



Helping Those on HCBS Waiting Lists: Positive Impacts of the ACA

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The Affordable Care Act and Medicaid Expansion may help states decrease waiting lists for home and community-based services (HCBS).

- States expanding Medicaid have cost savings and increased revenue that could be used to expand HCBS programs.
- 2021 data shows that about 70% of people on HCBS waiting lists live in non-expansion states.
- 13 of 14 states reporting no HCBS waiting lists implemented expanded Medicaid expansion, and the fourteenth (South Dakota) voted to expand Medicaid in 2022

The ACA helps expand HCBS.

- The ACA includes important provisions to increase, improve, and extend options through which states may provide HCBS.

Medicaid expansion helps provide services for people on waiting lists.

- Expanded eligibility for Medicaid means that some of people on waiting lists who could not qualify for Medicaid under the traditional disability categories can now access Medicaid services, which includes some community-based services.

Medicaid cuts will likely increase HCBS waiting lists.

- Proposals to cut Medicaid will drastically decrease federal funding to states without significantly changing state responsibilities to care for people with disabilities and other populations served by HCBS.
- HCBS services are cost-efficient relative to institutions, but are still costly and thus unlikely to be expanded under decreased federal funding.
- Many states anticipate a growing demand for HCBS services while facing serious workforce shortages and related rising costs.

Introduction

Expanded services and coverage under the Affordable Care Act (ACA) and its Medicaid expansion provide states opportunities to decrease waiting lists for Medicaid home and community-based services (HCBS) and generally increase access to services for people with disabilities. HCBS programs offer states a great degree of flexibility to design a Medicaid-funded program that targets a special set of Medicaid services only to a limited population, both in size and type of service needs. Demand for HCBS programs has increased with the growth in the population of people with disabilities and as states move away from institutional settings. The demand for Medicaid HCBS outpaced available slots soon after the programs began.¹ The ACA responded to the increasing demand for HCBS by increasing opportunities and incentives for states to expand and innovate their HCBS programs. Those HCBS opportunities provide states with more flexibility in designing programs and create broader availability of HCBS, thus putting less pressure on traditional HCBS programs with waitlists.² The ACA also created Medicaid expansion, which covers many adults with disabilities, including some on HCBS waiting lists, who previously fell into coverage gaps and could not access non-HCBS Medicaid services.³ The ACA has had a positive impact on those needing HCBS.

Medicaid Expansion does not increase waiting lists

HCBS waivers are designed to allow waitlists as part of state flexibility

In general, Medicaid programs cannot have waiting lists for services—any services a person qualifies for must be made available.⁴ But Medicaid waiver programs can cap enrollment and maintain a waitlist if demand is greater than the enrollment cap. Since 1981, states have been able to use HCBS waivers to help provide long-term services and supports outside of institutions. These waiver programs allow states to waive certain Medicaid requirements and allow them to craft a program of eligibility and services, such as respite for family caregivers, that are not available to the broader population of Medicaid enrollees and applicants.⁵ States have a great deal of flexibility in HCBS programs and may ask to increase the enrollment cap or otherwise amend their programs as needs of the HCBS population changes. For example, many states have HCBS programs that allow a person to have greater income than traditional Medicaid eligibility limits or the state may treat children as their own household so parental income will not count in an eligibility determination.

Waiting lists for HCBS are not new

Waiting lists for HCBS are part of the design of many HCBS programs offered through Medicaid 1915(c) or 1115 waivers, which allow states to create waiting lists that otherwise

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would not be permissible.⁶ HCBS programs are generally a “win-win” for both state budgets and people with disabilities. People with disabilities and their families generally prefer HCBS over institutional alternatives, while HCBS are also more cost-efficient and help states meet legal obligations regarding the rights of people with disabilities.⁷ Although HCBS programs have become increasingly more cost-efficient, state HCBS expenditures and waitlists have continued to grow.⁸ Although there is variation among states and HCBS programs, between 2016 and 2021, the number of people on waiting lists fluctuated, from 656,000 in 2016 to 820,000 in 2018, back to 656,000 in 2021.⁹

