



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 saved millions in spending on people with disabilities, savings that could be used to expand HCBS programs.
- From 2013 to 2015, states that expanded Medicaid added only one quarter the number of people to their waitlists as states that did not expand Medicaid.
- Nine of the 11 states reporting no waiting lists expanded Medicaid.

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 categories now access Medicaid services, which includes some community-based services.

Block granting and per capita caps for Medicaid will likely increase HCBS waiting lists.

- Proposals to decrease federal Medicaid spending through block grants or per capita caps 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.

The Affordable Care Act (ACA) and Medicaid expansion provide states opportunities to decrease waiting lists for Medicaid home and community-based services (HCBS) and generally increase access to services. 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 for people with disabilities. The demand for Medicaid HCBS outpaced available slots in such programs 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. 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. The ACA has had a positive impact on those needing HCBS.

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

In general, Medicaid programs cannot have waiting lists for services—if a person qualifies for a service, that service must be available to him.² Since 1981, states have been able to use HCBS waivers to 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 that are not available to the broader population of Medicaid enrollees and applicants, such as respite for family caregivers. States can also cap enrollment for these programs and have a waitlist if demand is greater than the enrollment cap. 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 in traditional Medicaid or the state may treat a child as his own household so the parental income will not count in an eligibility determination.

Medicaid expansion may help states shorten waiting lists.

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.³ For example, Arkansas saved a projected \$45.4 million in spending just on enrollees with disabilities in SFY 2016.⁴ Since Arkansas spends an average of about \$20,100 per waiver recipient per year, those savings could pay for over 2,200 new waiver slots; an increase that could nearly cut the state's waitlist by over 75 percent.⁵ Similarly, if Virginia expanded Medicaid, the estimated savings and revenue would generate about \$500 million over the next 9 years, which, even accounting for the state share of the expansion, could move thousands of people off Virginia's waiting lists.⁶ In contrast, it would cost Texas \$2.4 billion in state funds to clear the waitlists, just accounting for the HCBS costs, but would only cost \$310 million in state funds for Medicaid expansion.⁷ This difference reflects the enhanced federal match for Medicaid expansion and the state examples show how Medicaid expansion may improve

waiting lists but that refusing to expand Medicaid would not generally resolve the waiting lists issue.

Expanding Medicaid does not increase waiting lists while instead providing services to adults without disabilities. Overall, from 2013 to 2015, the 19 states that have not expanded Medicaid added a total of over 86,000 people to their waiting lists, more than four times the total waiting list growth in the 31 states (and Washington, D.C.) that did expand Medicaid.⁸ In fact, nine of the 11 states that report they have no waiting lists are expansion states and the states with the longest waiting lists have not expanded Medicaid.⁹

The ACA helps states expand HCBS.

The ACA did not exclude people with disabilities or fail to address HCBS waiting lists. In fact, the ACA included provisions to expand HCBS availability in states by increasing, improving, and extending options through which states may provide HCBS.¹⁰ The ACA also created the Community First Choice option and the Balancing Incentives Payment Program, which reward states through increased federal matching funds to increase access to HCBS programs — much the same way states are rewarded for expanding Medicaid. Evidence suggests that people have shifted from traditional HCBS waivers into these new HCBS programs related to the ACA.¹¹ This indicates a broader availability of HCBS and thus less pressure on the traditional HCBS programs that have waitlists.

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 that 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. This includes individuals with disabilities, such as adults with autism or chronic illnesses.¹² 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.¹³ The services for people on waiting lists “pie” did not get split among more people, but instead got bigger such that more people with disabilities actually receive some pie.

HCBS waiting lists will get longer and slower under Medicaid block grants and per capita caps.

Proposals to change the Medicaid program by capping federal spending through block grants or per capita caps will likely make HCBS waiting lists much worse. Such proposals will do exactly what they say, cut federal spending. However, this cut in federal spending simply shifts

costs to the states. States will not have substantially different responsibilities under block grants and will have less federal funding, yet their citizens will still have the same needs. While HCBS is more cost-efficient than institutional care, it is still a significant part of state budgets.¹⁴ 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.¹⁵

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.¹⁶ There is no indication that block grants or per capita caps will do anything to eliminate this duty, but overwhelming evidence indicates they would sharply cut federal funding and thus 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.

