaid provides health insurance for low-income and disabled populations. It covers 1 in 5 Americans and is the primary source of long-term care coverage for the aged and disabled (CRS 2023). Campbell (this issue) describes Medicaid’s overall complexity as “many Medicais,” which is partly driven by its federalist design that allows states significant control over who benefits, what services are covered, and how the program is administered (Michener 2018). And as we describe below, the web of programs that make up Medicaid long-term care are unusually complex.

Medicaid’s growth in nonentitlement spending has been significant. While institutional long-term care is an entitlement, most HCBS are not. Nonentitlement spending, which is nearly all spent on HCBS, has grown from 3% of Medicaid-funded long-term-care in 1989 to more than 27%

today (Murray et al. 2021). Overall Medicaid spending on HCBS rose from less than 10% of total long-term care spending in the 1980s to 59% by 2019 (KFF 2023).

There are a few explanations for this growth. First, community-based long-term care is popular, and the public has demanded that disabled people of all ages should be able to remain in the community rather than be forced into institutions (Ryan and Edwards 2015). Medicaid policies historically preferenced institutional long-term care, where it was an entitlement, and offered limited supports in the community. Public sentiment and the disability-rights movement helped generate the legal framework that enhanced the growth of HCBS. Passage of the 1990 Americans with Disabilities Act (ADA) and the 1999 *Olmstead v. LC* Supreme Court ruling mandated that people with disabilities had a right to live in the community, albeit not an unlimited right (Dinerstein 2016). The *Olmstead* decision was driven by growing discontentment, particularly in the disability-rights movement, with Medicaid's bias toward institutional care, which the claimants successfully argued violated the ADA (Dinerstein 2016; Williams 2000).

The increase in Medicaid HCBS, however, was also wrapped up in budgetary concerns (Gonçalves, Weaver, and Konetzka 2020; Skira, Wang, and Konetzka 2022). Medicaid spending on institutional care was growing rapidly as the population aged. While the hope was expanding access to home care services would better control overall long-term care costs, in practice, aggregate costs did not necessarily decline. While individual costs fell, more people ended up receiving benefits in what is called the “woodwork effect” (Beauregard and Miller 2020; Grabowski 2006). This was especially concerning for states; although Medicaid constitutes 9% of the federal budget, it accounts for approximately 20% of state budgets (MACPAC 2022). The goal, then, was to shift away from expensive institutional care without generating a woodwork effect that could lead to even higher costs overall.

The authority to provide more HCBS under the Medicaid program arose from the 1981 Omnibus Reconciliation Act, which added section 1915(c) to the Social Security Act (Beauregard and Miller 2020). Additional waiver authorities for HCBS come from section 1115, which are focused on experimentation and demonstration projects, although the vast majority of HCBS waiver services are covered by section 1915(c). However, while this provided states waiver authority to cover HCBS, these services were not mandated. States could choose whether to offer them, and if they did, states could waive requirements under Medicaid rules, thus

allowing them to limit services to particular groups or geographic regions and to cap the number of recipients. This flexibility has led some to call it “federalism by waiver” (Thompson and Burke 2009).

The rules that states must follow to use waiver authority and provide HCBS reflect the tension between costs and the right to live in the community. Indeed, the *Olmstead* decision did not sanction a “boundless” right. (Rosenbaum 2016). The state must place people in community settings, but only if this entails reasonable changes to existing programs. At the same time, if the state claimed a financial constraint, it had to “demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace” (*Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 [1999]; cited in Dinerstein [2016: 18]).

In practice, federal rules governing state waivers reflect the attempt to balance increasing access to HCBS with controlling costs. Authorized for 3 to 5 years, with the key rationale of reducing the risk for institutionalization, there are four key requirements services must meet: (1) they cannot cost more than what they would cost in an institution; (2) they must protect people’s health and welfare; (3) they must set “adequate and reasonable” provider standards to meet beneficiary needs; and (4) they must be person-centered (CMS 2024). Over time, waiver authorities have increased, most recently in the Affordable Care Act, which increased incentives for states to expand their Medicaid HCBS (Beauregard and Miller 2020; Ryan and Edwards 2015).

There is an abundant literature focused on waiver policies. This literature documents their complexity, such as the huge variation in who and what is covered. It also describes the quality of services and their impact on beneficiaries (e.g., Thompson and Burke 2009). There is also robust documentation in recent years regarding the gap between service demands and needs versus the actual supply (Kreider and Werner 2023; Vardaman et al. 2021). However, there is little evidence on how states, in practice, directly ration access to these waiver services using administrative practices, such as wait lists, as opposed to policy design, such as limiting benefits to certain groups or geographic regions.