However, waitlists remain an incomplete picture of need for these services. For example, the lists likely represent fewer people than it may appear, as many people are on waiting lists for multiple HCBS programs, but will ultimately only use one.¹⁰ States have expanded HCBS enrollment at a rate of about 6 percent each year, but this expansion has not kept up with the demand for HCBS. In fact, many states report a growing need for HCBS waiver services, while also expressing serious concern about workforce shortages that have been exacerbated by the COVID-19 pandemic.¹¹

The size of waiting lists depends on the HCBS program and the state. People with intellectual and/or development disabilities (ID/DD) represent most of the waiting list population, even though physical/ambulatory disability is the most prevalent disability in the United States.¹² Although people with ID/DD are the most prevalent waitlist population, many states report concern about a growing need for HCBS services, particularly for older adults and children with disabilities.¹³

Medicaid expansion may help states shorten HCBS waiting lists.

Overall studies show that Medicaid expansion is good for state budgets.¹⁴ Many states that expanded Medicaid have generated savings and revenue that not only offset the cost of expansion, but also create a surplus that could be used to expand HCBS.¹⁵ Research shows that Medicaid expansion generally has a positive impact on state budgets. For example, a case study on Medicaid expansion in Michigan estimated that expansion would lead to a \$43 million increase in net revenue for SFY 2021.¹⁶ Similarly, Virginia realized significant cost savings from expanding Medicaid in 2019. The state initially estimated it would save \$270 million in SFY 2020, but after one year of expansion, savings were larger than expected. The governor’s amended budget for FY 2020 included additional savings of nearly \$211.7 million for a total of over \$481 million.¹⁷ In 2021, the American Rescue Plan (ARPA) added a financial incentive for Medicaid expansion by increasing a state’s base Federal Medical Assistance Percentage (FMAP) by 5% for two years in states newly expanding Medicaid. This increase is in addition to the ACA’s current enhanced FMAP of 90% for Medicaid expansion states.¹⁸ Although states that

expand Medicaid may not generate enough savings to completely clear waitlists, the savings could make a significant impact on waitlists by providing funding to expand those services.¹⁹

Some opponents have argued that Medicaid expansion diverts funding from older adults and people with disabilities and exacerbates waiting lists. Yet, studies indicate this is untrue. Medicaid Expansion does not increase HCBS waiting lists and actually provides services to people with disabilities that were otherwise without them, including people on waitlists.²⁰ As of 2021, fourteen states reported having no wait lists for Medicaid HCBS. Thirteen of those fourteen states had expanded Medicaid and the 14th state (South Dakota) voted to expand Medicaid in 2022.²¹ In comparison, data from that same year shows that over nearly 70% of people on Medicaid waiting lists lived in non-expansion states. In addition, as explained below, expanding Medicaid provides services some individuals who are awaiting HCBS.²²

Medicaid expansion helps provide services for people on waiting lists

The ACA does not shift resources from people with disabilities on waitlists, but brings other people with disabilities into Medicaid who previously had no or very limited access to needed health care. In states that expanded Medicaid, many adults who have disabilities who do not meet the “disabled” standard for Medicaid or whose income exceeds some of the limited Medicaid eligibility categories, such as for parent-caretakers, have gained access to necessary Medicaid services, including HCBS. This includes individuals with disabilities, such as adults with behavioral health conditions or other chronic health conditions.²³ In these states, such individuals may now join the large majority of people on waiting lists who receive non-HCBS Medicaid services, such as medical care and some in-home services such as personal care services in some states.²⁴ The ACA did not split the piece of the “pie” representing services for people on the waiting lists among more people but instead the ACA grew the pie such that more people with disabilities actually receive some pie.

