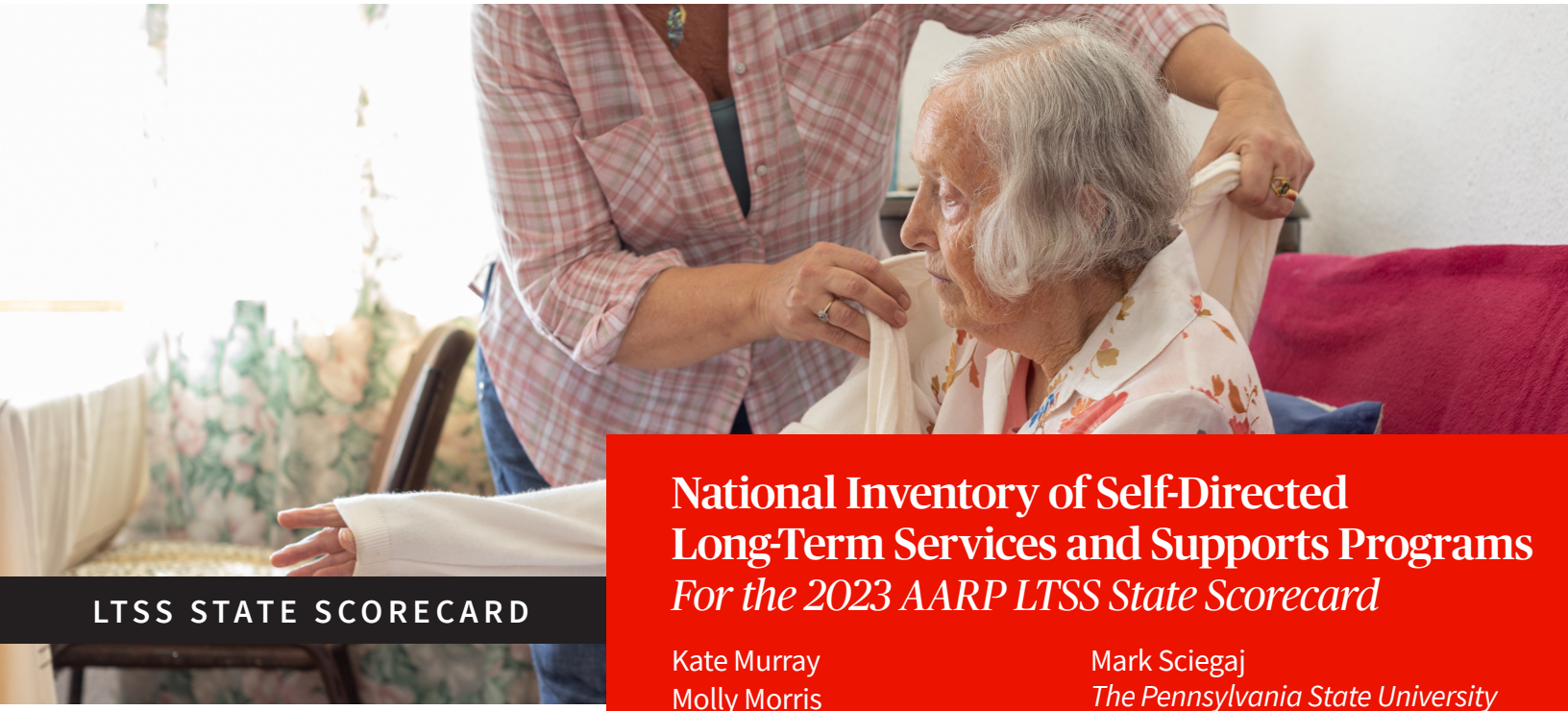

LTSS STATE SCORECARD

National Inventory of Self-Directed Long-Term Services and Supports Programs

For the 2023 AARP LTSS State Scorecard

Kate Murray
Molly Morris
Merle Edwards-Orr
Applied Self-Direction

Mark Sciegaj
The Pennsylvania State University

Brendan Flinn
AARP Public Policy Institute

About this Paper

The National Inventory of Self-Directed Long-Term Services and Supports Programs builds upon the 2023 LTSS State Scorecard and provides more data and analysis about self-direction across the United States. The LTSS State Scorecard is a project from AARP Foundation and AARP, funded by The SCAN Foundation, The Commonwealth Fund, and The John A. Hartford Foundation.

AARP Foundation
For a future without senior poverty.

THE scan FOUNDATION

The John A. Hartford Foundation

Introduction

The following report presents the findings from the 2023 Self-Direction National Inventory (the 2023 Inventory), conducted by Applied Self-Direction. This work was performed in support of the broader *2023 Long-Term Services & Supports* (LTSS) *State Scorecard* (the *Scorecard*), which is supported by the AARP Foundation, The Commonwealth Fund, The SCAN Foundation, The John A. Hartford Foundation, and AARP.[1]

About self-direction and other key terms

Self-direction is a model of LTSS delivery that empowers older adults and people with disabilities and chronic conditions to decide for themselves how, when, and from whom they receive services and supports. Self-direction affords participants with more choice, control, and flexibility relative to other models of care and typically includes either or both employer authority and budget authority. **Employer authority** allows participants to recruit, hire, schedule, manage, and terminate workers of

[1] Susan Reinhard, Rodney Harrell, Carrie Blakeway Amero, Brendan Flinn, Ari Houser, Paul Lingamfelter, Rita Choula, Selena Caldera, Edem Hado, and Julie Alexis. Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, 2023 Edition. Washington, DC: AARP Public Policy Institute, September 28, 2023.

their choosing, often family members, friends, or neighbors familiar with their needs and preferences. **Budget authority** grants even more decision-making control, allowing participants to set worker wages, and in some cases even to purchase goods and services that support their independence. While self-direction offerings vary nationally in the degree of control afforded to participants, all share the belief that people with disabilities understand their own needs best.

