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Medicaid's Role for Seniors and People with Disabilities: Current State Trends

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MEDICAID'S ROLE FOR SENIORS AND PEOPLE WITH DISABILITIES: CURRENT STATE TRENDS

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ABSTRACT

Medicaid fills a gap in the U.S. health care system as the primary payor for long-term services and supports (LTSS). These services enable seniors, people with disabilities, and those with chronic illnesses to live independently in the community, outside of nursing homes and other institutions. Most Medicaid home and community-based services (HCBS) are covered at state option, unlike nursing home care, which all state Medicaid programs must cover. States have substantial flexibility in designing their Medicaid HCBS programs under federal law, and Medicaid provides an important source of federal funding to states to help meet the LTSS needs of seniors and people with disabilities. The optional nature of most HCBS puts the populations receiving these services at risk if Medicaid's federal financing structure were to change in a way that would decrease federal funding to states, such as through a block grant or per capita cap. These remarks were delivered at Saint Louis University School of Law's 31st Annual Health Law Symposium: The Struggle for the Soul of Medicaid *on April 5, 2019, and have been edited for clarity.*

* Associate Director, Kaiser Family Foundation Program on Medicaid and the Uninsured. Remarks from Saint Louis University's 31st Annual Health Law Symposium: *The Struggle for the Soul of Medicaid*.

I am going to take us through some topics related to seniors and people with disabilities, reflecting Medicaid's important role for these populations. First, I'll provide a quick overview of Medicaid enrollment and spending for people with disabilities and seniors, including long-term services and supports (LTSS). Then, I will talk about different policy choices that states are making in this space, illustrating the substantial flexibility available to states under federal law. Next, I will take a deeper dive into Medicaid home and community-based services (HCBS), drawing on some data that the Kaiser Family Foundation (KFF) just released yesterday[1] that illustrates the current state landscape. I also will cover a little bit about LTSS delivery systems. Finally, I will consider what changing the current federal Medicaid financing system could mean for HCBS.

When most people think about Medicaid, they may immediately confuse it with Medicare. But if they get beyond that, what next comes to mind is a health insurance program for poor people. What may not be top of mind is that Medicaid is also an incredibly important source of coverage for seniors, people with disabilities, and people who have chronic conditions and need LTSS. Although seniors and people with disabilities make up less than a quarter of Medicaid enrollment, they account for over sixty percent of spending, which leads policymakers to pay attention to these populations.[2]

The majority of Medicaid enrollment is relatively healthy low-income adults and children, but the majority of spending is for seniors and people with disabilities.[3] Why is that? The data show, not surprisingly, that people with disabilities and seniors have LTSS needs that Medicaid plays a large role in covering.[4] But these populations also have greater acute care spending, compared to low-income adults and children, as a result of their more intensive medical needs.[5] So, it is higher spending both on the acute care side, as well as the LTSS side, that is driving costs for seniors and people with disabilities.

Medicaid fills gaps in the current health care system, and LTSS coverage is one of the key gaps.[6] LTSS help people with self-care tasks like eating, bathing,

1. FY 2017 data were presented in this talk. Updated data for FY 2018 are now available. *See generally* Molly O'Malley Watts et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, KAISER FAM. FOUND. (2020), http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending; MaryBeth Musumeci et al., *Key State Policy Choices About Medicaid Home and Community-Based Services*, KAISER FAM. FOUND. (2020), http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services.

2. Robin Rudowitz et al., *Medicaid Financing: The Basics*, KAISER FAM. FOUND. 4 (2019), http://files.kff.org/attachment/Issue-Brief-Medicaid-Financing-The-Basics.