Medicaid cuts will make HCBS waiting lists longer and slower

Proposals to change the Medicaid program by cutting federal spending will likely make HCBS waiting lists much worse. However, this cut in federal spending simply shifts costs to the states. States will not have substantially different responsibilities and will have less federal funding, yet their residents will still have the same needs. While HCBS is more cost-efficient than institutional care, it is still a significant part of state budgets.²⁵ Given that HCBS participants are often some of the most costly when looking at Medicaid per person expenditure averages by group, it is likely that when looking to save money, states look at trimming, not expanding, HCBS programs.²⁶

The responsibility on states to meet the needs of people with disabilities, which has historically focused on institutional care, does not go away under decreased funding, but will only rise as our population ages and the prevalence of disability continues to increase. State funded institutions and services for people with disabilities pre-date Medicaid by more than 100 years.²⁷ There is no indication that Medicaid cuts or administrative red tape will do anything to eliminate this duty, but overwhelming evidence indicates they make it harder for states to provide these costly and critical HCBS services. Promises of increased flexibility are not likely to give the states more money to work with such that they could really expand HCBS. Instead states indicate that they desperately need increased funding to address challenges.

Conclusion

Overall, expanded Medicaid coverage and services even if not specific to people with disabilities who need HCBS has helped those individuals and not taken services away. The need for HCBS is rising in states as are costs due to workforce issues. Medicaid cuts are more likely to harm access to HCBS than help people with disabilities receiving Medicaid.

ENDNOTES

¹ The HCBS 1915(c) waiver program launched during the Reagan administration in 1981 and was incorporated into the Social Security Act in 1983. There was a slowdown in waiver expansion in the late 1980s as the federal government tightened scrutiny on the program in the mid-1980s, which lasted until 1994 when the waiver process was simplified. Carol Beatty, *Implementing Olmstead by Outlawing Waiting Lists*, 49 TULSA L. REV. 728-29 (2014), <https://digitalcommons.law.utulsa.edu/cqi/viewcontent.cgi?referer=&httpsredir=1&article=2906&context=tlr>; CMS, Home and Community Based Service Authorities, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html> [hereinafter CMS, HCBS Authorities]. States increasingly began to create HCBS programs under that authority, but by 1990 the waivers only served 500,000 people, compared to 1.5 million served through 1915(c) waivers in 2013. Allen J. Le Blanc, M. Christine Tonner & Charlene Harrington, *Medicaid 1915(c) Home and Community-Based Waivers Across the States*, 22 HEALTH CARE FINANCING REV. 159, 170 (2000), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4194662/pdf/hcfr-22-2-159.pdf>. Demand for services continues to outpace available slots; Alice Burns et al., Kaiser Family Found., *A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021* (2022), <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021/> [hereinafter KFF Waitlists 2016-2021]. By the late 1990s, multiple lawsuits in different states challenged the lack of available HCBS services and the waitlists. *See, e.g., McMillan v. McCrimmon*, 807 F. Supp. 475, 481 (C.D. Ill. 1992); *Benjamin H. v. Ohl*, No. 3:99-0338, 1999 WL 344783552 (S.D. W. Va. July 15, 1999) (granting a preliminary injunction for access to ICF level services, including HCBS); *Doe v. Chiles*, 136 F.3d 709, 717 (11th Cir. 1998) (finding long waiting lists and waits of several years violated Medicaid's reasonable promptness requirement). Although cases were initially successful, courts quickly began to find in the state's favor and upholding waitlists. *See, e.g., Makin v. Hawaii*, 114 F. Supp. 2d 1017 (D. Haw. 1999) (finding that the plaintiffs, representing the over 800 individuals on Hawaii's waiting lists, did not have a right to waiver services under Medicaid's reasonable promptness requirement).

² The ACA created the Community First Choice option to provide in-home personal attendant services and supports to individuals. *See, e.g.*, 42 U.S.C. 1396n(k); Medicaid.gov, *Community First Choice (CFC) 1915(k)*, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html> (describing the origins of the program in the ACA and that five states have approved CFC services). It also amended the § 1915(i) state plan option for HCBS to make it more attractive to states and extended the Money Follows the Person Rebalancing Demonstration to continue helping people move from institutional settings back to the community. It also created the Balancing Incentive Payment Program that ended gradually between 2015 and 2017 that gave states federal incentives to prioritize HCBS services. *See* David Machledt, Nat'l Health L. Program, *Promoting Community Living: Updates on HCBS & the ACA* (2012), <https://healthlaw.org/resource/promoting-community-living-updates-on-hcbs-the-aca/>.