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 would not be permissible.¹⁷ 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.¹⁸ Although HCBS programs have become increasingly more cost-efficient, waiting lists have grown almost every year since they have been tracked, as have state HCBS expenditures.¹⁹ Although there is variation among states and HCBS programs, from 2005 to 2015 waiting lists increased by an average rate of 14 percent per year.²⁰ This increase could reflect the increased prevalence of people with disabilities in the U.S. population. However, 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.²¹ States have expanded HCBS enrollment at a rate of about 6 percent each year, but this expansion has not kept up with the population requesting the services.²²

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.²³ Although people with ID/DD are the most prevalent waitlist population, children’s HCBS programs are the most likely to have waiting lists.²⁴ However, waiting lists for children’s programs are actually concentrated in certain states. For example, two-thirds of the children’s

program waitlist population is concentrated in Texas, a state that has not expanded Medicaid.²⁵

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 LAW REV. 728-29 (2014), <http://digitalcommons.law.utulsa.edu/cgi/viewcontent.cgi?article=2906&context=tlr>; Authorities, Ctrs. Medicare & Medicaid Servs, <https://www.medicaid.gov/medicaid/hcbs/authorities/> [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.cms.gov/Research-Statistics-Data-and-Systems/Research/HealthCareFinancingReview/downloads/00winterpg159.pdf>; Terrence Ng, et al., *Medicaid Home and Community-Based Services Programs: 2013 Data Update*, KAISER FAMILY FOUND. (Oct. 18, 2016), <http://kff.org/medicaid/report/medicaid-home-and-community-based-services-programs-2013-data-update/> [hereinafter KFF HCBS Update]. 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 *See* 42 U.S.C. § 1396a(a)(8); *see also* 42 C.F.R. § 440.230(c); 42 C.F.R. § 440.240.

³ Deborah Bachrach, et al., *States Expanding Medicaid See Significant Budget Savings and Revenue Gains*, STATE HEALTH REFORM ASSISTANCE NETWORK (Mar. 2016), http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2016/rwjf419097. In addition, Medicaid spending growth in expansion states has also been less than in non-expansion states. *Id.*

⁴ *Id.* at 4.

⁵ This figure was calculated based on the cited savings and average waiver participant cost in Arkansas. The average cost per 1915(c) waiver participant in Arkansas as of 2013 was 20,097 and the total waiting list as of 2015 in Arkansas was 2,893. KFF HCBS Update, *supra* note 1, at 39, 46. The estimated number of additional waiver slots is supported by reports from Arkansas that increasing funding for their Elder Choices waiver by \$22.7 million served an additional 683 individuals; increasing spending for the waiver for adults with physical disabilities by \$8.6 million served an additional 800 individuals; and increasing spending for the Alternative Community Services by \$55.6 million served an additional 273 individuals. STAFF OF S. COMM. ON HEALTH, EDUCATION, LABOR, AND PENSIONS, 113TH CONG., SEPARATE AND UNEQUAL: STATES FAIL TO FULFILL THE COMMUNITY LIVING PROMISE OF THE AMERICANS WITH DISABILITIES ACT 68 (2013), <http://www.help.senate.gov/imo/media/doc/Olmstead%20Report%20July%2020131.pdf>. The waitlist in Arkansas is estimated to be about 3,007 individuals as of 2014. *Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers Services*, KAISER FAMILY FOUND. (2014), <http://kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0>.

⁶ It is estimated that Virginia would save \$1.64 billion and spend about \$1.6 billion in costs on Medicaid expansion over nine years. At the same time, the state would see an additional \$492 million in revenue from sales and income tax over the next nine years as a result of the expansion. Massey Whorley & Michael J. Cassidy, *Medicaid Expansion Would Pay for Itself*, THE COMMONWEALTH INST. (Aug. 2013), www.thecommonwealthinstitute.org/wp-content/uploads/2013/08/medexpays_for_itself.pdf. 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, <http://www.dbhds.virginia.gov/library/developmental%20services/sb627%20cost%20analysis%20impact%20analysis%20sep%2029.pdf>.

⁷ As of 2013, Texas had 204,550 people on the 1915(c) waitlist and spent an average of \$26,733 per person on HCBS waivers per year, which does not account for other Medicaid services individuals may use. KFF HCBS Update, *supra* note 1, at 39, 46. Texas has a federal matching rate for traditional Medicaid services of 56.18 and 92.33 for Medicaid expansion for 2017, which means the state gets a greater match for state dollars that go toward Medicaid expansion. ASPE FMAP 2017 Report, <https://aspe.hhs.gov/basic-report/fy2017-federal-medical-assistance-percentages>. The coverage gap for Texas, the number of people who would be eligible for Medicaid if it were to be expanded, is estimated at 684,000. Rachel Garfield & Anthony Damico, *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid*, KAISER COMM'N ON MEDICAID AND THE UNINSURED 8 (Oct. 2016), <http://kff.org/uninsured/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>. The estimated cost per person covered by Medicaid expansion for 2016 is \$5,910 per year. CTR. MEDICARE & MEDICAID SERVS., 2015 ACTUARIAL REPORT ON THE FINANCIAL OUTLOOK FOR MEDICAID 29 (2015), <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/ActuarialStudies/Downloads/MedicaidReport2015.pdf>.

