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Promising Practices and Emerging Trends

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

For the AARP 2020 State Scorecard on Long-Term Services and Supports

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Introduction

The research team from Applied Self-Direction (ASD) conducted a National Inventory (Inventory) of publicly funded self-directed long-term services and supports (LTSS) programs in the United States to support the development of the AARP 2020 State Scorecard on Long-Term Services and Supports. This Inventory builds on the 2011, 2013, and 2016 Inventories conducted by the National Resource Center for Participant-Directed Services at Boston College, the predecessor organization to ASD, and reflects the impact of changes in federal policy designed to promote growth of self-directed LTSS as well as the ever-changing landscape of state Medicaid programs across the country. At the request of AARP, this Inventory also examines the extent to which self-directed LTSS programs support family caregivers by allowing them to be paid workers and by offering respite services available to family caregivers.

The following sections describe the 2019 Inventory project methods, key findings, and emerging trends.

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Definitions and Methods

For this Inventory, ASD developed definitions of "self-direction" and a "self-direction program" to guide our data collection. This was necessitated because states have begun adding tightly limited self-directed service categories to traditional service offerings—for example, allowing participants to only self-direct their transportation services. Because transportation is only provided on an intermittent basis and these programs offered no other opportunities to self-direct, we excluded such programs from the 2019 Inventory. As a result of these somewhat narrower definitions, we excluded five programs (three in Utah, one in North Dakota, and one in New Jersey) that were previously included in the 2016 Inventory. We also developed a definition of "respite" to exclude respite services provided in an institutional setting. (Definitions can be found in Appendix 1.)

Self-direction program data were collected from March through August 2019. The ASD team conducted reviews of state Medicaid waiver applications and program websites for general program information. The ASD team also conducted 61 interviews with state staff from 44 states and had written correspondence with program staff in every state.[1] Program enrollments were obtained from state program administrators. In a few instances, the project team was referred to the program's Financial Management Services (FMS) entities for enrollment data. Enrollment numbers were shared with ASD's State Program Membership and FMS Membership to verify for accuracy.

Key Findings

1. **Since 2016, states have continued to add new programs while also consolidating existing programs.** The 2019 Inventory identified 267 self-direction programs nationally (Table 1). Consistent with the 2016 Inventory, ASD counted all self-directed service options operating under a single Medicaid waiver as one single program. The 2019 Inventory found 70 new self-direction programs that were implemented since the 2016 Inventory and 43 programs from 2016 that were either discontinued or consolidated under a comprehensive Medicaid waiver. [2]

2. **The number of individuals enrolled in self-directed LTSS programs has grown considerably.** The 2019 Inventory found 1,234,214 individuals enrolled in self-directed LTSS programs nationally (Table 1), an increase of 175,325 since the 2016 Inventory. While California enrollments (n= 606,078) still account for nearly half (49%) of the national total, this percentage continues to decline as other states report marked increases in program enrollment. California represented 60% of the total enrolled in the 2011 Inventory, 56% of the total in the 2013 Inventory, and 53% in the 2016 Inventory.

3. **Medicaid remains the largest funding source for self-direction programs.** Medicaid has remained the primary funding source for self-direction since the earliest effort to inventory self-direction programs by Doty and Flanagan in 2002.[3] Funding sources are reported in Table 3. All forms of Medicaid accounted for 66% of self-direction program funding sources in 2019.

1 One state chose to respond to the interview questions in writing rather than via a telephone interview.

2 The methodology for counting programs has changed since 2016. 'Feeder' programs have been excluded from the program total (for more information on 'feeder' programs, see page 7). Also, Veterans programs are now counted individually, rather than by state. Therefore, the sum of programs in 2019 cannot be obtained simply by adding new programs and subtracting discontinued programs from the 2016 total.

3 Doty, P., & Flanagan, S. (2002). Highlights: Inventory of consumer-directed support programs. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services. https://aspe.hhs.gov/pdf-report/highlights-inventory-consumer-directed-support-programs. Retrieved June 28, 2019.