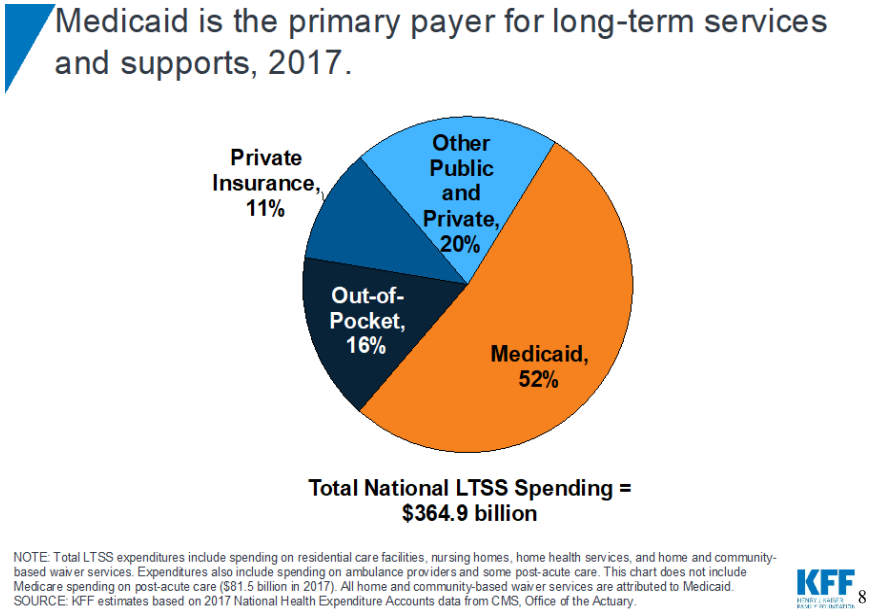
3. *Id.* at 6.

4. *See id.*

5. *Id.* at 7.

6. Erica L. Reaves & MaryBeth Musumeci, *Medicaid and Long-Term Services and Supports: A Primer*, KAISER FAM. FOUND. 5 (2015), http://files.kff.org/attachment/report-medicaid-and-long-term-services-and-supports-a-primer.

or dressing, and household activities such as preparing meals.[7] People with a range of disabilities need LTSS: intellectual or cognitive disabilities, physical disabilities, mental health disabilities, conditions associated with frailty from aging, and chronic conditions. We are all one traumatic health event or accident away from a disability that would cause us to need LTSS. And as we age, many of us are likely to find ourselves relying on these services. But, LTSS coverage, other than through Medicaid, frequently is limited.



Medicaid covers over half of LTSS financing in the United States.[9] It is the sole source of coverage for many of these services, and it makes services affordable, as they are typically too expensive for people to pay out of pocket. Most people think that if they have Medicare, their long-term care needs will be covered. But, Medicare has only very limited post-acute care coverage and no LTSS coverage, which is something that many people do not realize until they are at a point where they actually need services.[10]

One of the health policy topics most discussed about Medicaid and LTSS is rebalancing where services are provided among institutional settings vs. community settings. This is really more about balancing, rather than re-

7. *Id.* at 1.

8. KFF estimates based on 2017 National Health Expenditure Accounts, Office of the Actuary.

9. *Id.*

10. Reaves & Musumeci, *supra* note 6, at 1.

balancing, because the system was never balanced in the first place.[11] The Medicaid program has been criticized for having a historical, institutional bias. State Medicaid programs have to pay for nursing home care,[12] but nearly all home and community-based services (HCBS) are optional. Home health services is the one exception.[13]

So, there has been an incentive built into the system where Medicaid LTSS spending was going predominantly to institutional settings because nursing home coverage is required. Over the last several decades, states have worked hard to shift that balance, and 2013 was the first year that the majority of Medicaid LTSS spending went to HCBS as opposed to institutional care.[14] That has been driven by a number of reasons: beneficiary preferences to receive care in the home, the fact that HCBS typically cost less than comparable institutional care, and states' community integration obligations under the Americans with Disabilities Act and the Supreme Court's *Olmstead* decision.[15] *Olmstead* found that people with disabilities should be served in the least restrictive environment: in the community to the extent possible.[16] Fifty-seven percent of total Medicaid LTSS dollars are spent in the community as of 2016. But there is substantial variation in the balance of LTSS spending by institutional vs. community setting among states and also by population within states.[17]

Now, I'll describe some of the key state policy choices in Medicaid LTSS. The big takeaway is that the minimum Medicaid coverage pathway that states must provide for seniors and people with disabilities is limited to people who get Supplemental Security Income (SSI) benefits, which is the federal cash assistance program for people who are both poor and disabled.[18] State Medicaid

11. MaryBeth Musumeci, *Measuring Long-Term Services and Supports Rebalancing*, KAISER FAM. FOUND. 1 (Feb. 2, 2015), http://files.kff.org/attachment/fact-sheet-measuring-long-term-services-and-supports-rebalancing.