Consequently, we examine how states ration, or more specifically use administrative practices to determine who gets services, either prior to or regardless of eligibility. We analyze waiver programs, and we document how states are employing administrative burdens, especially wait lists, to directly ration access to HCBS for disabled individuals, although we also describe the indirect burdens that arise from program complexity.

Methods

We employed a range of data collection approaches. First, to describe Medicaid waivers and related burdens, including who is eligible, what services are covered, enrollment capacity, and descriptions of how programs manage excess demand (e.g. wait lists), we accessed all approved Medicaid waiver applications from the Center for Medicare and Medicaid Services (CMS). These are publicly available on the CMS website. We also drew on a waiver database generated by the Medicaid and CHIP Payment and Access Commission, which is a nonpartisan legislative branch agency that provides policy analysis and recommendations to the federal government on Medicaid (CMS n.d.; MACPAC 2020).

The number of individuals on state wait lists came primarily from the Kaiser Family Foundation, which conducted surveys of all states (KFF 2022, 2023). We also collected primary documents from states to generate additional details on waiver programs, including how their wait lists function or how they determine priority for eligible individuals to access waiver slots. Some states, such as Texas, Louisiana, and Ohio, had additional details on their wait lists available on their websites. We also cross-checked descriptions in the approved state waiver applications with information available on state websites. States typically employed similar descriptions used in their applications and on their websites. We also searched media coverage during 2022 and 2023 on Medicaid waiver wait lists to cross-check previous data collection.

Finally, in 2023 CMS proposed a rule change regarding Medicaid waiver waitlists (CMS 2023b). Specifically, they proposed that states must report on their wait lists, including the number of people on them, how long people are on them, whether they have been screened for eligibility, and how frequently they are rescreened for eligibility. The rule was finalized in June 2024 (CMS 2024). Using keyword searches (specifically “wait,” “waiting,” and “wait lists”), we reviewed the more than 2,100 comments on these proposed rule changes.¹ While the primary focus of these comments was on changes to payment policies for home care workers included in the broader rule change, we focused on the approximately 7% of comments that discussed the wait list rules. We refer to this rule change throughout the article as the 2024 CMS rule change.

1. Comments will be cited in subsequent endnotes with reference to the proposed rule change, which the CMS posted online at [regulations.gov](https://www.regulations.gov) (CMS 2023a).

Results

We describe the array of administrative burdens that shape access to Medicaid HCBS waiver benefits. We first describe the burdens that indirectly ration access to benefits, including how to find a waiver program and navigating the eligibility process, and then we detail burdens that directly ration access, particularly wait lists. Broadly, we document both learning and compliance costs generated by rationing, but we also detail the particular role opaqueness plays in generating burdens.

Indirect Rationing: Navigating How to Find a Waiver Program

Program Complexity, Opaqueness, and Learning Costs. Federalized programs, including Medicaid, are well understood to be complex and laden with burdens that impede access (Campbell 2014; Michener 2018). Waivers, as we describe below, substantially increase that complexity. Waiver rules, which allow states to limit benefits to specific populations and geographic regions, led to a proliferation of waiver programs within states. Consequently, the first learning cost is figuring out which waiver programs are available and relevant for the disabled person. Both the number of these programs and their complexity, in terms of who and what is covered, make it difficult to figure out which program will serve someone's needs.

As table 1 shows, there are 264 active section 1915(c) and section 1115 waivers for Medicaid HCBS across the 50 states and the District of Columbia. There is no single "type" of waiver in terms of eligible populations or services provided. For example, Arizona covers most of its HCBS through the Medicaid state plan and a section 1115 waiver, while Connecticut covers them through its Medicaid state plan and 10 different 1915(c) waiver programs. There is also no consistency in what each waiver covers, with categories ranging from adult day care and respite services to medical devices and environmental modifications. Table 2 presents an array of varying services and supports. There is also variation within these categories (e.g., which assistive devices or personal care services are covered). It is sometimes unclear how particular services differ from one another (e.g., residential habilitation vs. day habilitation, attendant care vs. personal care services).

There is substantial variation across and within states regarding which populations are eligible, how eligibility is determined, and how many individuals can be served, making these complex systems confusing for the public. Although there are broad categorical populations covered under these waivers (e.g., the aged, developmentally disabled, physically disabled,