TABLE 1

Self-Direction Programs and Enrollment (Comparison of 2011-2019 Inventories)

	2011 Inventory	2013 Inventory	2016* Inventory	2019 Inventory	Change from 2016-2019
Self-Direction Program Count	233	261	253	267	N/A**
Self-Direction Participant Count	739,711	811,218	1,058,889	1,234,214	+16.56%

* Program enrollment data not available for 10 programs. Count reflects enrollment numbers collected by earlier inventories for a total of 4.78% of the total participant count.

** Percentage change in program counts cannot be shown. Program counts from 2016 – 2019 are not comparable due to a change in methodology for how self-directed LTSS programs are counted (see footnote 2).

TABLE 2

Self-Direction Participants by State (Comparison of 2011-2019 Inventories)

	2011 Inventory	2013 Inventory	2016 Inventory	2019 Inventory	Change from 2016-2019
Alabama	89	79	260	2,069	+695.77%
Alaska	3,688	4,601	3,802	3,152	-17.10%
Arizona*	2,140	1,466	4,000	3,240	-19.00 %
Arkansas*	4,928	4,465	3,661	3,010	-17.78%
California*	480,000	450,374	540,190	606,078	+12.20%
Colorado	19,550	2,660	4,355	9,006	+106.80%
Connecticut	2,429	4,809	3,650	3,045	-16.58%
Delaware*	35	1,042	1,407	1,620	+15.14%
District of Columbia	1	2	33	641	+1,842.42%
Florida*	1,984	4,880	3,196	4,703	+47.15%
Georgia	2,849	2,008	3,769	3,387	-10.14%
Hawaii*	2,271	2,424	2,959	3,655	+23.52%
Idaho*	1,178	640	2,170	2,708	+24.79%
Illinois*	8,327	5,689	35,434	64,713	+82.63%
Indiana	905	762	375	314	-16.27%
Iowa*	3,095	2,193	8,430	9,705	+15.12%
Kansas*	3,416	14,073	10,333	9,530	-7.77%
Kentucky	4,332	3,228	10,676	10,439	-2.22%
Louisiana	2,235	3,833	4,875	1,344	-72.43%
Maine	930	1,292	1,076	1,212	+12.64%
Maryland	7,175	273	583	1,051	+80.27%
Massachusetts*	19,460	13,254	41,590	38,898	-6.47%
Michigan*	9,355	60,939	72,192	50,802	-29.63%

Table 2 continued on page 4

TABLE 2

Self-Direction Participants by State (Comparison of 2011-2019 Inventories) *continued*

	2011 Inventory	2013 Inventory	2016 Inventory	2019 Inventory	Change from 2016-2019
Minnesota*	5,736	18,653	17,878	36,896	+106.38
Mississippi	3,750	600	3,457	3,291	-4.80%
Missouri	15,270	25,921	29,205	41,237	+41.20%
Montana	4,832	1,956	3,399	2,277	-33.01%
Nebraska	2,346	4,729	3,550	2,879	-18.90%
Nevada**	1,238	436	572	1,003	+75.35%
New Hampshire	1,770	1,508	1,444	2,199	+52.29%
New Jersey*	2,587	7,264	15,415	18,559	+20.40%
New Mexico*	4,400	4,700	2,535	3,544	+39.80%
New York*, **	10,252	10,372	30,759	83,701	+172.12%
North Carolina*	70	1,426	1,856	3,473	+87.12%
North Dakota	432	701	1,239	455	-63.28%
Ohio	1,082	962	1,433	2,490	+73.76%
Oklahoma	953	865	1,235	1,721	+39.35%
Oregon	23,512	18,340	30,012	28,817	-3.98%
Pennsylvania*	19,157	22,958	20,018	23,589	+17.84%
Rhode Island*	1,642	1,961	2,102	1,591	-24.31%
South Carolina	1,786	2,323	3,442	2,875	-16.47%
South Dakota	1,036	925	98	166	+69.39%
Tennessee*	1,186	2,046	2,852	4,147	+45.41%
Texas*	7,964	11,744	24,677	14,086	-42.92%
Utah	2,875	1,682	2,072	2,662	+28.47%
Vermont	4,310	5,956	5,074	4,632	-8.71%
Virginia*	7,809	10,885	19,582	26,831	+37.02%
Washington	22,585	44,150	48,540	40,357	-16.86%
West Virginia	690	1,236	2,250	2,694	+19.73%
Wisconsin*	9,563	20,784	24,258	42,669	+75.90%
Wyoming	506	1,149	929	1,051	+13.13%