12. Robin Rudowitz et al., *10 Things to Know About Medicaid: Setting the Facts Straight*, KAISER FAM. FOUND. 5 (Mar. 6, 2019), http://files.kff.org/attachment/Issue-Brief-10-Things-to-Know-about-Medicaid-Setting-the-Facts-Straight.

13. MaryBeth Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, KAISER FAM. FOUND. 3 (Apr. 2019), http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending.

14. STEVE EIKEN ET AL., IBM WATSON HEALTH, MEDICAID EXPENDITURES FOR LONG-TERM SERVICES AND SUPPORTS IN FY 2016 6 (May 2018).

15. MaryBeth Musumeci & Henry Claypool, *Olmstead's Role in Community Integration for People with Disabilities Under Medicaid: 15 Years After the Supreme Court's Olmstead Decision*, KAISER FAM. FOUND. 2 (June 2014), http://files.kff.org/attachment/issue-brief-olmsteads-role-in-community-integration-for-people-with-disabilities-under-medicaid-15-years-after-the-supreme-courts-olmstead-decision.

16. Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 582, 602 (1999).

17. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 2, 6.

18. MaryBeth Musumeci et al., *Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey*, KAISER FAM. FOUND. 1, 3–4 (2019), http://files.kff.

programs also must offer Medicare savings programs, which wrap around and provide some help with Medicare out of pocket costs for low-income Medicare enrollees, but the only pathway to full Medicaid coverage that states must offer is for SSI beneficiaries.[19] There are a number of additional optional pathways that states can pick and choose among to expand Medicaid coverage for seniors and people with disabilities, but these other pathways to expand eligibility are not required.[20]

Turning to covered benefits, as I mentioned, home health services are the only HCBS required by Medicaid.[21] There are a number of optional benefits that states can choose to cover; the primary ones include personal care services, Community First Choice attendant services, and waiver services. States are picking and choosing among these options, with variation in HCBS benefit packages among states.[22]

KFF's newest data show that 4.6 million people are receiving Medicaid HCBS as of FY 2017.[23] Eighty-six percent of these enrollees are receiving optional services, all but the fourteen percent receiving home health services.[24] There is some enrollment in the newer state plan authorities like Community First Choice and Section 1915 (i), However, these newer state options have not supplanted HCBS waivers.[25] Waivers continue to be the predominant delivery and financing mechanism for HCBS; they allow states to expand Medicaid financial eligibility to reach more people.[26] But, they also allow states to cap enrollment, which can result in waiting lists.[27]

Waivers account for nearly seventy percent of Medicaid HCBS spending as of FY 2017. Home health is seven percent of spending, so the vast majority of Medicaid HCBS spending, like enrollment, is going to optional services.[28] National spending per enrollee across all states and across all HCBS program

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19. *Id.* at 3.

20. *Id.*

21. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 3.

22. *Id.*

23. *Id.* at 1.

24. *Id.*

25. *See* Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 3, 7.

26. *See id.* at 3, 7.

27. MaryBeth Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, KAISER FAM. FOUND. 1 (2019), http://files.kff.org/attachment/Issue-Brief-Key-Questions-About-Medicaid-Home-and-Community-Based-Services-Waiver-Waiting-Lists.

28. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 5.

authorities amounted to $17,800 in FY 2017. Per enrollee spending varies among the different types of HCBS that states choose to include in their benefit packages.[29] For example, home health spending per enrollee is about $8,900, which reflects, at least in part, shorter periods of service utilization compared to some of the other services.[30] Section 1915 (i), at $8,600 per enrollee, is a newer authority. It allows states to provide "preventive" HCBS to people who do not yet meet an institutional level of care but still have some level of functional need.[31] That functional eligibility standard is likely driving the relatively lower per enrollee spending for Section 1915 (i) HCBS as opposed to Section 1915 (c) waiver services, which are the most costly, at $27,800 per enrollee.[32]

Per enrollee spending also differs among the different types of HCBS waivers. As I noted, Section 1915 (c) waiver spending per enrollee is nearly $28,000, while Section 1115 waiver spending is around $12,000 per enrollee.[33] This difference is in part driven by the populations states are serving under each waiver authority. States tend to serve people with intellectual and developmental disabilities, which tend to have higher costs, under Section 1915 (c), even if they are serving other populations under Section 1115. By contrast, Section 1115 waivers tend to serve seniors and people with physical disabilities, which have relatively lower per enrollee costs.[34]

In addition to variation by program authority, HCBS spending per enrollee also varies among states. In FY 2017, three states spent less than $10,000 per enrollee and ten other states spent over $30,000.[35] This is driven by a number of factors including the different choices that states are making about what services to offer, what the benefit package includes, and the scope of covered services.[36]

States make different choices about the target populations served by HCBS waivers. Every state is serving people with intellectual and developmental disabilities, seniors, and people with physical disabilities through some Medicaid HCBS waiver authority.[37] Coverage of other target populations varies. About half of states have waivers covering people with traumatic brain or spinal cord injuries.[38] Eighteen states have waivers for children who are medically

29. *Id.* at 6.

30. *Id.*

31. *See id.* at 3.

32. *Id.* at 6.

33. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 6.

34. *Id.* at 6–7.

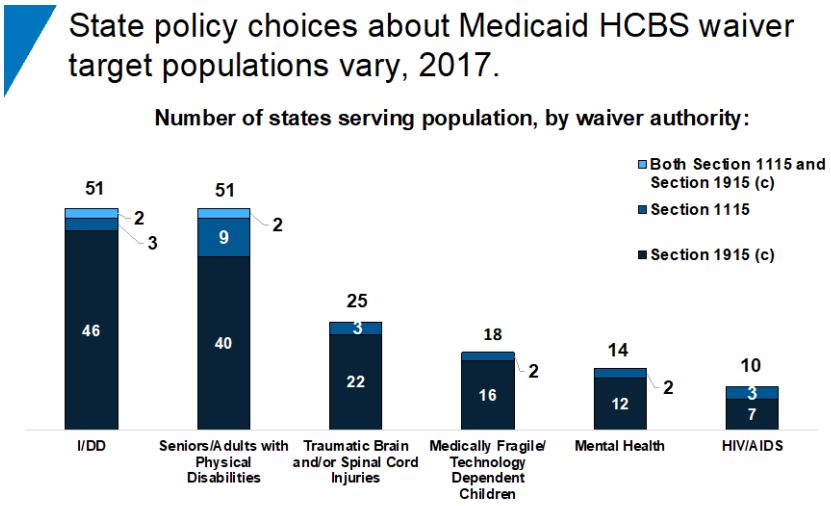
35. *Id.* at 6.

36. *Id.*

37. MaryBeth Musumeci & Molly O'Malley Watts, *Key State Policy Choices About Medicaid Home and Community-Based Services*, KAISER FAM. FOUND. 8 (Apr. 4, 2019), http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services.