Table 1 Data on State Medicaid HCBS Waivers and Wait Lists

	Total waivers	Wait list total for intellectual/ developmental disability waivers (2021)	Wait list total for all other waivers (2021)	Total waiver slots*
Alabama	7	1,000	0	16,569
Alaska	5	772	0	3,218
Arizona	0	0	0	NC
Arkansas	4	3,246	0	3,218
California	6	0	7,960	157,754 (NC)
Colorado	9	3,037	0	51,211
Connecticut	10	1,943	1,627	29,857
Delaware	2	0	0	2,600 (NC)
Florida	4	22,621	54,502	104,104
Georgia	4	7,095	0	49,293
Hawaii	2	0	0	2,735 (NC)
Idaho	2	0	0	16,579
Illinois	9	19,051	0	162,619
Indiana	4	3,153	0	46,246
Iowa	7	5,161	12,238	32,392
Kansas	7	4,512	2,287	30,069
Kentucky	5	9,409	0	33,374
Louisiana	7	0	13,210	24,415
Maine	5	2,292	170	7,704
Maryland	8	9,715	21,464	29,503
Massachusetts	10	0	0	38,787
Michigan	5	0	1,830	30,062
Minnesota	5	0	0	85,742
Mississippi	5	2,864	8,206	32,950
Missouri	11	256	0	46,055
Montana	3	2,184	449	5,787
Nebraska	4	2,989	0	11,395
Nevada	3	313	366	5,774
New Hampshire	4	0	0	9,069
New Jersey	1	0	0	11,878 (NC)
New Mexico	5	3,525	15,225	11,440
New York	5	0	0	83,327 (NC)
North Carolina	5	15,000	885	30,775
North Dakota	5	65	8	6,480
Ohio	8	1,948	0	121,099
Oklahoma	6	5,165	0	27,014
Oregon	6	14	144	64,356
Pennsylvania	7	17,415	0	138,158

(continued)

Table 1 Data on State Medicaid HCBS Waivers and Wait Lists (*continued*)

	Total waivers	Wait list total for intellectual/ developmental disability waivers (2021)	Wait list total for all other waivers (2021)	Total waiver slots*
Rhode Island	1	0	0	NC
South Carolina	8	24,038	152	39,633
South Dakota	4	0	0	4,600
Tennessee	4	4,573	0	9,727
Texas	6	279,388	32,757	74,919
Utah	9	4,231	513	9,152
Vermont	1	0	0	NC
Virginia	4	22,831	0	54,217
Washington	8	0	0	71,155
West Virginia	4	211	2	11,593
Wisconsin	4	1,064	0	76,438
Wyoming	4	520	0	2,890
Washington, DC	3	0	0	6,982
Total	265	481,601	173,995	

Notes: HCBS = home- and community-based services. NC = states that had a 1115 waiver that had no caps on enrollment. Wait list data from KFF (2022) and Burns, Mohamed, and O'Malley Watts (2023). Waiver and waiver slot totals from CMS (2023) and MACPAC (2023).

etc.), with the exception of HIV/AIDS status, each of these categories varies across states, and often within states across waiver programs, in terms of how eligibility is defined. Even seemingly self-evident categories are interpreted differently. For example, in some states intellectual disabilities require a specific IQ score, whereas in other states they are based on broader criteria.

Indirect Rationing: Complicated Application Processes

After finding the right waiver, the next stage is applying. This brings its own burdens. The general burdens involved in applying to Medicaid are well documented (see Herd 2023). However, there are unique burdens associated with Medicaid waiver programs, as we detail below.

Compliance Costs Associated with Applying to Multiple Programs. Beneficiaries are often eligible for multiple waivers. For example, Louisiana

Table 2 Sampling of Services Covered under Waiver Programs

Respite care	Homemaker	Overnight respite care
Personal care services	Day habilitation	Personal assistance services
Attendant care	Residential habilitation	Prevocational services
Day supports	Case management	Independent living skills training
Residential supports	Nursing	Residential-based supported community living
Supported employment	Home health aide	Financial management services
Group supported employment	Transportation	Independent support broker
Environmental modifications	Adult day care	Live-in caregiver

Source: CMS (2023); MACPAC (2022).

has seven waivers. Individuals with intellectual disabilities could qualify for a Residential Options Waiver, a Children's Choice Waiver, a Supports Waiver, and/or a New Opportunities Waiver (MACPAC 2022). The waivers even cover similar services, such as employment supports, day habilitation, and respite. Illinois, in contrast, has nine waivers. Individuals with developmental and intellectual disabilities are eligible for three of them, and those who are aged or have other disabilities are eligible for two of them. Adding to the complexity, there are overlapping services across the waivers.

Some states have waivers that provide temporary services until the individual becomes eligible for a waiver with intensive services. For example, the Texas Home Living waiver was designed for exactly this purpose. Other states, like Maryland, have waivers that provide cash assistance to purchase medical equipment or services until individuals become eligible for waivers providing comprehensive supports.