⁸ Based on data available from the Kaiser Commission on Medicaid and the Uninsured. KFF HCBS Update, *supra* note 1, at 47; Terence Ng, et al., KAISER COMM'N ON MEDICAID & THE UNINSURED, *Medicaid Home and Community-Based Services Programs: 2012 Data Update* 45 (2015), <http://files.kff.org/attachment/report-medicaid-home-and-community-based-services-programs-2012-data-update>; Terence Ng, et al., KAISER COMM'N ON MEDICAID & THE UNINSURED, *Medicaid Home and Community-Based Services Programs: 2011 Data Update* (2014). Thirty-one states have expanded Medicaid. Current Status of State Medicaid Expansion, KAISER FAMILY FOUND. (Jan. 1, 2017) <http://kff.org/health-reform/slide/current-status-of-the-medicaid-expansion-decision/>. The non-expansion states represent 80.18% of waiting list growth, but only 39.22% of the states.

⁹ See explanation of the use of Kaiser Family Foundation HCBS data, *supra* note 8.

¹⁰ The ACA created the Community First Choice option to provide in-home personal attendant services and supports to individuals. 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. See David Machledt, *Promoting Community Living: Updates on HCBS & the ACA*, NAT'L HEALTH L. PROG. (2012), <http://www.healthlaw.org/publications/search-publications/HCBS-ACA>.

¹¹ KFF Medicaid HCBS Update, *supra* note 1.

¹² NAT'L COUNCIL ON DISABILITY, THE IMPACT OF THE AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES: A 2015 STATUS REPORT 10-11, 29-31, 48-51 (Jan. 2016), http://www.ncd.gov/sites/default/files/NCD_ACA_Report02_508.pdf (citing increased access to care for those with chronic illnesses in expansion states and increased access to necessary services, including autism services, under Medicaid expansion).

¹³ Ninety-three percent of people with intellectual and developmental disabilities and 100 percent of older adults on HCBS waiting list are enrolled in Medicaid and receiving services available to all Medicaid recipients, such as personal care services, medical equipment, prescriptions, and other medical care. KFF HCBS Update, *supra* note 1, at 45. One survey in Ohio showed that many people on waiting lists had no current area of need. Ohio Dept. of Developmental Disabilities, HCBS Waivers Waiting List 2015 Factsheet, <http://dodd.ohio.gov/OurFuture/Documents/WaitingListFactSheet.pdf> (citing that 46% of individuals surveyed indicated not current area of need).

¹⁴ KFF HCBS Update, *supra* note 1, at 15; Steve Eiken, et al., TRUVEN HEALTH ANALYTICS for CTRS. MEDICARE & MEDICAID SERVS., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014: Managed LTSS Reached 15 Percent of LTSS Spending* (2016), <https://www.medicaid.gov/medicaid/ltss/downloads/ltss-expenditures-2014.pdf>.

¹⁵ MACPAC, Report to the Congress on Medicaid and CHIP, Medicaid's Role in Providing Assistance with Long-Term Services and Supports 40, 58-61; see, e.g., Nat'l Assoc. of State Units on Aging, *The Economic Crisis and its Impact on State Aging Programs* 8 (Dec. 2008) (finding states cutting eligibility and services when budget cuts needed to be made).

¹⁶ Beatty, *supra* note 1, at 716-18.

¹⁷ 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 more narrow population. See CMS, HCBS Authorities, *supra* note 1; Machledt, *supra* note 10.

¹⁸ See, e.g., 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/>.

¹⁹ KFF Medicaid HCBS Update, *supra* note 1, at 12, 17.

²⁰ KFF Medicaid HCBS Update, *supra* note 1, at 13.

²¹ For example, Texas has a total Current Interest List of 212,989 as of June 2016, but indicated the unduplicated count across all five lists was 110,019. Texas Department of Aging and Disability Services, Interest List Reduction, <https://www.dads.state.tx.us/services/interestlist/>.

²² Greg Peterson, et al., *Impacts of Waiting Periods for Home and Community-Based Services on Consumers and Medicaid Long-Term Care Costs in Iowa*, ASPE, U.S. DEPT. OF HEALTH & HUM. SERVS. (2014), <https://aspe.hhs.gov/basic-report/impacts-waiting-periods-home-and-community-based-services-consumers-and-medicare-long-term-care-costs-iowa>.

²³ W. ERICKSON, C. LEE & S. VON SCHRADER, CORNELL UNIV., 2015 DISABILITY STATUS REPORT: UNITED STATES 9 (2016), http://www.disabilitystatistics.org/StatusReports/2015-PDF/2015-StatusReport_US.pdf; Pamela Doty presenting on behalf of Terence Ng, HCBS Waiver Wait Lists: National Estimates 2012, Presentation before the HCBS Waiver Conference 3 (Sept. 10, 2013), http://www.nasuad.org/documentation/HCBS_2013/Presentations/9.11%2010.00-11.15%20Roosevelt.pdf.

²⁴ *Id.*

²⁵ *Id.* at 4. Most of the remaining children on waiting lists for children's waivers are in Louisiana, Maryland, Wisconsin, Colorado, and Iowa. *Id.*