Part I: The 2023 Self-Direction National Inventory

The 2023 Inventory builds on previous inventories completed in 2011, 2013, 2016, and 2019 and specifically seeks to provide an overview of all publicly funded self-directed LTSS nationwide,[2] including estimates of numbers of participants, populations served, funding sources, and other key variables. It also covers significant trends influencing the overall LTSS landscape, such as the well-documented national shortage of direct care workers. Because this is the first inventory since the COVID-19 pandemic emerged in March 2020, the following also reports on the pandemic's effect on self-direction programs.

Methods

Self-direction program data were collected from October 2022 through February 2023. We first conducted a comprehensive review of publicly available information via state Medicaid waiver applications, Medicaid state plan documentation, and state websites across all 50 states and the District of Columbia. Building on these findings, we conducted 65 interviews with state agency staff from 43 states and corresponded with administrators in every state. Self-direction enrollment numbers were primarily provided by state program administrators. In a few cases when enrollment data were not available from state administrators, we used data provided by financial management services (FMS) entities or from enrollment estimates reported by the state in Medicaid waiver or state plan documentation. To support data accuracy, we shared enrollment findings with Applied Self-Direction's state and FMS members for final review.[3]

Recognizing the pandemic's potential effect on state LTSS programs, the *Scorecard* team redesigned its rubric for measuring state progress for 2023.[4] Similarly, Applied Self-Direction updated its approach for measuring the growth of self-direction. Previous inventories reported both the number of individuals enrolled in self-direction *and* the number of self-directed programs nationwide. The 2023 Inventory no longer includes a program count. See key finding 8 below for an in-depth explanation of why a program count is no longer a meaningful metric. We are confident that self-direction enrollment is currently the most accurate and appropriate measure of growth for the purpose of this report.

Also, the 2023 Inventory includes only self-directed options that involved a personal care-type service (e.g., activities of daily living and/or instrumental activities of daily living support). In some states, people may be able to self-direct more limited services such as transportation or respite via existing Medicaid authorities. However, these instances were not included in this report unless the option to self-direct a personal care-type service was also available under the same authority. It is important to note there is a robust national network of self-directed respite programs that were not considered within the scope of this report.

[2] The inventories in 2011, 2013, and 2016 were completed under the auspices of the National Resource Center for Participant-Directed Services at Boston College, the predecessor organization to Applied Self-Direction.

[3] Membership, Applied Self-Direction, https://appliedselfdirection.com/membership

[4] Susan Reinhard, Ari Houser, Carrie Amero, Paul Lingamfelter, Reimagining the State LTSS Scorecard, https://ltsschoices.aarp.org/blog/reimagining-state-ltss-scorecard

Key findings

1. **The number of people self-directing has increased considerably since 2019.** There are 1,520,267 people self-directing nationwide, according to the 2023 Inventory. This represents a 23 percent increase since 2019 (table 1). This level of growth suggests that both interest and enrollment in self-direction have accelerated over the past three years. By comparison, enrollment grew by 17 percent from 2016 to 2019.

   For the 2023 Inventory, most states (44) reported an overall increase in self-direction enrollment, while only a few states (seven) reported a decrease (table 2). Notably, six states have more than doubled self-direction enrollment since 2019. California continues to account for a significant share (48 percent) of the total national enrollment, though this percentage continues to trend downward since the first inventory in 2011.[5]

TABLE 1. NATIONAL SELF-DIRECTION ENROLLMENT (COMPARISON WITH 2011–23 INVENTORIES)

State	2011	2013	2016	2019	2023	Change from 2019 to 2023
Self-direction total enrollment	739,711	811,218	1,058,889	1,234,214	1,520,267*	+23.16%

*Program enrollment data were not available for certain funding sources in seven states. Total enrollment reflects enrollment numbers collected by earlier inventories—for a total of 0.43 percent of the participant count.

TABLE 2. SELF-DIRECTION ENROLLMENT, BY STATE (COMPARISON WITH 2011–23 INVENTORIES)

State	2011	2013	2016	2019	2023	Change from 2019 to 2023
Alabama	89	79	260	2,069	6,685	223.10%
Alaska	3,688	4,601	3,802	3,152**	2,424	–23.10%
Arizona*	2,140	1,466	4,000	3,240	1,607	–50.40%
Arkansas*	4,928	4,465	3,661	3,010	2,303	–23.49%
California*	480,000	450,374	540,190	606,078	726,304	19.84%
Colorado	19,550	2,660	4,355	9,006	10,884	20.85%
Connecticut	2,429	4,809	3,650	3,045	6,865	125.45%
Delaware*	35	1,042	1,407	1,620	2,010	24.07%
District of Columbia	1	2	33	641	1,607	150.70%
Florida*	1,984	4,880	3,196	4,703	14,340	204.91%
Georgia	2,849	2,008	3,769	3,387	4,145	22.38%
Hawaii*	2,271	2,424	2,959	3,655	3,952	8.13%
Idaho*	1,178	640	2,170	2,708**	4,444	64.11%
Illinois*	8,327	5,689	35,434	64,713**	42,961	–33.61%
Indiana	905	762	375	314	334	6.37%

[5] California represented 60 percent of total self-direction enrollment in 2011, 56 percent in 2013, 53 percent in 2016, and 49 percent in 2019.

