



Home and Community-Based Services Improve Outcomes While Reducing Costs

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Long-term services and supports (LTSS) refer to a wide range of health and social services provided to individuals who need help with activities of daily living, such as eating, bathing, and dressing, or with instrumental tasks, such as medication management, meal preparation, community participation, and employment.¹

An estimated 17.6 million adults in the US (approximately 6.2%) have functional needs for LTSS.² Nearly half of adults currently needing LTSS are under the age of 65.² However, the number of older adults needing LTSS is rapidly growing as the US population ages. Many children also have developmental and functional needs for LTSS.³

Medicaid, a joint federal-state healthcare program, is the primary payer of formal LTSS in the United States. Within LTSS, Medicaid Home and Community-Based Services (HCBS) help support individuals across the lifespan to live, work, and engage in their communities with choice and control over how they receive services and supports. HCBS includes a wide range of supports, such as personal assistance, day services, employment supports, transportation, home modifications and enabling technologies, family caregiver supports, health and behavioral supports, and service coordination and navigation.⁴

Approximately 8.4 million individuals currently receive Medicaid HCBS,⁵ however, there remains significant unmet needs. Over 600,000 individuals are on waiting lists or interest lists for Medicaid HCBS waivers.⁶ Only about 24% of children and 48% of adults with intellectual and developmental disabilities (IDD) are known to state IDD services agencies.⁷ Most individuals rely on unpaid support from family caregivers. Over 63 million family caregivers provide care to individuals with disabilities and older adults,⁸ with an estimated economic value of over \$1 trillion annually.⁹

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Moreover, there is a long-standing “institutional bias” within Medicaid, where nursing homes and other institutional services are mandatory benefits that states must provide, while HCBS are optional.¹⁰ This forces many individuals with disabilities and older adults into more costly institutional settings when their needs and preferences could be better met in the community.

Shifting away from systems that rely on institutional care towards HCBS is often referred to as “rebalancing.” Bipartisan efforts at the national and state levels have contributed to significant progress in rebalancing over the last several decades. However, wide variations in HCBS access exist across states and different populations needing HCBS.⁵

This brief highlights research on the value of Medicaid HCBS. It summarizes major findings from decades of research which demonstrates that access to high-quality HCBS not only improves outcomes but can also reduce overall healthcare costs.



Medicaid HCBS on average cost less than nursing homes and institutional settings

- In 2023, average annual Medicaid LTSS expenditures were \$17,298 per person for individuals receiving HCBS and \$54,462 for individuals in institutional settings.⁵
- Among individuals with IDD in 2021, average annual expenditures were \$51,835 per person for individuals receiving Medicaid HCBS waiver services and \$146,050 for individuals residing in ICF/IIDs⁷ (Intermediate Care Facilities for Individuals with Intellectual Disabilities).

Transitioning individuals from nursing homes and institutional settings back to the community improves outcomes and achieves cost savings

- The Money Follows the Person (MFP) program is a proven Medicaid demonstration that helps states transition older adults and people with disabilities back to the community. Forty-seven states have participated in the program at some point, assisting more than 127,000 individuals.¹¹

- The national evaluation of the program found that after returning to the community, individuals' quality of life significantly improved and costs were lower.¹² Individuals reported outcomes included improved life satisfaction, reduced unmet needs and barriers to community participation, decreased depression, and enhanced feelings of being treated with dignity and respect.¹² In addition, average per-person Medicaid health and LTSS costs were 23-30% lower following transitions to the community.¹²
- State-specific evaluations of MFP programs in Connecticut, Georgia, and Washington have found similar cost savings.¹³⁻¹⁵
- One analysis found that states with robust MFP programs were more likely to show declines in nursing home utilization, occupancy, and expenditures.¹⁶

Shifting systems away from reliance on nursing homes and institutional settings and improving access to HCBS reduces costs over time