- ³ See Molly O'Malley Watts et al., Kaiser Family Found., *State Variation in Medicaid LTSS Policy Choices and Implications for Upcoming Policy Debates* (2021), <https://www.kff.org/report-section/state-variation-in-medicaid-ltss-policy-choices-and-implications-for-upcoming-policy-debates-issue-brief/> (See Box 1) [hereinafter KFF Policy Choices 2021].
- ⁴ See 42 U.S.C. § 1396a(a)(8); see also 42 C.F.R. §§ 440.230(c); 440.240.
- ⁵ See 42 U.S.C. § 1396n(c).
- ⁶ Waiting lists are not a feature of all HCBS programs, including § 1915(i) and Community First Choice (§ 1915(k)) programs, which offer similar services to what is often a narrower population. See CMS, HCBS Authorities, *supra* note 1.
- ⁷ U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-23-105457, *Medicaid: Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities* 1-4 (2023), <https://www.gao.gov/assets/gao-23-105457.pdf> [hereinafter GAO MEDICAID EXPENDITURES]; Joseph Caldwell, Brandeis Lurie Inst., *Reducing Costs for Families and States by Increasing Access to Home and Community-Based Services* (2022) 1,4, <https://heller.brandeis.edu/community-living-policy/images/reducing-cost-hcbs.pdf> [hereinafter Lurie Inst. Reducing Costs for Families]; Arpita Chattopadhyay, Yang Fan & Sudip Chattopadhyay, *Cost-efficiency in Medicaid Long-term Support Services: The Role of Home and Community Based Services*, SPRINGERPLUS (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3710567/>.
- ⁸ Molly O'Malley Watts, Kaiser Family Found., *Medicaid Home & Community-Based Services: People Served and Spending During COVID-19* (2022) Fig. 2, <https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/> (noting that HCBS continues to make up a larger percentage of Medicaid LTSS spending) [hereinafter KFF HCBS During COVID-19]. Between 2019 and 2020 there was modest growth in HCBS spending. *Id.*
- ⁹ KFF Waitlists 2016-2021, *supra* note 1.
- ¹⁰ KFF Waitlists 2016-2021, *supra* note 1. For example, one study found that when waiver services are provided on a "first-come, first-serve basis" many people will enroll based on anticipation of future need. Medicaid & CHIP Payment & Access Comm'n, *Issue Brief: State Management of Home-and Community-Based Services Waiver Waiting Lists* (2020), <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf> [hereinafter MACPAC HCBS Waiting Lists].
- ¹¹ See MACPAC HCBS Waiting Lists, *supra* note 10, at 10; KFF HCBS During COVID-19, *supra* note 8.
- ¹² See KFF Waitlists 2016-2021, *supra* note 1 (noting that people with I/DD make up 84% of the waiting lists in states that do not screen for waiver eligibility and 60% in states that do determine eligibility before placing people on waiting lists. Ctrs. Disease Control & Prevention, *Disability Impacts All of Us*, <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html> (on prevalence of disability in the United States).
- ¹³ See, MACPAC HCBS Waiting Lists, *supra* note 10, at 10.
- ¹⁴ The White House, *The Effects of Earlier Medicaid Expansions: A Literature Review* (2021),

<https://www.whitehouse.gov/cea/written-materials/2021/06/22/the-effects-of-earlier-medicaid-expansions-a-literature-review/> [hereinafter White House, *Effect of Medicaid Expansion*].

¹⁵ See Matthew Buettgens & Urmi Ramchandani, Urban Institute, *Research Report: 3.7 Million People Would Gain Health Coverage in 2023 If the Remaining 12 States Were to Expand Medicaid Eligibility* 19-20 (2022), <https://www.urban.org/sites/default/files/2022-08/3.7%20Million%20People%20Would%20Gain%20Health%20Coverage%20If%20the%20Remaining%20States%20Were%20to%20Expand%20Medicaid.pdf> (noting that studies show net gains in several states that have expanded Medicaid); Jesse Cross-Call, Ctr. Budget & Policy Priorities, *Medicaid Expansion Continues to Benefit State Budgets, Contrary to Critics' Claims* (2018), <https://www.cbpp.org/research/health/medicaid-expansion-continues-to-benefit-state-budgets-contrary-to-critics-claims>.