State	2011	2013	2016	2019	2023	Change from 2019 to 2023
Iowa*	3,095	2,193	8,430	9,705	11,686	20.41%
Kansas*	3,416	14,073	10,333	9,530	10,701	12.29%
Kentucky	4,332	3,228	10,676	10,439	12,949	24.04%
Louisiana	2,235	3,833	4,875	1,344	2,283	69.87%
Maine	930	1,292	1,076	1,212	1,572	29.70%
Maryland	7,175	273	583	1,051	2,632	150.43%
Massachusetts*	19,460	13,254	41,590	38,898	49,553	27.39%
Michigan*	9,355	60,939	72,192	50,802	68,229	34.30%
Minnesota*	5,736	18,653	17,878	36,896	41,356	12.09%
Mississippi	3,750	600	3,457	3,291	4,127	25.40%
Missouri	15,270	25,921	29,205	41,237	50,639	22.80%
Montana	4,832	1,956	3,399	2,277	2,941	29.16%
Nebraska	2,346	4,729	3,550	2,879	2,895	0.56%
Nevada	1,238	436	572	1,003	928	–7.48%
New Hampshire	1,770	1,508	1,444	2,199	2,350	6.87%
New Jersey*	2,587	7,264	15,415	18,559	29,789	60.51%
New Mexico*	4,400	4,700	2,535	3,544	4,801	35.47%
New York*	10,252	10,372	30,759	83,701	142,407	70.14%
North Carolina*	70	1,426	1,856	3,473	4,615	32.88%
North Dakota	432	701	1,239	455	546	20.00%
Ohio	1,082	962	1,433	2,490	2,157	–13.37%
Oklahoma	953	865	1,235	1,721	2,325	35.10%
Oregon***	23,512	18,340	30,012	28,817	30,078	4.38%
Pennsylvania*	19,157	22,958	20,018	23,589	23,045	–2.31%
Rhode Island*	1,642	1,961	2,102	1,591**	2,971	86.74%
South Carolina	1,786	2,323	3,442	2,875	5,132	78.50%
South Dakota	1,036	925	98	166**	1,851	1,015.06%
Tennessee*	1,186	2,046	2,852	4,147	4,763	14.85%
Texas*	7,964	11,744	24,677	14,086	20,200	43.40%
Utah	2,875	1,682	2,072	2,662	3,603	35.35%
Vermont	4,310	5,956	5,074	4,632	4,837	4.43%
Virginia*	7,809	10,885	19,582	26,831	31,751	18.34%
Washington	22,585	44,150	48,540	40,357	60,748	50.53%
West Virginia	690	1,236	2,250	2,694	4,961	84.15%
Wisconsin*	9,563	20,784	24,258	42,669**	42,767	0.23%
Wyoming	506	1,149	929	1,051	1,214	15.51%

* State contracts with managed care organizations to administer part or all of its LTSS programs, as reported by the State Medicaid Integration Tracker© compiled by Advancing States. Advancing States, State Medicaid Integration Tracker, Q4 2022, http://www.advancingstates.org/sites/nasuad/files/u34188/CY2022%20Q4%20State%20Integration%20Tracker%20v3.pdf
** Findings in 2023 suggested these 2019 enrollment figures may have been inaccurate.
*** 2023 self-direction enrollment was not available for the Medicaid 1915(i) state plan option in Oregon, and no historical data were available to estimate enrollment.

2. **The Medicaid 1915(c) waiver is the most frequently used funding source for self-direction, and the adoption of additional Medicaid authorities is growing.** About 90 percent of states use at least one 1915(c) waiver to provide self-direction (table 3). The 1915(c) waiver has historically been the primary approach used by states, with 88 percent of them using this authority to offer self-direction in 2019. States have increasingly begun to use additional Medicaid authorities to administer self-direction. There was also some small growth in the usage of the 1915(k) State Plan Option–from 14 percent in 2019 up to 16 percent in 2023- and the 1915(i) State Plan Option–from 4 percent in 2019 up to 8 percent in 2023. See appendix I for a breakdown, by state, of the availability of self-direction funding sources.

TABLE 3. AVAILABILITY OF SELF-DIRECTION, BY FUNDING SOURCE

Funding Source	Number of States Using This Funding Source to Offer Self-Direction in 2023	Percentage of States Using This Funding Source to Offer Self-Direction In 2023 *(n = 51)*
Medicaid 1915(c) Waiver	46	90.19%
Medicaid 1915(j) State Plan Option	7	13.73%
Medicaid 1915(k) State Plan Option	8	15.69%
Medicaid 1915(i) State Plan Option	4	7.84%
Medicaid 1115 Demonstration Waiver	14	27.45%
Medicaid 1915(b) Waiver	21	41.18%
Medicaid State Plan	17	33.33%
State General Revenue	12	23.53%
Veterans Health Administration	38	74.51%
Older Americans Act	2	3.92%
Other funding mechanism	6	11.76%

3. **Enrollment in Veteran-Directed Care (VDC) has increased significantly.** In the 2023 Inventory, there were 6,041 people self-directing via VDC. This represents a 157 percent increase over 2019's VDC enrollment of 2,353 people. The average number of people served per VDC site has grown to 88 Veterans per site in 2023, up from an average of 33 Veterans per site in 2019. Despite this growth, the overall number of states offering VDC dropped from 41 states to 38 states. However, the Veterans Health Administration has committed to expanding VDC to every Veterans Affairs Medical Center (VAMC) by the end of fiscal year 2026, which should lead to the program's continued growth.[6]

[6] US Department of Veterans Affairs, VA amplifies access to home, community-based services for eligible Veterans, https://www.va.gov/opa/pressrel/pressrelease.cfm?id=5757

4. **Most states have at least one self-direction offering for adults over age 65, adults with physical disabilities, and adults with intellectual and developmental disabilities. Self-direction is less widely available for other populations.** Nearly all states have options to self-direct for adults over age 65 and adults with physical disabilities (all states except North Dakota; Illinois, Maryland and Tennessee have self-direction available to older adult participants through Veteran-Directed Care). About 92 percent of states make these offerings available to adults with intellectual and developmental disabilities. Although these findings suggest that the availability of self-direction for these populations has become the norm nationally, it is important to note that widespread availability does not guarantee a high rate of enrollment within the eligible population. Further advocacy may still be needed to ensure equitable access to self-direction, regardless of population. See table 4 for the availability of self-direction according to population type; see appendix II for a further state-by-state breakdown of the availability of self-direction according to population type.