- Analyses of state spending over a 15-year period found that investments in HCBS often result in short-term spending increases, but over time lead to reduction in institutional spending and long-term cost savings.¹⁷⁻²⁰
- Other state-specific and national studies²¹⁻²³ have also consistently demonstrated that rebalancing helps states contain overall LTSS costs and produce cost savings:
 - A recent study examining HCBS for older adults (65 years and over) found that expansion of HCBS was associated with more older adults receiving services and lower costs.²¹
 - Another study examining dually-eligible individuals with IDD across five states found that higher levels of HCBS spending were associated with reduced institutional placements.²²
- Cuts to Medicaid HCBS could drive more individuals with disabilities and older adults into nursing homes and institutional placements, increasing costs to states. A recent economic analysis of California estimated that if just 3% of current HCBS beneficiaries ended up in nursing homes, it would result in a net spending increase of \$57 million in the first year and \$1.17 billion over the next five years.²⁴

Unmet needs for HCBS contribute to worse community living and health outcomes, driving higher overall healthcare costs

- There is growing recognition that social determinants of health play a key role in health outcomes and costs. HCBS provide essential social supports that improve health and social outcomes.²⁵⁻²⁷ Individuals with LTSS needs are significantly more likely to experience housing, food, and job insecurity, transportation barriers, and unmet healthcare needs.^{28,29} They also report higher levels of stress, social isolation, and loneliness compared with individuals without LTSS needs.^{28,29}
- A population-based study in Texas found that unmet needs for HCBS were associated with negative physical and mental health outcomes, including suicidal ideation.³⁰
- One study of older adults and individuals with physical disabilities receiving Medicaid HCBS across 13 states found that 80% reported unmet needs in areas including assistance with daily activities, assistive technology, home modifications, transportation, and other services.²⁶
 - Unmet needs for HCBS were consistently associated with worse community living outcomes, including limited community participation, fewer interactions with friends and family, and less control of life.²⁶
 - Unmet needs were also related to worse health outcomes, including less routine preventive physical and dental care and higher emergency department visits and hospitalizations.²⁶
- A body of emerging research has similarly found that access to HCBS can reduce avoidable emergency department visits and hospitalizations, which can contribute to higher overall healthcare costs.
 - A recent study following older adults in 11 states over time found that initiation of HCBS was associated with decreased hospitalizations and emergency department visits.³¹
 - Prior studies have found that greater amount and generosity of HCBS were associated with a lower risk of hospitalizations, including potentially avoidable hospitalizations.^{32,33}
 - Another study found that the scope of HCBS was associated with increased chance of being discharged from a skilled nursing facility to a community setting.³⁴

High-quality person-centered planning and care coordination more efficiently meet needs and desires of HCBS beneficiaries, producing better health and community living outcomes

- Person-centered planning is a facilitated approach to planning services and supports that prioritizes the needs, goals, and values of the individual.³⁵ This approach is an ongoing process that is directed by the person who receives the support.³⁵ Regulations require person-centered planning in all federally funded HCBS programs, including Medicaid HCBS.³⁶ However, the extent to which individuals report that their planning and service coordination is person-centered varies significantly across states and by individual service user characteristics.³⁷
- An emerging body of research has found that high-quality person-centered planning contributes to improved health and community living outcomes.
 - A study of individuals with physical disabilities and older adults receiving HCBS across 12 states found that high-quality person-centered planning was associated with reduced unmet needs and more positive community living outcomes, including greater community participation, feelings of control, and satisfaction with how days were spent.³⁸
 - Similarly, studies of individuals with IDD receiving HCBS across 36 states found that high-quality person-centered planning was associated with greater social inclusion, reduced unmet needs related to community participation, and more positive health outcomes -including lower unmet mental health needs, better self-reported health, and fewer emergency department visits.^{39,40}
- Programs that effectively provide integrated care coordination across health and LTSS have demonstrated impacts on reducing avoidable hospitalizations, readmissions, and institutional placements.^{41,42}

Self-direction, including flexibility to hire family members, contributes to better outcomes and helps address workforce shortages

- Self-direction is a model in which people receiving HCBS hold greater control over their services and supports than in traditional arrangements.⁴³ When a person self-directs, they decide how, when, and from whom their services and supports will be delivered. As a model, self-direction prioritizes participant choice, control, and flexibility. This contrasts with "traditional" services received from an agency, where the agency controls most aspects of service delivery.⁴³