Compliance Costs Due to Vague Eligibility Categories. Documenting disability can also entail high compliance costs. Some aspects of eligibility are straightforward, such as age-based or disease-based (e.g., HIV/AIDS) requirements. Others are less transparent. For example, California describes eligibility for its developmental disabilities waiver as follows:

To benefit from the HCBS Waiver, you or your family member must meet three conditions: (1) You must have a formal diagnosis of intellectual disability or developmental disability and be a regional center

consumer, (2) You must undergo an evaluation that determines a level of care based on your disabilities that would be available in a licensed health care facility for people with an intellectual disability, and (3) You must have “full scope” Medi-Cal eligibility—either through your own, your family’s eligibility or, if you are under the age of 18, through something called “institutional deeming.” (CDDS 2018)

In addition to complicated bureaucratic language, completing all three steps are intensive, time consuming, and often financially costly. While there is variation, these are typical kinds of compliance costs required to gain eligibility.

Even seemingly straightforward (albeit time consuming) processes are not always straightforward. For example, this Montana mother, whose son has autism, commented on revisions in procedures for proving a diagnosis:

When you say Board Certified. . . you guys have now changed it to be that a neuropsychologist has to actually diagnose him, which would be the third person diagnosing him. He was diagnosed by a social worker who did the ADOS [Autism Diagnosis Observation Schedule] test and a child psychologist. But he is now no longer able to get ABA [Applied Behavioral Therapy] paid for because he didn’t get his diagnosis through a neuropsychologist, which is apparently a new thing. . . . And so I did call. It takes about 8 months to get off the waiting list just to possibly see a neuropsychologist. Also, I just want to make it clear that this is Montana, so there’s only a handful of neuropsychologists in the entire state. (MDPHHS n.d.)

She lays out the compliance costs, including both time and money, involved in proving just one component of the broader eligibility determination process.

Direct Rationing: Accessing the Waiver

Gaining eligibility for Medicaid and a waiver does not necessarily mean gaining access to services. Because these services are not entitlements, one may be deemed eligible for them but still not be able to access waiver benefits. There are enrollment caps, which vary substantially (see table 1). For example, Tennessee and Massachusetts have roughly the same population, but across all waiver programs, the former has an enrollment cap of 9,727, and the latter has an enrollment cap of 38,787. Maryland and Wisconsin have similar populations, but the former’s enrollment cap is

29,503 and the latter's enrollment cap is 76,438. Wait lists are key to how states manage caps—or, to put it differently, how states ration access to HCBS. Indeed, 37 states currently have an active wait list for Medicaid-funded HCBS (see table 1).

Caps and Wait Lists Structure Inequality among the Disabled. Wait lists do not just pattern inequality by inhibiting the right for disabled people to live in the community; they also pattern inequality among the disabled. People with intellectual disabilities constitute more than 70% of wait list slots (Burns, Mohamed, and O'Malley Watts 2023). They also wait longer, with typical wait times of over 5 years compared to just under 3 years for those without intellectual disabilities (Burns, Mohamed, and O'Malley Watts 2023). Given their disability, they especially struggle to independently manage waiver burdens.

Compliance Costs Due to Waiting. Table 1 provides an overview of the magnitude of the problem. Current estimates are that around 700,000 individuals are on wait lists around the country, although as table 1 highlights, there is significant variation around the country in who bears the cost, with places like Texas, Florida, and North Carolina having especially long wait lists. About one half of waiver applications noted the use of a wait list (CMS n.d.).

A significant cost of wait lists is time. States have not systematically reported how long people wait (although the 2024 CMS rule change will require them to do so moving forward), although it is estimated that disabled people spend an average of 3 years waiting (Burns, Mohamed, and O'Malley Watts 2023). In Texas, individuals have been on its "interest list" for up to 17 years (TDHHS n.d.). Media stories are laden with examples of long waits. For example, a 17-year-old in Florida with cerebral palsy, who cannot bathe, use the bathroom, eat, or dress without assistance, has been waiting for 16 years for waiver services. His 60-year-old mother is increasingly concerned that she will not be able to lift him (Griffin 2022).

Opaque Wait List Management Strategies Generate High Learning Costs. There is limited information on wait lists in waiver applications. The first issue is that many states provide little information regarding basic facts about their wait lists. For example, a few states with lengthy wait lists do not note that they have a wait list in their waiver applications. Florida has a wait list with more than 80,000 individuals on it, but they do not discuss it in their application (KFF 2022). Connecticut has a wait list that is up to 10

years long, but they also do not mention a wait list in their waiver application (Smink 2023). Many states also do not publicly report the number of individuals on their wait lists (CMS n.d.).