   While 47 percent of states make some form of self-direction available to adults with serious mental illness, only 14 percent of states have offerings targeting this specific population. Several such self-direction behavioral health pilots have become inactive since 2019, and further research is needed to understand this trend. In Texas, state officials are actively working to embed self-direction for people with serious mental illness into an existing Medicaid authority after the recent completion of a successful pilot program.[7]

TABLE 4. AVAILABILITY OF SELF-DIRECTION ACCORDING TO POPULATION TYPE

Population type	Number of States with Self-Direction Available for Each Population Type	Percentage of States with Self-Direction Available for Each Population Type *(n = 51)*
Adults over age 65 (65+)	50*	98.04%
Adults with physical disabilities (APD)	50**	98.04%
Adults with intellectual and developmental disabilities (AIDD)	47	92.16%
Adults with serious mental illness (ASMI)	24	47.06%
Adults with traumatic brain injury (ATBI)	47***	92.16%
Children with physical disabilities (CPD)	30	58.82%
Children with intellectual and developmental disabilities (CIDD)	44	86.27%
Children with serious emotional disturbances (CSED)	24	47.06%
Children with traumatic brain injury (CTBI)	29	56.86%
Other population (OP)	38	74.50%

*Three of these states serve this population only via VDC.
** Two of these states serve this population only via VDC.
*** Thirteen of these states serve this population only via VDC.

[7] Texas Council on Consumer Direction, March 2021 meeting, https://texashhsc.v3.swagit.com/videos/151439

Fewer states offer self-direction to children—across various populations—than to adults, but seven states began to offer self-direction to children in 2023. This finding may point to an emerging national trend.

5. **The pandemic accelerated the expansion of self-direction nationwide.** States reported that self-direction uptake rates spiked during the early days of the pandemic due to a combination of factors. Potentially, the most important was that most states created a temporary emergency option via Appendix K of Medicaid waivers through the Centers for Medicare & Medicaid Services (CMS) to allow legally responsible individuals, such as spouses and parents of minor children, to serve as paid caregivers, in addition to other options to expand family caregiving.[8] The option to pay legally responsible individuals served as a crucial lifeline for people whose regular caregiving arrangements were interrupted. It also protected health and safety by allowing people who were generally at elevated risk of COVID-related complications to receive paid services from people with whom they lived. In turn, this arrangement allowed them to maintain service continuity while limiting their exposure risk—at a time when COVID-19 testing resources and treatment protocols were limited and vaccines not yet available.

   In addition, states reported that self-direction was critical in filling a void left by the widespread closure of day services across the country. People who had previously attended day services were able to stay home and receive alternative support from family members. Because family members were able to be paid, often via CMS's Appendix K, this option proved to be more sustainable than relying on natural supports—and safer than using agency-based caregivers who were likely to be serving multiple clients and could unknowingly transmit COVID-19. In many instances, states temporarily allowed for services to be delivered virtually via self-direction for health and safety reasons. Some states even reported that self-direction flexibilities allowed families to transition their loved ones from nursing homes, which faced unique and well-documented challenges with health and safety, back into family homes. Further investigation will be needed to determine to what extent the 23 percent growth in self-direction enrollment from 2019 was driven by the expansion of options for paying family caregivers—and to what extent this growth will be permanent or temporary.

   The pandemic galvanized federal investment in Medicaid, particularly in home and community-based services (HCBS). The 6.2 percent enhanced federal match from the Families First Coronavirus Response Act (FFCRA) was instrumental in funding states' responses to a rapidly changing landscape.[9] The American Rescue Plan Act (ARPA) funding made available to states starting in 2021 to improve HCBS also helped them make historic investments in self-direction expansion and enhancement.[10] Key state initiatives made possible through added federal funding included the following:

   - Reducing or eliminating waiver waitlists
   - Adding rate increases, hazard pay, and other increased compensation for caregivers

[8] Centers for Medicare & Medicaid Services, Emergency Preparedness and Response for Home and Community Based (HCBS) 1915(c) Waivers, https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html

[9] 116th Congress, H.R.6201 - Families First Coronavirus Response Act, https://www.congress.gov/bill/116th-congress/house-bill/6201/text

[10] 117th Congress, H.R.1319 - American Rescue Plan Act of 2021 https://www.congress.gov/bill/117th-congress/house-bill/1319/text

- Adding new self-directed options through CMS's Appendix K to waivers that had never previously offered the model, with the intent to offer permanent self-direction through their base 1915(c) waivers
- Streamlining onboarding processes to eliminate wait times for accessing self-directed services

The extent to which pandemic-driven program design changes will remain permanent is not yet fully known. At the time of our interviews earlier in 2023, state administrators could not officially confirm which flexibilities would be adopted beyond the pandemic, but many respondents were actively grappling with whether to continue allowing the payment of legally responsible individuals. Most interviewees were certain that the flexibility to complete certain activities virtually related to enrollment, reporting, and monitoring would remain.