38. *Id.*

fragile or technology dependent, fourteen states have waivers for people with mental health disabilities, and ten states have waivers targeted to people with HIV/AIDS.[39]



A notable difference between Medicaid state plan benefits, like home health and personal care, and waivers is that state plan benefits must be provided to anyone who is eligible and for whom they are medically necessary. Waivers give states additional flexibility in a couple of ways.[41] One example is that states can cap waiver enrollment and have waiting lists. Another is that waivers provide a means to expand income limits to make more people eligible for the program.[42] States are taking advantage of this flexibility to counter Medicaid's historical institutional bias and increase community integration. For example, seventy-eight percent of Medicaid HCBS waivers are using the federal maximum financial eligibility limit: 300% of SSI, or just over $2,300 per month for an individual in 2019.[43]

Also, the vast majority of states are setting their waiver financial and functional eligibility criteria at the same level as their institutional eligibility

39. *Id.*
40. *Id.*
41. *See generally* Musumeci & O'Malley Watts, *supra* note 37, at 4, 10.
42. *Id.* at 7, 9.
43. *Id.* at 9.

criteria.[44] This avoids creating a perverse incentive where people might be eligible for Medicaid institutional care but not eligible for Medicaid HCBS

Just over half of Section 1915 (c) waiver enrollment is comprised of seniors and people with physical disabilities. Seventy percent of the spending for these waivers, however, is for people with intellectual and developmental disabilities.[45] This is a population that generally has more intensive needs, which is driving their relatively higher spending.

There is substantial variation in Section 1915 (c) waiver spending per enrollee by target population. The group with the highest per enrollee spending, over $44,000, is people with intellectual and developmental disabilities. This is closely followed by people with traumatic brain and spinal cord injuries: about $43,000 per enrollee.[46] Other groups have lower per enrollee spending, due to the generally less costly services provided to and less intensive needs of those populations.[47] For example, Section 1915 (c) waiver per enrollee spending for people with HIV/AIDS is $4,900.

As I already mentioned, HCBS waivers allow states to cap enrollment, which can result in waiting lists.[48] Waiting lists have been a feature of the program since waivers were created because states are allowed to limit enrollment.[49] KFF has been tracking state waiver waiting lists since 2002. As of 2017, there are just over 700,000 people across the country waiting for waiver services. Forty out of fifty-one states (we count Washington D.C., along with the fifty states) have a waiting list for at least one waiver target population. Waiting lists grew about eight percent from 2016 to 2017, which is consistent with the average annual percentage change in waiting list enrollment over the last fifteen years, which was nine percent.[50]

44. MaryBeth Musumeci & Molly O'Malley Watts, *Key State Policy Choices About Medicaid Home and Community-Based Services*, KAISER FAM. FOUND. 9–10 (Apr. 4, 2019), http://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services.

45. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 5.

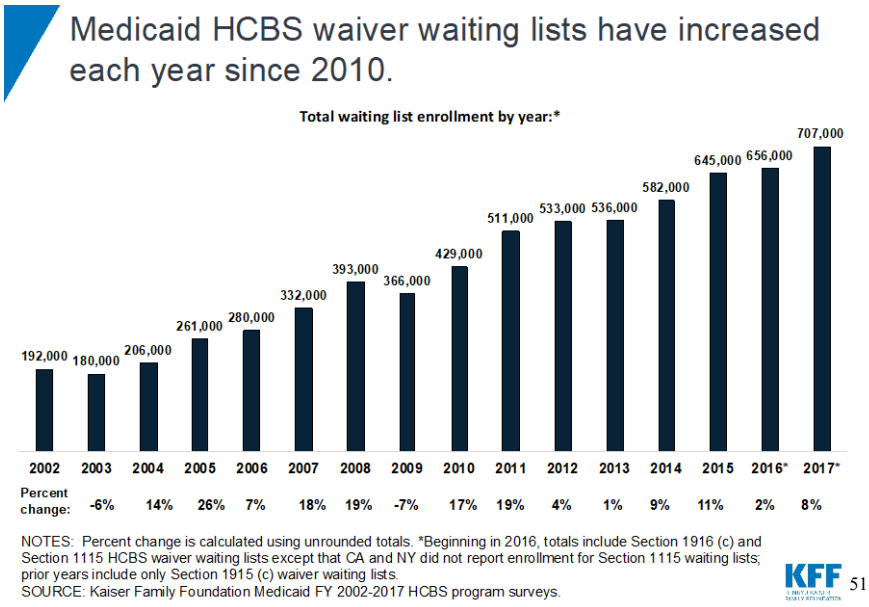
46. *Id.* at 7.