- Self-direction is one of the most evidence-based models of HCBS delivery. Most notably, the Cash and Counseling demonstration tested a budget authority model with a randomly selected control group of Medicaid beneficiaries not self-directing. Evaluations found that self-direction resulted in reduced unmet needs, greater satisfaction with services, positive health outcomes, and improved quality of life outcomes for participants as well as family caregivers.⁴⁴⁻⁴⁶
- Other studies of self-directed programs within states have supported similar outcomes across a wide range of disability populations receiving HCBS.⁴⁷⁻⁵³ Many individuals within self-directed programs have hired family and friends, which has also been associated with better outcomes.⁵⁴ Hiring family members and friends can help address workforce shortages^{52,54,55} and improve delivery of more culturally and linguistically, person-centered supports.⁵⁶
- Veteran-Directed HCBS (Veteran-Directed Care Program since 2018) are for individuals enrolled in Veterans Administration Health Care and at-risk of nursing home placement.⁵⁷ One study examined beneficiaries' perspectives on Veteran-Directed HCBS. Participants described the program as promoting freedom and choice and improving their mental health and community participation.⁵¹

An adequate direct care workforce is essential to ensuring access to HCBS and achieving better outcomes

- There is a longstanding direct care workforce crisis that is driven by many structural forces, including low wages and lack of benefits, economic and demographic shifts, labor and immigration policies,⁵⁸ and demanding work conditions. Individuals, families, and providers face growing challenges to recruit and retain workers.
 - Recent studies have found that upwards of 69% of agencies serving HCBS beneficiaries report that they have stopped accepting or turned away new referrals due to staffing issues.^{59,60}
 - Studies have consistently found high turnover rates and low tenure for direct care workers.^{60,61}
- An inadequate direct care workforce limits the ability of states to expand access to HCBS, reduces quality, and jeopardizes safety of individuals. Experts project that more than 1.3 million new direct care workers will be needed by 2030.⁶²
 - One study found that direct support professional turnover was associated with increased emergency room visits, incidents of abuse and neglect, injuries, and behavioral events for individuals with IDD.⁶³
- While additional research is needed on outcomes, states and providers are actively undertaking a wide range of strategies to strengthen recruitment and retention of the direct care workforce.⁶⁴⁻⁶⁶

Conclusion

Home and Community-Based Services (HCBS) support individual well-being and strengthen the broader LTSS healthcare system. By enabling individuals to receive services in their communities rather than institutional settings, HCBS promotes choice, independence, and social connection. These services are associated with improved health outcomes, including fewer emergency department visits and hospitalizations, which can decrease overall healthcare costs. At the same time, HCBS result in greater cost savings than institutional care. “Rebalancing” systems away from institutions and toward HCBS benefits consumers, families, healthcare systems, and taxpayers.



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References

1. Centers for Medicare & Medicaid Services. (2026, March 10). *LTSS overview*. CMS. <https://www.cms.gov/training-education/partner-outreach-resources/american-indian-alaska-native/ltss-ta-center/information/tribal-leaders/ltss-overview>
2. Community Living Equity Center. (2024). *Who needs LTSS?* [Data dashboard]. The Lurie Institute for Disability Policy. <https://heller.brandeis.edu/community-living-policy/clec/who-needs-ltss.html>
3. *2022-2023 National Survey of Children's (NSCH) Health data query* (Data Set Indicator 1.10: One or more functional difficulties). (2023). Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). <https://nschdata.org/browse/survey/results?q=11039&r=1>
4. Centers for Medicare & Medicaid Services. (2026, March 10). *Home- and Community-Based Services*. CMS. <https://www.cms.gov/training-education/partner-outreach-resources/american-indian-alaska-native/ltss-ta-center/information/ltss-models/home-and-community-based-services>
5. Carpenter, A., Stepanczuk, C., Murray, C., & Wysocki, A. (2025). *Trends in users and expenditures for Home and Community-Based Services as a share of total Medicaid Long-Term Services and Supports users and expenditures, 2023*. Mathematica for Centers for Medicare and Medicaid (CMS). <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2023.pdf>
6. Burns, A., Wolk, A., & O'Malley Watts, M. (2025, November 20). *A look at waiting lists for Medicaid Home- and Community-Based Services from 2016 to 2025*. KFF. <https://www.kff.org/medicaid/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2025/>
7. Larson, S., Neidorf, J., Pettingell, S., Nye-Lengerman, K., & Vegas, L. (2026). *Long-Term Supports and Services for individuals with intellectual or developmental disabilities: Status and trends through 2021*. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. https://ici-s.umn.edu/files/aaQxdJjAit/risp_2021_final_acc?preferredLocale=en-US
8. Resendez, J., Cantor, K., Frank, L., Kueppers, G., Cothran, F. A., Choula, R. B., Caldera, S., Raimondi, A., Rainville, G., "Chuck," Guengerich, T., Lampkin, C. L., & Cuzzo, J. (2025). *Caregiving in the US: Research report*. AARP; National Alliance for Caregiving. https://www.caregivingintheus.org/wp-content/uploads/2026/03/caregiving-in-us-2025.doi_10.26419-2fpfi.00373.001.pdf
9. Houser, A., Caldera, S., Flinn, B., & Choula, R. (2026). *Valuing the invaluable 2026: Family caregivers' contribution reaches \$1 trillion*. AARP Public Policy Institute. <https://doi.org/10.26419/ppi.00402.001>
10. Maniates, H. (2024). *Why did they do it that way? Home and Community-Based Services: Medicaid: The more you learn* [Research Brief]. National Association of Medicaid Directors. <https://medicaidirectors.org/wp-content/uploads/2024/04/NAMD-Understanding-HCBS-04-11-24.pdf>
11. Kantoris, C., Murray, C., & Ross, J. (2025). *Money Follows the Person (MFP): Updated MFP grant recipient transitions as of December 31, 2023*. Mathematica for Centers for Medicare and Medicaid (CMS). <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/mfp-trantns-brief-2023.pdf>