Once pandemic-related Appendix K emergency provisions expired in November 2023, six months after the COVID-19 Public Health Emergency ends, states either adopted self-direction policies into their HCBS authorities or let those and other PHE flexibilities lapse. Notably, states may have waiver and related amendments pending with CMS that would permanently extend self-direction policies; those states are allowed to continue PHE-era policies while such amendments remain pending with CMS and until those amendments are finalized. As states finalize these policy decisions and operationalize them into their base waivers, additional analysis will be necessary to quantify the extent of permanent changes.

6. **Additional factors also continue to contribute to growth in self-direction.** The caregiver workforce shortage, which long predated the pandemic, was further exacerbated by pandemic-related disruptions. State feedback indicates that challenges with worker recruitment and retention have reached an all-time high since 2019, and states shared mixed responses about whether there has been any noticeable improvement recently. Further research is needed to determine whether the percentage of caregivers in self-direction who are family members of the care recipient has increased over time, but this result seems likely based on information shared by states during interviews.

   Meanwhile, greater demand for labor in the wake of the pandemic spurred employers to offer more competitive starting wages and benefits in the private sector, which intensified ongoing challenges with HCBS workforce recruitment and retention. Although states attempted to minimize workforce losses by increasing compensation for caregivers, the Medicaid-funded HCBS industry is not positioned to respond to market changes as rapidly as the private sector. However, most states reported that self-directed services seemed less affected by workforce shortages than agency services. While further research is needed to compare levels of unmet need among people who self-direct versus people who use traditional services, self-directed services seem to have lower rates of turnover among caregivers than among agency-based caregivers. As a result, anecdotal evidence suggests self-directed caregiving arrangements tend to be more resilient over time; this could be partly because participants often hire people with whom they have existing relationships. However, many family caregivers in self-direction may be the only caregivers available for their loved ones and would have to provide a similar level of unpaid support if they left their employment through self-direction.

   Another understudied possible factor in the growth of self-direction is that the model can effectively support historically marginalized and underserved communities, including racial and ethnic minorities. Increased awareness of self-direction, not only via improved case manager training but also through informal means such as social media, has anecdotally expanded access

to culturally competent support among underserved communities. One promising example is California's In-Home Supportive Services (IHSS) program, which is by far the nation's largest self-direction offering. IHSS reported as of December 2022 that nearly 70 percent of program recipients were people of color and that Hispanic and Black recipients constituted 31.4 percent and 13.9 percent of total IHSS enrollment, respectively.[11]

As a result of the factors described here, the self-directed model is commanding greater state attention and resources than ever before. Numerous states, such as Maine and Indiana, have introduced or are in the process of introducing new options to self-direct for populations that previously could not access the model. Also, states have demonstrated greater interest in making access more equitable, including creating videos about self-direction to ensure that every eligible person receives consistent information and can make an informed choice about whether to participate, as well as significantly expanding outreach among minority communities.

In the few states where growth was not evident or enrollment declined, challenges with access were a common theme across interviews. Multiple states with enrollment declines shared that challenges with implementing Electronic Visit Verification (EVV) systems had caused people to disenroll from self-direction—due to problems using the system and/or payment delays for caregivers. Other states noted that the enrollment process for self-direction took weeks or even months and that people who needed care immediately were more likely to refer their preferred caregiver to an agency if there were barriers to accessing self-direction. States that have limited or no growth in self-direction enrollment may find it useful to analyze their participant enrollment and caregiver time-tracking processes and adjust these processes as needed.

7. **States that demonstrated the greatest growth in Medicaid-funded enrollment tend to offer self-direction with budget authority.** *Budget authority*—CMS's term for the option for participants to control a flexible budget through which they can set workers' rates of pay and potentially purchase items that support independence and community integration—shows promise. It could combat the workforce crisis in a way that is cost-neutral for states. Allowing participants greater control and flexibility with the rate of pay may support worker recruitment and retention efforts. For example, the ability to pay a higher rate for an overnight shift that is otherwise difficult to fill may be especially helpful. Also, the ability to increase workers' pay over time—something available through budget authority—can increase a worker's probability of remaining in that job.

   In contrast, some self-direction is included only with what CMS terms *employer authority*—that is, the ability to recruit staff of one's choosing, set their schedules, manage their performance, and terminate as necessary. Although employer authority is a cornerstone of self-direction, our findings suggest that combining employer authority with budget authority may maximize the impact and benefits of the self-directed model.

   The 10 states with the largest reported growth in self-direction enrollment all offered self-direction with budget authority. Meanwhile, the majority of the seven states that reported a decrease in self-direction enrollment did not offer budget authority. Most states (44) have at least one Medicaid-funded offering that includes budget authority. Of this group, 35 states allowed participants to purchase individual-directed goods and services through at least one self-direction offering.

[11] California Department of Social Services, IHSS Program Data, December 2022 data, https://www.cdss.ca.gov/inforesources/ihss/program-data

More research is needed to better understand the impact of budget authority on self-direction uptake rates; however, states that are struggling to increase self-direction should consider adding budget authority if they have not already done so. In addition, self-direction advocates in states that do not offer budget authority should consider exploring this option, as budget authority can add considerable flexibility while remaining cost neutral.

8. **As self-direction is made more widely available, it is becoming deeply embedded within a complex array of Medicaid authorities.** In earlier inventories, it was common for states to offer self-direction as a stand-alone, niche option—for example, through a particular 1915(c) waiver that was exclusively self-directed. Therefore, it was previously more common for states to require participants to commit to an "all-or-nothing" approach to self-directing instead of allowing participants to select both traditional agency and self-directed services. Our review of Medicaid waivers and state plans indicates that the latter approach is becoming more common.