However, there is especially limited information regarding how wait lists are managed—that is, how states determine which individuals come off the wait list, and when. For example, some states note they operate on a first-come first-served basis, which was noted on 25 out of 135 approved waiver applications (CMS n.d.). While this seems straightforward and transparent, in practice, it is not. Texas provides a good example. Its wait list for those with developmental and intellectual disabilities, which is first come first served, includes nearly 280,000 individuals. More than half have been on the wait list for at least 5 years, with about 85% having been on it for more than 2 years (TDHHS n.d.). What is not clear for families on the wait list is the following: Will addresses be periodically updated? How many times will those who rise to the top be contacted before they are passed over? Texas did not reach between 35% and 50% of those that had moved to the top of the list (TDHHS n.d.).

The other element of opaqueness in Texas, which is common in first-come first-served states, is the use of emergency slots. These slots aim to keep people who are imminently at risk out of institutions. Texas provides little information about how to access them or how they work, even though the state has a large number of these slots, which they call “crisis diversion” waivers. In 2020–21, Texas enrolled 1,300 individuals into the developmental disability waiver program, but the state used more than 300 slots for crisis diversion (TDHHS 2021). A flyer put out by Texas to explain the waiver provides no detail or discussion of the crisis diversion waiver, despite the relatively large number of individuals who ultimately access services this way. (The full flyer is provided in appendix 1.) Note that simply calling to be put on the interest list would not necessarily activate the procedure necessary to get a crisis diversion waiver (TDHHS n.d.; TCHCBS 2018).

States not using a first-come first-served basis pull people off wait lists based on “priority categories,” which generally reflect the level of need and risk of institutionalization but are described vaguely. While there was variation across states, the exact details regarding who would or would not fall into varying priority categories is sparse. Very few eligible individuals could read the approved federal government waiver and have certainty about their precise priority category, which determines whether they receive services. For example, Kentucky’s “Supports for Community Living” waiver, for those with developmental and intellectual disabilities,

details its procedures in the following way: “If waiver capacity is not adequate for all eligible applicants, individuals will be selected for waiver entrance based on the date of their waiver application and their category of need, with individuals in crisis meeting criteria for emergency need receiving preference.” There is no additional detail in the waiver application regarding how the category of need is determined or what qualifies as “emergency need.” Indeed, there is no documentation on Kentucky’s Department of Medicaid services website. The waiver wait list for those with developmental and intellectual disabilities in Kentucky, as of 2021, was more than 9,000 individuals long (Burns, Mohamed, and O’Malley Watts 2023; KFF 2022).

Georgia describes its prioritization approach to its wait list in the following way: “The Department of Behavioral Health and Developmental Disabilities awards funding to individuals who are determined urgent and most in need, based on their planning list needs assessments” (GDCH 2014). In a pamphlet put out by the state titled “A Guide to Medicaid Waiver Programs in Georgia,” they state: “A person may be selected from the waiting list based on the severity of need, the availability of informal/family support, the length of time on the waiting list, and a person’s continued eligibility for the level of care provided in a nursing home or ICF-ID/DD” (GDCH 2014). Georgia’s wait list for those with intellectual and developmental disabilities is more than 7,000 individuals, yet these individuals have very little specific information that can help them understand how and when they will get off that list.

Alabama’s primary waiver for those with intellectual and developmental disabilities provides a few more details on their approach to prioritizing who accesses services. As of 2021, Alabama had 1,000 individuals with intellectual or developmental disabilities on wait lists for Medicaid waiver programs. Similar to Kentucky and many other states, access is determined based on how long one has waited balanced with priority categories. The waiver states: “Applicants are determined eligible for the waiver and placed on a waiting list, ranked by criticality and length of time waiting. Applicants are selected from the waiting list basically in rank order. Selection criteria is defined in the Administrative Code.” There is no more information about “criticality” on Alabama’s Medicaid website or in the waiver. In short, there is almost no transparency in how the state determines who comes off their waiting list to receive services.

Other states do provide more details regarding how priority determines whether and when individuals will receive access to waiver services, but ambiguity remains. For example, Virginia, which has almost 15,000 people

on its developmental disability waiver, prioritizes based in part on when services will be needed, such as in 1 year, 1–5 years, or more than 5 years. Each category has additional details to clarify the placement, but key criteria overlap. For example, the descriptions for both the priority 1 and priority 2 categories include this criterion: “An immediate jeopardy exists to the health and safety of the individual due to the unpaid primary caregiver having a chronic or long-term physical or psychiatric condition or conditions that significantly limit the ability of the primary caregiver or caregivers to care for the individual; there are no other unpaid caregivers available to provide supports.” It is not clear how the state actually determines what is an “immediate jeopardy” to people’s health and safety or what qualifies as a condition that would impede the caregiver’s ability to provide support.