12. Coughlin, R., Ward, J., Denny-Brown, N., Hagen, B., Maurer, K., Morris, E., Smoot, J., Steiner, A., & Perez, B. (2017). Money Follows the Person demonstration: Overview of state grantee progress, January to December 2016. In *Mathematica Policy Research Published Reports*. Mathematica Policy Research.
13. Xing, J., Mancuso, D., & Felver, B. E. M. (2017). *Transitioning residents from nursing homes to community living: Impact of Washington state's Roads to Community Living (RCL) demonstration on Medicaid Long-Term Services and Supports costs*. Washington State Department of Social & Health Services. <https://www.dshs.wa.gov/sites/default/files/rda/reports/research-8-33.pdf>
14. Robison, J., Porter, M., Shugrue, N., Kleppinger, A., & Lambert, D. (2015). Connecticut's 'Money Follows the Person' yields positive results for transitioning people out of institutions. *Health Affairs*, 34(10: Variety Issue), 1628-1636. <https://doi.org/10.1377/hlthaff.2015.0244>
15. Landers, G., Fuller, K., & Zhou, M. (2017). Medicaid savings continue in the year after end of participation in the program, Money Follows the Person. *Journal of the Georgia Public Health Association*, 7(1), 42-44. <https://doi.org/10.21633/jgpha.7.107>
16. Kaye, H. S. (2019). *Evidence for the impact of the Money Follows the Person program*. Community Living Policy Center, Brandeis University. <https://doi.org/10.48617/rpt.358>
17. Harrington, C., Ng, T., & Kitchener, M. (2011). Do Medicaid Home and Community Based Service waivers save money? *Home Health Care Services Quarterly*, 30(4), 198-213. <https://doi.org/10.1080/01621424.2011.622249>
18. Kaye, H. S., LaPlante, M. P., & Harrington, C. (2009). Do noninstitutional long-term care services reduce Medicaid spending? *Health Affairs*, 28(1), 262-272. <https://doi.org/10.1377/hlthaff.28.1.262>
19. Guo, J., Konetzka, R. T., & Manning, W. G. (2015). The causal effects of home care use on institutional long-term care utilization and expenditures. *Health Economics*, 24(S1), 4-17. <https://doi.org/10.1002/hec.3155>
20. Kaye, H. S. (2012). Gradual rebalancing of Medicaid Long-Term Services and Supports saves money and serves more people, statistical model shows. *Health Affairs*, 31(6), 1195-1203. <https://doi.org/10.1377/hlthaff.2011.1237>
21. McGarry, B. E., & Grabowski, D. C. (2023). Medicaid Home and Community-Based Services spending for older adults: Is there a "woodwork" effect? *Journal of the American Geriatrics Society*, 71(10), 3143-3151. <https://doi.org/10.1111/jgs.18478>
22. Jan, S., Steinway, C., Brensinger, C., Teng, O., Chen, J., Liu, Q., & Shults, J. (2026). State-based variations in risk of institutional placement among dually eligible non-elderly adults with intellectual / developmental disabilities. *Disability and Health Journal*, 19(2), 101973. <https://doi.org/10.1016/j.dhjo.2025.101973>
23. Grage, W.-F., & Walls, G. (2013). *State studies find Home and Community-Based Services to be cost-effective* (Spotlight No. 2). AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf
24. *How could cuts to Medi-Cal Home and Community-Based Services impact California?* (2025). [Research Brief]. ATI Advisory. <https://www.chcf.org/wp-content/uploads/2025/10/HowCutsMediCalHomeCommunityBasedServicesImpactCA.pdf>