47. *See id.*

48. Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 1.

49. *Id.* at 3.

50. *See id.* at 2.



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There are several important things to note about waiting lists. First, waiting list enrollment is dynamic.[52] Some people leave waiting lists and begin receiving waiver services during a year, while other people seeking services move onto waiting lists. Twenty-seven states were able to report how many people moved off of their waiting lists: 67,000 people across those states left a waiting list and got Medicaid waiver services in 2017.[53] Another important thing to note about waiting lists is that state policies about screening for eligibility vary.[54] Some states determine waiver eligibility when they put a person on a waiting list, while other states do not. In addition, a person's circumstances can change while they are on a waiting list. So, waiting list comparisons among states are not all apples to apples in terms of whether everyone who is waiting ultimately will be found eligible for services.[55]

Two-thirds of waiting list enrollment is comprised of people with intellectual and developmental disabilities, and less than one-third is seniors and adults with physical disabilities. Other target populations account for a very tiny share of waiting list enrollment.[56] The average waiting time for waiver services is thirty months, but that varies substantially by state and by target population

51. *Id.* at 1 fig. 1.

52. *Id.* at 2.

53. Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 2.

54. *Id.* at 4.

55. *See id.*

56. *Id.* at 2–3.

within a state.[57] In addition, most states are using some sort of priority criteria when deciding who to serve. So, when a waiver slot becomes available, states are not necessarily serving the first person on the list but also are considering whether people on the waiting list meet certain crisis or emergency criteria, whether they are transitioning from a nursing home to the community, whether they are at risk of going into a nursing home, or some other criteria to determine who is served next.[58]

In the last several years, the health policy world has discussed whether state choices to adopt the Affordable Care Act's (ACA's) Medicaid expansion may or may not be impacting states' ability to serve seniors and people with disabilities.[59] There are a few things to note about this based on KFF's data. First, waiting lists predate the ACA Medicaid expansion—they are a function of the way HCBS waiver authority was set up.[60] Another thing that is important to note is that the ACA expansion population and people with disabilities are not mutually exclusive populations, though they sometimes are talked about as if they are.[61] It is true that people who get federal SSI benefits are not eligible for expansion coverage, but that is only a very small slice of people with disabilities in the Medicaid program.[62] SSI is a very strict disability standard to meet. There are many people with functional needs that do not rise to that standard.[63] There also are people with disabilities receiving Social Security Disability Insurance who are in their twenty-four month Medicare waiting period and therefore uninsured but could gain coverage through the ACA expansion while they wait for Medicare.[64]

From looking at the waiting list data from 2013, the year before expansion became effective in most states, to 2017, the most current year of data, the data do not support a conclusion that there is a relationship between whether a state has expanded and whether its waiting list has changed.[65]

A notable Medicaid LTSS delivery system trend is that over half of the states now have capitated managed LTSS delivery systems for at least some seniors

57. *Id.* at 3.

58. Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 3.

59. *Id.* at 3–4.

60. *Id.* at 3.

61. *Id.* at 4.

62. *See id.*

63. Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 3. *See also* MaryBeth Musumeci et al., *How Might Medicaid Adults with Disabilities Be Affected by Work Requirements in Section 1115 Waiver Programs?*, KAISER FAM. FOUND. 1 (2019), https://www.kff.org/medicaid/issue-brief/how-might-medicaid-adults-with-disabilities-be-affected-by-work-requirements-in-section-1115-waiver-programs/.

64. Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 4.