Comments to the federal government, submitted in regard to the 2024 CMS rule change requiring states to be more transparent regarding their wait lists, signaled the lack of transparency. For example, the Medicaid and CHIP Payment and Access Commission, a nonpartisan legislative branch agency that had done research on these wait lists, noted the following: “Greater transparency around waiting lists may help address issues related to beneficiary confusion and accuracy of waiting list information. We heard in interviews that individuals and families may not understand waiting lists or be unaware of how long they will have to wait to receive services” (MACPAC 2022).²

Advocacy groups for people with disabilities also commented. The Tennessee Disability Coalition noted the following: “At this time, it is unclear as to the number of people waiting to receive HCBS in Tennessee. . . . We frequently field calls from people with disabilities and their families who are considering a move to Tennessee with questions about access to HCBS and their quality, and we can only support their decision-making through anecdotes and unreliable or outdated publications.”³ They also noted that the opaqueness “hinders the work of self-advocates and advocacy organizations to better services for people with disabilities.”

The Autism Society of America’s vice president for public policy also commented: “States vary in the criteria and screening process they use to deem individuals [on wait lists] eligible. This then affects their different levels of waitlists, creating confusion among individuals waiting for services. We recommend that CMS requires states to also publicly

2. Comment ID: CMS-2023-0070-1292, June 30, 2023 (CMS 2023a).

3. Comment ID: CMS-2023-0070-0783, June 28, 2023 (CMS 2023a).

report the criteria they use to determine placement and movement within the waitlist.”⁴

Opaqueness as a Way to Conceal Rationing. In recent years, long wait lists for HCBS have become controversial. Indeed, this is what helped motivate the 2024 CMS rule change to HCBS. CMS had received repeated feedback from public responses during community feedback sessions and in response to a formal Request for Information that indicated “a need to improve public transparency and processes” regarding wait lists (CMS 2023a).

Comments on the proposed 2024 CMS rule change illustrated people’s frustrations with the opaqueness of these lists, and the sense that states might manipulate processes. For example, the Michigan Developmental Disability Council said a common definition of a wait list was needed to ensure “that states don’t circumvent the requirement.”⁵ A home care agency in Maine was more specific: “We urge CMS to include additional measures that make clear the criteria in which states determine who is eligible to be on a waiting list, how states determine priority for who comes off of the waiting lists, and *whether states maintain separate waiting lists or registries for people who are eligible for HCBS, but have been determined by the state to not have a prioritized need.*”⁶ In short, advocates were clear that they believed that states might try to conceal the actual number of people waiting for services.

In addition to pressure on the federal government, states received public pressure to address the problems with wait lists. Numerous media stories as well as advocacy from families and organizations, such as Florida’s DD Waitlist Campaign and 2 Long 2 Wait in North Carolina, pushed some states to address their lengthy wait for services (*PBS News Hour* 2023; Tan 2021). Families and advocacy organizations also sued, questioning whether existing wait lists meet the “reasonable” standard for waiting described in the *Olmstead* decision, including class-action lawsuits in Florida and Ohio (DRO n.d.; Ochoa 2019).

In response, some states used additional funding to end wait lists. Oklahoma and Wisconsin increased state funds to shrink their wait lists. As of the spring of 2023, Oklahoma processed 240 of the 5,000 individuals on the wait list with new state funds, approved in 2022 (Daniels 2022; Forman 2023). In 2017, Wisconsin increased funding and changed payment

4. Comment ID: CMS-2023-0070-1375, June 30, 2023 (CMS 2023a).

5. Comment ID: CMS-2023-0070-0967, June 30, 2023 (CMS 2023a).

6. Comment ID: CMS-2023-0070-0251, June 13, 2023 (CMS 2023a); emphasis added.

policies with the express purpose of eliminating its wait lists for adults with disabilities. By 2021, the wait list was gone (Gunn 2021).

Instead of increasing funding, however, other states exacerbated learning costs, using opaqueness to conceal how their wait lists worked, including how individuals could get on them or get off them. Ohio provides an illustrative example. They made changes to their wait lists after a 2016 class-action lawsuit, *Ball v. DeWine*, accused the state of violating the American with Disabilities Act by improperly institutionalizing people with developmental disabilities. In response to the lawsuit, Ohio ceased using a first-come first-served basis and began placing individuals into bins based on priority levels determined by a “waitlist assessment tool.” Individuals are only placed on a waiting list if they have an immediate or current need, which means facing a “substantial risk of harm” in the next 30 days for the former and in the next 12 months for the latter. Ohio then reduced its wait lists by 70,000 individuals, including only those assessed as having immediate or current needs on wait lists (Burns, Mohamed, and O’Malley Watts 2023). A common “risk” is having a primary caregiver who is ill or disabled themselves. Precisely how the state determines whether the risk is for harm within 30 days, within 12 months, or within more than 12 months is not stated.