25. Biggar, A., & Hood, A. (Eds.). (2019). A primer on managed care: Multiple chronic conditions. *Generations*, (Spring 2019; Supplement 3), 1-88. https://nachw.org/wp-content/uploads/2020/07/NACDD/CDC215_A%20Primer%20on%20Managed%20Care-%20Multiple%20Chronic%20Conditions.pdf#page=13
26. Chong, N., Akobirshoev, I., Caldwell, J., Kaye, H. S., & Mitra, M. (2022). The relationship between unmet need for Home and Community-Based Services and health and community living outcomes. *Disability and Health Journal*, 15(2), 101222. <https://doi.org/10.1016/j.dhjo.2021.101222>
27. Kim, S. (2025). A scoping review of Home and Community-Based Services and older adults' health outcomes. *Journal of Social Service Research*, 51(1), 179-195. <https://doi.org/10.1080/01488376.2024.2408618>
28. Bixby, L. (2025, November). *Addressing the health consequences of structural ableism and racism: Disparities in chronic health conditions and social determinants of health at the intersection of disability and race/ethnicity*. American Public Health Association Annual Meeting.
29. Bixby, L. (2025, August). *Disparities in health, healthcare, and social determinants of health at the intersection of disability and race/ethnicity*. Annual Meeting of the American Sociological Association.
30. Caldwell, J., Daniels, E., & Stober, K. (2025). Unmet needs for Long-Term Services and Supports and associations with health outcomes. *Disability and Health Journal, Community Living Policy*, 18(3, Supplement), 101678. <https://doi.org/10.1016/j.dhjo.2024.101678>
31. Keesee, E., Fabius, C. D., Kim, J., Stevenson, D., & Keohane, L. M. (2026). Medicaid Home and Community-Based Services initiation and acute services use. *JAMA Health Forum*, 7(3), e260206. <https://doi.org/10.1001/jamahealthforum.2026.0206>
32. Segelman, M., Intrator, O., Li, Y., Mukamel, D., & Temkin-Greener, H. (2019). Variations in HCBS spending, use, and hospitalizations among Medicaid 1915(c) waiver enrollees. *World Medical & Health Policy*, 11(3), 231-247. <https://doi.org/10.1002/wmh3.315>
33. Xu, H., Weiner, M., Paul, S., Thomas III, J., Craig, B., Rosenman, M., Carney Doebbeling, C., & Sands, L. P. (2010). Volume of Home- and Community-Based Medicaid waiver services and risk of hospital admissions. *Journal of the American Geriatrics Society*, 58(1), 109-115. <https://doi.org/10.1111/j.1532-5415.2009.02614.x>
34. Wang, S., Temkin-Greener, H., Simning, A., Konetzka, R. T., & Cai, S. (2021). Medicaid Home- and Community-Based services and discharge from skilled nursing facilities. *Health Services Research*, 56(6), 1156-1167. <https://doi.org/10.1111/1475-6773.13690>
35. *Person-Centered planning and practice: Final report*. (2020). National Quality Forum. https://www.n-a-q.org/assets/site/PersonCenteredness/pcpp_final_report%20.pdf
36. Bradley, V. J. (2024). *Person-Centered Planning: Choosing the approach that works for the person*. NCAPPS. <https://ncapps.acl.gov/docs/Resources/NCAPPS%20Person-Centered%20Planning%20Choosing%20the%20Approach%20that%20Works%20for%20the%20Person%20Accessible.pdf>
37. Caldwell, J., Stober, K., & Daniels, E. (2025). *Who receives Person-Centered Planning? Demographic predictors among service users with intellectual and developmental disabilities in the United States* [Manuscript submitted for publication]. Lurie Institute for Disability Policy, Brandeis University.
38. Chong, N., Caldwell, J., Kaye, H. S., & Mitra, M. (2024). Outcomes of Person-Centered Planning in Medicaid Home- and Community-Based Services. *The Gerontologist*, 64(6), gnae017. <https://doi.org/10.1093/geront/gnae017>