65. *Id.* at 1.

and people with disabilities.[66] Not all of these programs are statewide. When moving from fee-for-service to managed care, states tended to start with enrolling seniors and adults with physical disabilities. More recently, we are seeing an increasing trend of states moving people with intellectual and developmental disabilities into these delivery systems.[67]

Sometimes, states consider managed care delivery systems as a potential way to save money. There is mixed evidence of whether there are cost savings when using managed care to provide LTSS to seniors and people with disabilities.[68] There is some evidence of lower utilization of costly services such as avoidable emergency room visits and hospitalizations, but overall, evidence of savings is inconclusive and inconsistent.[69] Managed LTSS offers the opportunity to provide better coordinated and integrated care in what is often a fragmented delivery system, but there is also the risk, particularly for people who are relying on services to meet their basic daily needs, of not getting the care they need because of the perverse incentive that capitation can provide.[70]

The failed 2017 ACA repeal and replace effort in Congress would have affected Medicaid more broadly, beyond just the ACA. The bills would have replaced federal financing for the Medicaid program as a whole. While those legislative attempts were defeated in Congress, a similar initiative is in President Trump's proposed FY 2020 budget.[71] Such a financing change could have implications for HCBS.

Right now, federal Medicaid financing is guaranteed to states with no pre-set limit.[72] The repeal and replace proposals would have changed the model to a block grant or per capita cap. Block grants and per capita caps have some differences between them, but they are more similar than they are different in that they both would substantially limit and cap the federal funding that is available to states.[73]

66. *See, e.g.*, Molly O'Malley Watts et al., *Medicaid Section 1115 Managed Long-Term Services and Supports Waivers: A Survey of Enrollment, Spending, and Program Policies*, KAISER FAM. FOUND. 6 (Jan. 2017), https://www.kff.org/medicaid/report/medicaid-section-1115-managed long-term-services-and-supports-waivers-a-survey-of-enrollment-spending-and-programpolicies/.

67. *See, e.g.*, *id.*

68. *See* Joshua M. Wiener et al., *Strategies to Reduce Medicaid Spending: Findings from a Literature Review*, KAISER FAM. FOUND. 21 (2017), http://files.kff.org/attachment/Issue-Brief-Strategies-to-Reduce-Medicaid-Spending-Findings-from-a-Literature-Review.

69. *Id.*

70. *Id.* at 22.

71. OFFICE OF MGMT. & BUDGET, EXEC. OFFICE OF THE PRESIDENT, A BUDGET FOR A BETTER AMERICA FISCAL YEAR 2020 42–43 (2019).

72. Rudowitz et al., *Medicaid Financing: The Basics*, *supra* note 2, at 1.

73. Robin Rudowitz, *5 Key Questions: Medicaid Block Grants & Per Capita Caps*, KAISER FAM. FOUND. 2 (Jan. 2017), http://files.kff.org/attachment/Issue-Brief-5-Key-Questions-Medicaid-Block-Grants-&-Per-Capita-Caps.

What this would mean is that states would be left with some hard choices. If states do not want to raise taxes or reduce spending in other areas, they are left with cutting Medicaid enrollment, cutting provider payment rates, or cutting services. That makes the pathways and services for seniors and people with disabilities (most of which are optional) at risk for cuts.[74]

To sum up, Medicaid fills an important gap in our health care system by providing HCBS that typically are not available through other payers. It is a substantial federal funding source to states to help them meet their independent community integration obligations under the ADA and *Olmstead*.[75] The data do not support a conclusion that there is a relationship between ACA expansion and waiver waiting list changes.[76] Finally, the optional nature of most HCBS puts the populations receiving these services at risk if Medicaid's federal financing structure were to change in a way that would decrease federal funding to states.[77]

74. *See* Robin Rudowitz, *No Easy Choices: 5 Options to Respond to Per Capita Caps*, KAISER FAM. FOUND. 1–2 (June 2017), http://files.kff.org/attachment/Issue-Brief-No-Easy-Choices-5-Options-to-Respond-to-Per-Capita-Caps.

75. *See generally* Musumeci & Claypool, *supra* note 15.

76. *See* Musumeci et al., *Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists*, *supra* note 27, at 4.

77. Musumeci et al., *Medicaid Home and Community-Based Services Enrollment and Spending*, *supra* note 13, at 7–8.