A key issue is that the key criterion—substantial risk, which determines who can get a spot on a wait list and who is prioritized to come off the waitlist if a spot opens up—is explicitly undefined. The Ohio Department of Developmental Disabilities (n.d.) website notes the following regarding the definition of “substantial risk”:

There’s no definition of substantial risk. This was intentional because no definition will be able to include every situation and/or nuance that can occur, nor can a definition speak to “degrees” of risk or “harm.” Consider the actual definitions of the words themselves: Substantial=having substance, real, true (not imaginary or illusory); Risk=possibility of loss or injury; peril (danger); Harm=physical or mental damage; injury. Assess to what degree of risk there’s to the person and what is the actual likely harm that could occur in order to help you assess the person’s situation. Is it substantial (real, true, and is there substance to it)?

Individuals trying to access HCBS services in Ohio are told that the primary factor determining whether or not they are eligible for services, in practice, cannot be defined. This opaqueness ensures that individuals cannot determine themselves whether they have a chance at receiving services and that the state will likely not be held accountable, by either the public or the

federal government, for those determinations. The opaqueness also allows Ohio to conceal politically unpopular rationing.

Louisiana made a choice similar to Ohio's by switching from a first-come first-served basis to prioritization, which helped them conceal the way they were rationing, as we describe below. The state claimed it had "eliminated" its 25-year-old wait list for those with intellectual disabilities in 2018. They created a tiered system based on how quickly supports would be needed. Applicants are screened with a system titled Screening for Urgency of Need and then placed into one of five categories based on the timing of when services are needed: (1) "emergent" is in the next 90 days; (2) "urgent" is in the next 3–12 months; (3) "critical" is in the next 1–2 years; (4) "planning" is in the next 3–5 years; and (5) no unmet needs.

Effectively, however, Louisiana concealed their wait list by renaming it. While the wait list is gone, there is now a "registry" for individuals falling into categories other than emergent or urgent. As of the spring of 2023, the registry included more than 13,000 individuals; yet Louisiana claims they no longer have a wait list. This is how a *PBS News Hour* (2023) story described what happened: "In 2018, Louisiana's waitlist for IDD services had nearly 30,000 people. To emphasize community-based care, the state introduced a new system called Screening for Urgency of Need (SUN), which identified individuals in urgent or emergent need of services and provided them with the necessary assistance. Those who didn't meet the criteria were placed on a registry and were screened regularly or upon request. By 2020, the waitlist had been completely eradicated."

Under Louisiana's new system, only those classified as emergent or urgent are considered to be "waiting." Those deemed urgent are reassessed every year; those deemed critical every 2 years; those deemed planning every 3 years; and those with no unmet needs every 5 years. Individuals can request to be reassessed.

Budgetary constraints drove Louisiana's choice to effectively eliminate their wait list by renaming it a registry. This is the explanation provided on Louisiana's Department of Health website (2018): "Prior to this change, it would have cost the state \$832 million in new state and federal dollars to address the needs of all of the individuals on the waiting list. However, with this approach, meeting the needs of individuals with disabilities is resolved with a \$43 million investment (passed by the Legislature in 2018) which includes state funds and a federal match." The state does not meet the needs of all disabled individuals. Instead, it chose to ration, meeting the needs of only some disabled individuals.

The following comment on the 2024 CMS rule change, submitted by a home health care agency in South Carolina, illustrates the broader concerns with this kind of opacity: “The disparity in waiting lists across the country is difficult to discern given that states place individuals on the lists and manage them in many different ways. We are concerned that the use of alternate terms like ‘interest list’ and the differing approaches to how such lists are structured may lead to some states opting out of this reporting.”⁷

Discussion

There is robust evidence that Medicaid is embedded with burdens, such as lengthy applications and complex documentation requirements, which indirectly (*de facto*) ration access to the program. We know considerably less, however, about the burdens in nonentitlement Medicaid waiver programs, particularly HCBS for disabled individuals, which directly ration access. Although there is robust research on waivers, there is little discussion of the administrative procedures and burdens that shape who does and does not get access to services. Unlike entitlement programs, where access is guaranteed if individuals can navigate burdens, nonentitlement programs have limited capacity. They have to directly ration. We highlight the particular sets of burdens embedded in nonentitlement programs. We also demonstrate the distinct role that opacity plays, both by generating burdens and by concealing rationing, therein helping manage the political conflict between cost controls and disabled people’s right to live in the community.

Forms of *de facto* rationing, which are common in Medicaid entitlement programs, are exacerbated in nonentitlement waivers. Federalism ensures that there is significant state variation in how entitlement Medicaid programs are designed, administered, and experienced on the ground by the public (Herd et al. 2023; Michener 2018). By design, in large part because of cost controls, waivers allow for even greater variance than do Medicaid entitlement programs. With nearly 300 waiver programs, and little uniformity in their design and eligibility processes, this opacity and complexity generate high learning costs, making it difficult to sort out which programs and services are available, how to apply for them, and how to navigate complicated administrative requirements.