39. Daniels, E., Caldwell, J., & Stober, K. (2025). *Association of Person-Centered Planning and service coordination with health outcomes of adults with intellectual disabilities* [Manuscript submitted for publication]. Lurie Institute for Disability Policy, Brandeis University.
40. Stober, K., Caldwell, J., & Daniels, E. (2025). *The impact of Person-Centered Planning on social inclusion for adults with intellectual and developmental disabilities* [Manuscript submitted for publication]. Lurie Institute for Disability Policy, Brandeis University.
41. *Evaluations of integrated care models for dually eligible beneficiaries: Key findings and research gaps*. (2020). [Research Brief]. Medicaid and CHIP Payment and Access Commission (MACPAC). <https://www.macpac.gov/wp-content/uploads/2019/07/Evaluations-of-Integrated-Care-Models-for-Dually-Eligible-Beneficiaries-Key-Findings-and-Research-Gaps.pdf>
42. Dobson, C., Mosey, A., Plasencia, R., Muster, C., Gibbs, S., & Smith, L. (2021). *Demonstrating the value of Medicaid MLTSS programs* [2021 Edition]. MLTSS Institute; ADvancing States; Center for Health Care Strategies (CHCS). <https://www.advancingstates.org/sites/default/files/2021%20-%20Demonstrating%20the%20Value%20of%20MLTSS.pdf>
43. Centers for Medicare & Medicaid Services. (n.d.). *Self-Directed Services*. Medicaid. Retrieved April 2, 2026, from <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services>
44. Carlson, B. L., Foster, L., Dale, S. B., & Brown, R. (2007). Effects of Cash and Counseling on personal care and well-being. *Health Services Research*, 42(1 Pt 2), 467–487. <https://doi.org/10.1111/j.1475-6773.2006.00673.x>
45. Brown, R., Lepidus Carlson, B., Dale, S., Foster, L., Phillips, B., & Schore, J. (2007). *Cash & Counseling: Improving the lives of Medicaid beneficiaries who need personal care or Home and Community-Based Services: Final report*. Mathematica Policy Research.
46. De Milto, L. (2015). *Cash & Counseling*. Robert Wood Johnson Foundation.
47. Caldwell, J., & Heller, T. (2007). Longitudinal outcomes of a Consumer-Directed program supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, 45(3), 161–173. [https://doi.org/10.1352/1934-9556\(2007\)45%255B161:LOOACP%255D2.0.CO;2](https://doi.org/10.1352/1934-9556(2007)45%255B161:LOOACP%255D2.0.CO;2)
48. Sciegaj, M., Capitman, J. A., & Kyriacou, C. K. (2004). Consumer-Directed community care: Race/ethnicity and individual differences in preferences for control. *The Gerontologist*, 44(4), 489–499. <https://doi.org/10.1093/geront/44.4.489>
49. Caldwell, J., Heyman, M., Atkins, M., & Ho, S. (2022). Experiences of individuals Self-Directing Medicaid Home and Community-Based Services during COVID-19. *Disability and Health Journal*, 15(3), 101313. <https://doi.org/10.1016/j.dhjo.2022.101313>
50. Croft, B., & Parish, S. (2016). Participants' assessment of the impact of behavioral health Self-Direction on recovery. *Community Mental Health Journal*, 52(7), 781–792. <https://doi.org/10.1007/s10597-016-9999-0>
51. Mahoney, E. K., Milliken, A., Mahoney, K. J., Edwards-Orr, M., & Willis, D. G. (2019). "It's changed everything": Voices of veterans in the Veteran-Directed Home and Community Based Services program. *Journal of Gerontological Social Work*, 62(2), 129–148. <https://doi.org/10.1080/01634372.2018.1458054>
52. Matthias, R. E., & Benjamin, A. E. (2008). Paying friends, family members, or strangers to be home-based personal assistants: How satisfied are consumers? *Journal of Disability Policy Studies*, 18(4), 205–218. <https://doi.org/10.1177/1044207307311526>