   As of 2023, the data show a clear trend in which states are now including self-direction as an option within an ever-greater number of Medicaid authorities. Participants are increasingly given the option to select their preferred mix of traditional and self-directed services. As alluded to in key finding 2, more waivers than ever before now include an option to self-direct some or all waiver services. Also, there is a notable increase in the number of 1915(i) State Plan Amendments, which indicates more state interest in expanding self-directed services to individuals who do not, or do not yet, meet an institutional level of care. Finally, self-direction is also a major service delivery model in the growing number of states that have adopted a 1915(k) Community First Choice State Plan Amendment.

   Although these factors have created expanded choice and options for participants, they have also created complexity and potential for confusion around counting "self-direction programs." For example, self-direction enrollment has increased by 61 percent in New Jersey, a state that has recently consolidated an array of Medicaid authorities and associated "programs" into a single 1115 waiver. If we counted "programs" that were tied to Medicaid authorities, New Jersey's program count would decrease because the state has transitioned programs that were formerly housed within multiple Medicaid authorities to the single 1115.

   There are also increasing consistency challenges related to reporting on the "program" number, due to the increasing incidence of self-direction offered via concurrent Medicaid authorities. For example, several states, such as Connecticut, may offer self-directed services via a series of 1915(c) waivers and through a 1915(k) Community First Choice Option (CFC), with many participants receiving self-directed services through both the waiver and the CFC.

   Finally, the term *program* refers to different structures in different states. One state may refer to a "program" as the self-directed services available within a particular 1915(c) waiver, such as New Mexico's Mi Via program. Other states may refer to a self-directed service delivery option available across multiple waivers as a "program." For example, Colorado's Consumer-Directed Attendant Support Services (CDASS) and In-Home Support Services (IHSS) are two unique self-directed service delivery options across multiple 1915(c) waivers. In other words, the relationship between a "program" and a particular Medicaid authority may be one to one or one to many, depending on the state. For these reasons, we argue that analyzing self-direction design by state—and if further detail is needed, by population(s) served within each state—offers the most clarity while minimizing the potential for confusion.

Conclusion

We have made every effort to represent the growth and expansion of self-direction as accurately as possible. However, limitations remain due to varied state funding structures, reporting capabilities, and preferences. These limitations do not detract from the most important finding: self-direction is a growing and increasingly critical component of our LTSS infrastructure that offers unique advantages for participants, families, and funders.

Part II: Impact of national workforce shortages on self-direction and family caregiving

The COVID-19 pandemic exacerbated an ongoing nationwide shortage of direct care workers in the United States.[12] When the COVID-19 Public Health Emergency was announced, CMS began allowing states to implement temporary flexibilities on an emergency basis across their long-term care offerings.[13] In response, several states chose to expand self-direction features and offerings as a key strategy to reduce barriers to care during the pandemic. These barriers included the extreme difficulties participants faced when hiring—due to the lack of available workers.

In our interviews with state representatives, authors asked about the impact of workforce shortages on self-direction and the extent to which newly implemented flexibilities addressed shortages.

Several states reported that self-direction mitigated workforce shortages. Many state representatives reported a rise in self-direction enrollment attributed, in part, to the pandemic and the need for more flexibility in hiring. Specifically, self-direction programs often allow for hiring family members, friends, or acquaintances who would not otherwise be part of the direct care workforce. It was common for states to temporarily expand the opportunity to hire family members, even legal guardians, parents, or spouses, if flexibilities were not already in place before the pandemic. At the time of the interviews, most states were in the process of making final decisions about what to make permanent after the conclusion of the public health emergency. Often, representatives indicated these hiring flexibilities continue to be a key driver in expanding the pool of available workers. In a few instances, states specifically noted that the workforce shortage has not had much of a negative impact on self-direction because of these flexibilities.

In many states, workforce shortages* did *have a significant impact on self-direction. Despite the advantages offered by self-direction to mitigate barriers to hiring, challenges persist. Multiple state representatives reported that participants hiring workers still struggle to compete with other industries, such as the fast-food industry, that can offer both higher wages and a hiring process that requires minimal effort and wait time before receipt of the first paycheck. Also, while the ability to hire family members has been a lifeline for many participants, it is not necessarily a preference for the long term; rather, in an environment with a limited pool of workers, hiring family may simply be the only option.

Numerous states reported that self-direction does not work as well for people who do not have family or friends available to hire. It may be suitable only for people who already know someone they wish to hire. Federal rules require self-direction to be accessible to anyone who is eligible; however, given the dearth of available workers, some states have focused their self-direction enrollment efforts on people who do not need additional support to identify a worker. One state respondent noted that particularly in rural settings, “If you don’t know anyone to hire, there’s no one to hire.”

[12] Administration for Community Living, Strengthening the Direct Care Workforce, https://acl.gov/programs/direct-care-workforce

[13] Centers for Medicare & Medicaid Services, 1915(c) Waiver Appendix K COVID-19 Prepopulated Template Instructions, https://www.medicaid.gov/state-resource-center/downloads/covid-19-appendix-k-instructions.pdf

State efforts to recruit or support family caregivers to join the workforce

As part of the interviews, state representatives were asked whether they were aware of any efforts to recruit paid family caregivers to work for other participants beyond their own families.

Most state representatives anticipated family members were occasionally recruited beyond their own families but were not aware of formal strategies to implement this approach at scale. Many suggested that these types of arrangements tended to be informally shared by word of mouth or pursued only in unique circumstances. As an example, one state respondent noted, "That sister was an amazing staff. So, we asked her if she was interested in continuing working within this field, and another family hired her."