Direct rationing, however, creates unique burdens. The most common administrative procedure used to ration, and a key source of administrative

7. Comment ID: CMS-2023-0070-0903, June 29, 2023 (CMS 2023a).

burden, is wait lists. Despite their ubiquity, there is little existing research on wait lists (for exceptions see Bouek 2023; Burns, Mohamed, and O'Malley Watts 2023). We documented the distinct compliance and learning costs that come from this rationing technique. The compliance costs are exceptionally high, with individuals waiting up to 17 years in some states to access services. Less acknowledged, however, is that wait list management strategies are also very opaque, exacerbating learning costs. The public is provided with limited information about how wait lists function in practice.

Attention to the ways burdens can be used to directly ration services provides unique insights into the politics of burdens, specifically their effectiveness at concealing unpopular policies. While the opaqueness increases learning costs for beneficiaries, it provides political cover for states. Opaqueness in how wait lists are presented, managed, and even reformed allows policy actors to manage conflict. On the one hand, waiver programs are intended to save money. On the other hand, they are intended to ensure disabled people's right to live in the community. HCBS is popular, disabled people are viewed as "deserving," and there is a legal basis for their right to live in the community; therefore, attempts to ration pose a political problem. Concealing rationing is a way for policy actors to manage the reality that disabled people's right to live in the community is in fact a conditional right.

Attention to burdens that are used to directly ration also highlights the unique ways burdens generate inequality. Disabled people do not have a "right" to live in the community because these services are delivered through nonentitlement programs, and burdens exacerbate the costs disabled people pay for this choice. While social workers or caregivers sometimes help disabled people navigate burdens, inequitable access is institutionalized when states design programs that eligible populations by and large cannot navigate on their own. This also exacerbates inequality among disabled people. Those with cognitive disabilities are the most likely to face long wait lists, and long waits, for services, and they are also the least likely to independently navigate burdens. There is also evidence that racialized minorities have more limited access to waiver services (Harrington and King 2016). For example, a study of Medicaid claims records in North Carolina found that Black and Hispanic children with intellectual or developmental disabilities were significantly less likely to have a waiver slot than were comparable white children (Franklin et al. 2022).

These findings have important policy implications, especially given the use of waivers to cover a large fraction of long-term care services and the

broader growth in Medicaid nonentitlement spending. Indeed, federal policy makers have been paying increasing attention to waivers and wait lists. In particular, the programs' opaqueness has come under scrutiny. New federal rules enacted in 2024 require states to increase "transparency" around their waiver programs (CMS 2024). States must annually disclose the length of wait lists and how long people will wait for services once they are on a wait list as well as provide more details on how wait lists will be maintained. The question is whether states will abide by these new rules and how aggressively the federal government will enforce them. Stakeholder groups' public comments on the proposed rule change were almost universally supportive, but they did also express a concern that it would be easy for states to manipulate reporting by methods such as using alternative names for wait lists (CMS 2024). More broadly, this analysis points to the problems with this kind of programmatic complexity, the burdens it generates for the public, and the potential for that complexity to allow policy actors to—deliberately or not—mislead the public.

We do want to note a few limitations to this study. First, we did not attend to "redemption" costs, the burdens encountered when actually using the benefits, or what people experience once they come off a wait list (Barnes 2021). There are too few home-care workers to meet the demand, with low pay a central problem. As one home- and community-based care provider noted, "The largest barrier in the state is the pay because the reimbursement rate versus what you can pay your caregiver, puts you out of competition with like a gas station" (Vardaman et al. 2021, cited in Herd 2023: 518). Further study of this important and growing problem is needed. Second, the complexity of waiver programs, which we illustrate, makes these programs, including the kinds of burdens participants face, especially challenging to document. However, more systematic interviews with the public, especially those who are disabled or disabled family members, would be fruitful to help understand how burdensome procedures impact how they view waiver programs as well as their willingness to navigate these eligibility systems, including whether they get or seek help to do so. Finally, studies that focus on policy makers and the bureaucrats that design and implement these programs would be especially helpful to further unpack how they think about the complexity and opaqueness of these programs.

Conclusion

The use of Medicaid waivers to ensure disabled people's right to live in the community means that, in practice, it is a conditional right. Administrative

burdens help states manage this conditionality via rationing, and these burdens are also politically useful given public support for home and community-based care. The opaqueness and associated burdens with waiver programs are a way to conceal rationing, thereby demonstrating how burdens “neatly carry out the ‘how’ in the production of inequality, while concealing . . . the why” (Ray, Herd, and Moynihan 2023: 139).

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