53. San Antonio, P. M., Simon-Rusinowitz, L., Loughlin, D., Eckert, J. K., & Mahoney, K. J. (2007). Case histories of six consumers and their families in Cash and Counseling. *Health Services Research*, 42(1 Pt 2), 533-549. <https://doi.org/10.1111/j.1475-6773.2006.00674.x>
54. Kueakomoldej, S., Dinelli, E., Beestrum, M., Sadler, T., Caldwell, J., McHugh, M., & Heinemann, A. W. (2024). Self-Directed Home- and Community-Based Services improve outcomes for family caregivers: A systematic review. *The Gerontologist*, 64(8), gnae068. <https://doi.org/10.1093/geront/gnae068>
55. San Antonio, P., Simon-Rusinowitz, L., Loughlin, D., Eckert, J. K., Mahoney, K. J., & Depretis Ruben, K. A. (2010). Lessons from the Arkansas Cash and Counseling program: How the experiences of diverse older consumers and their caregivers address family policy concerns. *Journal of Aging & Social Policy*, 22(1), 1-17. <https://doi.org/10.1080/08959420903385544>
56. Gomes, A.-M., Novack, V. J., The, K. J., Hu, L. A., Siegel, R., Rambharose, J.-L., Nguyen, T., & Caldwell, J. (2026). *Circles of care: Home and Community-Based Service Supports for people of color with disabilities leaving institutional settings* [Manuscript submitted for publication]. Brandeis University.
57. *Veteran-Directed Care Program*. (2025, March 13). ACL Administration for Community Living. <http://acl.gov/programs/veteran-directed-home-and-community-based-services/veteran-directed-home-community-based>
58. *Direct care workers in the United States: Key facts*. (2025). PHI.
59. *The state of America's direct support workforce crisis*. (2024). American Network of Community Options and Resources (ANCOR). <https://www.ancor.org/wp-content/uploads/2024/12/The-State-of-Americas-Direct-Support-Workforce-Crisis-2024.pdf>
60. *NCI state of the workforce for intellectual and developmental disabilities 2024 survey report*. (2025). National Core Indicators Intellectual and Developmental Disabilities. https://idd.nationalcoreindicators.org/wp-content/uploads/2025/12/2024-NCI-IDD-SoTW_Final-Tagged.pdf
61. *National Core Indicators Aging and Disabilities state of the workforce in 2023 survey report*. (2024). National Core Indicators Aging and Disabilities. https://nci-ad.org/upload/reports/2023_NCI-AD_SoTW_FINAL_4_14_25.pdf
62. *Strengthening the direct care workforce*. (2025, January 15). ACL Administration for Community Living. <http://acl.gov/programs/direct-care-workforce>
63. Friedman, C. (2021). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion*, 9(1), 63-73. <https://doi.org/10.1352/2326-6988-9.1.63>
64. Tyler, D., Hunter, M., Porter, K., Horvath, M., & Suarez, G. (2024). *State efforts to improve direct care workforce wages: State case studies report*. RTI International. <https://aspe.hhs.gov/sites/default/files/documents/ba806f15767b42593752744aab3e17ba/dc-wages-state-case-studies.pdf>
65. *Direct Care Workforce Strategies Center*. (2026, January 14). ACL Administration for Community Living. <http://acl.gov/DCWcenter>
66. Tyler, D., Khavjou, O., Hunter, M., Porter, K., Horvath, M., Suarez, G., Squillace, M., Dey, J., & Oliveira, I. (2024). *State efforts to improve direct care workforce wages: Final report*. RTI International; HHS Office of the Assistant Secretary for Planning and Evaluation. <https://aspe.hhs.gov/sites/default/files/documents/e88ca623469819d2444d07fe9564fb67/strateffortsimprove-dcw-wages-final.pdf>