A few states reported formal initiatives to recruit family caregivers to work for others. For instance, it is the practice in one state that the FMS provider advises family members interested in providing additional support to add their name to a registry as a prospective worker. In another example, the educational curriculum for prospective workers emphasizes that it is not necessary to be related to the person they support and that other options to work for others are available.

When prompted, many state representatives agreed that recruiting family members to work for others could be helpful, but most interviewees emphasized that other strategies are also needed to address the worker shortage. A few state representatives were less optimistic and cited a general hesitancy to share workers in a tight labor market. Others expressed concern about leading such an approach as a state agency for fear of risking unintended joint employment under the Fair Labor Standards Act.

See appendix III for a comprehensive list of additional strategies used by states to address workforce shortages in self-direction.

Recommendations for future research and policy development

Based on the feedback and observations of state representatives about their workforce challenges, we propose the following recommendations to advance further research and policy on this issue:

1. **Further research is recommended to understand the impact of increased wages and benefits on workforce shortages in self-direction.** Presumably, raising pay rates for staff supporting self-direction would increase the availability of workers, but additional research is necessary to quantify such impact. Ideally, research should examine the impact of higher wages not only for direct care workers but also for information and assistance professionals who support participants who self-direct. Information and assistance professionals (who may be referred to as *support brokers*, *care coordinators*, or other terms depending on the state) help coach participants with strategies for worker recruitment and retention. Unfortunately, high turnover due to low wages is common for information and assistance professionals, and it can limit participants' access to information and resources on effectively recruiting and retaining workers. Increasing pay rates for these professionals could reduce ongoing issues with turnover and job vacancies.
2. **Further research is recommended to understand the full impact of paid family caregiving on workforce shortages in self-direction.** In the wake of the pandemic, participants have become increasingly reliant on family caregivers to deliver paid care through self-direction. State respondents reported that these arrangements have been popular, and there is strong advocacy among participants and their families to permanently adopt options for paid family caregiving. Research on this topic would ideally demonstrate how expanding options for paid family caregiving can improve participant outcomes as well

as explore the potential challenges in relying heavily on paid family members to compensate for a limited workforce. Some respondents raised concerns about the long-term sustainability of this approach to care, particularly in scenarios where aging parents are both the primary worker and support system.

3. **Further research is recommended to better understand the impact of budget authority on ameliorating workforce shortages in self-direction.** In states that offer budget authority as a component of Medicaid-funded self-directed services, participants control a flexible budget through which they can set workers' rates of pay and potentially purchase items that support independence and community integration. (In states without budget authority, the rate of pay for each self-directed service is set by the state, and the participant is typically authorized a certain amount of hours of service for a particular timeframe.) As mentioned in Part I of this paper, states with the largest reported increase in self-direction enrollment all offered budget authority. Further research is needed to understand whether including the budget authority option eases hiring difficulties for participants.
4. **States should include requirements in their FMS contracts to collect certain key data and metrics on the self-direction workforce.** The majority of state respondents reported that they had limited to no access to demographic data on self-direction workers. While some surmised that their FMS partners likely had access to some data, this situation is guaranteed only if the FMS agency's contract requires the collection and maintenance of such information. Without a basic understanding of this workforce, it will be difficult if not impossible for states to quantify the scope of workforce shortages or better understand how the workforce could be expanded.

Conclusion

Although self-directed services can mitigate the ongoing direct care workforce shortage, they are not a panacea, nor is the self-directed model immune to this nationwide crisis. States are undertaking a variety of creative approaches to address workforce shortages, including expanding options for self-direction. Further research on the effects of increasing wages and benefits, the role of paid family caregivers, and the impact of budget authority, combined with more rigorous workforce data collection efforts at the state level, would all be effective next steps to build on the findings on workforce challenges in the 2023 Inventory.

Appendix I: Availability of self-direction funding sources, by state

State	1915(c)	1915(j)	1915(k)	1915(i)	1115	1915(b)	State plan	State-funded	Veterans Health Administration	Older Americans Act	Other
Alabama	x	x			x	x			x		
Alaska			x				x		x		
Arizona					x				x		
Arkansas	x	x					x		x		
California	x	x	x	x			x	x	x		
Colorado	x								x		
Connecticut	x		x			x			x		
Delaware	x			x	x	x		x			
District of Columbia	x								x		
Florida	x	x				x	x		x		x
Georgia	x										
Hawaii	x				x				x		
Idaho	x			x		x			x		
Illinois	x				x	x			x		
Indiana	x							x			
Iowa	x					x			x		
Kansas	x				x						
Kentucky	x							x			
Louisiana	x					x			x		
Maine	x					x	x	x	x		
Maryland	x								x		
Massachusetts	x						x	x	x		
Michigan	x				x	x	x		x		
Minnesota	x					x	x	x	x		
Mississippi	x								x	x	
Missouri	x					x	x		x		
Montana	x		x			x	x		x		
Nebraska	x						x				
Nevada	x						x				
New Hampshire	x						x		x		
New Jersey					x			x	x		
New Mexico	x				x				x		
New York	x		x					x	x		x
North Carolina	x					x			x	x	
North Dakota	x										
Ohio	x					x			x		
Oklahoma	x										
Oregon	x	x	x	x	x	x	x	x	x		
Pennsylvania	x					x		x	x		x

State	1915(c)	1915(j)	1915(k)	1915(i)	1115	1915(b)	State plan	State-funded	Veterans Health Administration	Older Americans Act	Other
Rhode Island					x						
South Carolina	x					x					x
South Dakota	x										
Tennessee	x				x				x		
Texas	x	x	x		x		x		x		x
Utah	x						x		x		
Vermont					x			x	x		
Virginia	x					x			x		x
Washington	x		x			x	x		x		
West Virginia	x										
Wisconsin	x	x				x			x		
Wyoming	x								x		