¹⁶ David Slusky, Econofact, *Impact of Medicaid Expansion on State Budgets and Mortality* (2021), <https://econofact.org/impact-of-medicaid-expansion-on-state-budgets-and-mortality> (citing Helen Levy et al., *Macroeconomic Feedback Effects of Medicaid Expansion: Evidence from Michigan* 45 J. HEALTH POL. POL'Y L. 4-58 (2020), <https://read.dukeupress.edu/jhpl/article-abstract/45/1/5/140654/Macroeconomic-Feedback-Effects-of-Medicaid>).

¹⁷ The Commonwealth Fund, *The Impact of Medicaid Expansion on States' Budgets* (2020), <https://www.commonwealthfund.org/publications/issue-briefs/2020/may/impact-medicaid-expansion-states-budgets#25>.

¹⁸ White House, *Effect of Medicaid Expansion*, *supra* note 14,

¹⁹ Whether the savings from expansion would be sufficient to address waitlist needs, should a state choose to spend the savings in that way, would vary greatly by state because of waitlist numbers, average cost of waiver services, federal matching percentage by state and program, and other factors. *See, e.g.*, The State of Virginia generated cost estimates for decreasing the state's ID/DD waitlist of 8,800 and estimated it would cost about \$60.0 million by FY 2012 to move 2,165 individuals on to the ID/DD comprehensive waiver. Summary of Cost Analysis—SB627 Workgroup, App. A, <https://dbhds.virginia.gov/library/developmental%20services/sb627%20cost%20analysis%20impact%20analysis%20se%20p%2029.pdf>.

²⁰ Jesse Cross-Call, Ctr. Budget & Policy Priorities, *Medicaid Expansion Boosts Coverage and Services for People With Disabilities, Despite Critics' Claims* (2021), <https://www.cbpp.org/blog/medicaid-expansion-boosts-coverage-and-services-for-people-with-disabilities-despite-critics>.

²¹ Kaiser Family Found., *Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility* (2021), <https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>; *see also* Kaiser Family Found., *Status of State Medicaid Expansion Decisions: Interactive Map* (2023), <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

²² *Id.* Based on this data nearly 70% of people on HCBS waiting lists live in non-expansion states. This calculation excluded both South Dakota, which had not implemented Medicaid expansion in 2021 and North Carolina which recently voted to expand Medicaid.

²³ See KFF Policy Choices 2021, *supra* note 3; MaryBeth Musumeci & Kendal Orgera, Kaiser Family Found. *People with Disabilities Are At Risk of Losing Medicaid Coverage Without the ACA Expansion* (2020), <https://www.kff.org/medicaid/issue-brief/people-with-disabilities-are-at-risk-of-losing-medicaid-coverage-without-the-aca-expansion/>.

²⁴ See KFF Waitlists 2016-2021, *supra* note 1 (noting that, of the 36 states responding to the to the survey, all but five reported that people were receiving at least some state plan HCBS).

²⁵ KFF HCBS During COVID-19, *supra* note 8; see also Lurie Inst. Reducing Costs for Families, *supra* note 7 (noting that HCBS can be less-costly than institutional care); CMS, *Home and Community Based Services*, <https://www.cms.gov/outreach-and-education/american-indian-alaska-native/aian/ltss-ta-center/info/hcbs> (also noting that HCBS is less costly than institutional care).

²⁶ GAO MEDICAID EXPENDITURES, *supra* note 7, at 1; see also, e.g., Nat'l Assoc. of State Units on Aging, *The Economic Crisis and its Impact on State Aging Programs* 8 (Dec. 2008), <http://www.advancingstates.org/sites/nasuad/files/EconomicSurveyReport12.8.08.pdf> (finding states cutting eligibility and services when budget cuts needed to be made).

²⁷ Beatty, *supra* note 1, at 716-18.