Appendix II: Availability of self-direction according to population type, by state[14]

State	Adults					Children				
	65+ years	Physical disabilities	Intellectual/ developmental disabilities	Serious mental illness	Traumatic brain injury	Physical disabilities	Intellectual/ developmental disabilities	Serious emotional disturbance	Traumatic brain injury	Other population
Alabama	x	x	x		x	x	x			x
Alaska	x	x	x	x	x	x	x	x	x	x
Arizona	x	x	x		x*	x	x			
Arkansas	x	x			x*					
California	x	x	x	x	x	x	x	x	x	x
Colorado	x	x	x		x				x	x
Connecticut	x	x	x	x	x	x	x	x	x	x
Delaware	x	x	x	x	x	x	x	x	x	x
District of Columbia	x	x			x*					
Florida	x	x	x	x	x		x			x
Georgia	x	x	x		x	x	x			
Hawaii	x	x	x	x	x*	x	x	x		
Idaho	x	x	x		x*		x			x
Illinois	x*	x	x		x	x	x		x	x
Indiana	x	x								
Iowa	x	x	x		x				x	x
Kansas	x	x	x	x	x	x	x	x	x	x
Kentucky	x	x	x	x	x	x	x	x	x	x
Louisiana	x	x	x		x*		x			x
Maine	x	x	x		x					x
Maryland	x*	x*	x		x*		x			
Massachusetts	x	x	x	x	x	x	x	x	x	x
Michigan	x	x	x	x	x	x	x	x	x	x
Minnesota	x	x	x	x	x	x	x	x	x	x
Mississippi	x	x			x	x			x	x

[14] Targeting enrollment by population is not permitted when offering self-direction via a Medicaid 1915(k) State Option. Therefore, in states using 1915(k), at least one self-direction option is available across all population types.

State	Adults					Children				
	65+ years	Physical disabilities	Intellectual/ developmental disabilities	Serious mental illness	Traumatic brain injury	Physical disabilities	Intellectual/ developmental disabilities	Serious emotional disturbance	Traumatic brain injury	Other population
Missouri	x	x	x	x	x	x	x	x	x	x
Montana	x	x	x	x	x	x	x	x	x	x
Nebraska	x	x	x	x	x	x	x	x	x	x
Nevada	x	x	x	x	x	x	x	x	x	x
New Hampshire	x	x	x	x	x	x	x	x	x	x
New Jersey	x	x	x	x	x	x	x	x	x	x
New Mexico	x	x	x		x*	x	x			x
New York	x	x	x	x	x	x	x	x	x	x
North Carolina	x	x	x		x*		x			x
North Dakota			x				x			x
Ohio	x	x	x		x*		x			
Oklahoma	x	x	x				x			x
Oregon	x	x	x	x	x	x	x	x	x	x
Pennsylvania	x	x	x		x*		x			x
Rhode Island	x	x	x	x	x	x	x	x	x	x
South Carolina	x	x	x		x		x	x	x	x
South Dakota	x	x	x				x			
Tennessee	x*	x*	x		x*		x			
Texas	x	x	x	x	x	x	x	x	x	x
Utah	x	x	x	x	x		x			x
Vermont	x	x	x		x	x	x		x	
Virginia	x	x	x		x*	x	x	x	x	x
Washington	x	x	x	x	x	x	x	x	x	x
West Virginia	x	x	x		x		x		x	
Wisconsin	x	x	x	x	x	x	x	x	x	x
Wyoming	x	x	x		x		x			

*Available to this population only via Veteran-Directed Care.

Appendix III: Additional state strategies for addressing workforce shortages in self-direction

NOVEL RECRUITMENT STRATEGIES

- ✓ Partner with high schools, community colleges, or universities to offer training pathways in the field
- ✓ Connect participants with college career offices to promote job openings
- ✓ Create a "caregiving" job classification at local career centers, enabling participants to post relevant job listings and allowing potential employees to search for that type of job
- ✓ Target recruitment to older adults
- ✓ Recruit vocational rehabilitation job developers to advertise caregiving roles
- ✓ Recruit spouses living on military bases
- ✓ Sponsor radio ads

DEVELOP WORKER REGISTRIES

- ✓ Approaches to increased hiring flexibilities*
- ✓ Allow for family members, including parents, legal guardians, or spouses, to be hired
- ✓ Implement an exceptions process in hiring if a legal guardian is the only available caregiver
- ✓ Waive criminal background check requirements or create an exceptions process for hiring (at the discretion of the participant)
- ✓ Lessen or remove credentialing or certification requirements across the self-directed workforce or for immediate family members
- ✓ Allow for virtual renewal of certification or credentialing
- ✓ Reduce the minimum age for hiring to 16 on a case-by-case basis
- ✓ Remove caps on hours for workers

APPROACHES TO INCREASE WAGES AND BENEFITS

- ✓ Increase wages and benefits to be more competitive with other industries via CMS's Appendix K and/or funding from the American Rescue Plan Act
- ✓ Increase wages or benefits via state legislative mandates
- ✓ Add sick leave for workers
- ✓ Allow higher wages for workers with specialized skill sets
- ✓ Provide a bonus for recruitment and retention—for example, upon finishing the orientation process or after completing a set length of service
- ✓ Offer a stipend for developing a specialized skill or completing additional training

SYSTEMIC INITIATIVE TO ADDRESS WORKFORCE SHORTAGES

- ✓ Develop a statewide task force or collaborative to oversee research on workforce shortages and recommend strategies

* The listed hiring flexibilities were implemented temporarily by most states during the pandemic; however, many states were in the process of making these flexibilities permanent.

https://doi.org/10.26419/ppi.00217.001