* State contracts with managed care companies to administer part or all of its LTSS programs.

** Current year participant counts were not available for two programs in Nevada and one program in New York. 2016 participant counts were reported for the two programs in Nevada (572 participants) and one program in New York (735 participants).

TABLE 3
Self-Direction Programs by Funding Source

Funding Source*	Number Of Self-Direction Programs (2016)	Number Of Self-Direction Programs (2019) *
Medicaid State Plan	17	18
Medicaid 1115 Demonstration Waiver	13	18
Medicaid 1915 (b) or (b)/(c) Waivers	3	2
Medicaid 1915(c) Waiver	142	155
Medicaid 1915(i) State Plan Option	2	2
Medicaid 1915(j) State Plan Option	5	3
Medicaid 1915(k) State Plan Option	4	7
Veterans' Health Administration	60**	71
State General Revenue	7	13
Other Funding Mechanisms	11	20

* Funding sources for feeder programs (see "Emerging Trends" below) are included in the count so the total program count is over 267.

** The 2016 Inventory reported the number of states with a self-directed Veteran program, rather than the individual programs. The 2016 Inventory reported 31 states offering a self-directed Veteran program and 60 individual programs. The 2019 Inventory is reporting 71 individual programs across 41 states. The count for 2016 VHA-funded programs has been changed to the 2019 counting method to allow for comparison between the two years.

TABLE 4
Population Served by Self-Direction Programs

	2016		2019	
Population Served	Number of Programs	Percentage of Total Programs (n=208) *	Number of Programs	Percentage of Total Programs (n=267)
Adults ages 65 and older	58	28%	152	57%
Adults with Intellectual Disabilities/ Developmental Disabilities (ID/DD)	88	42%	86	32%
Adults with Physical Disabilities	70	33%	162	61%
Adults with Serious Mental Illness	4	2%	19	7%
Children with Intellectual Disabilities/ Developmental Disabilities (ID/DD)	69	33%	74	28%
Children with Physical Disabilities	**	**	24	9%
Traumatic Brain Injury	13	6%	26	10%
Veterans***	60	29%	71	27%
Other	45	18%	20	7%

* 208 out of 253 programs reported this information in 2016.

** Previous Inventories did not separate children with ID/DD and children with physical disabilities.

*** Programs serving Veterans are also reported as programs serving people over 65 and adults with physical disabilities

4. **Self-direction programs serve people of all ages and all types of disabilities.** The 2019 Inventory also looked at information on populations served by self-direction. More programs reported enrolling multiple populations. In 2016, roughly one-third (37%) of programs reporting population information reported that self-directed LTSS programs served multiple populations, in 2019, almost three-fourths (n=194 or 73%) reported enrolling multiple populations. Table 4 shows the number of programs by type of population served and the percentage these programs represent of the total programs reporting population information.

   As Table 4 shows, there were large increases in the number of programs serving adults with physical disabilities and adults ages 65 and older. It is not known whether this increase is due to new programs for these populations or better reporting. The 2016 Inventory was missing the populations served for 45 programs while the 2019 Inventory had no programs missing this information. In addition, there was a notable increase in the number of programs serving Veterans from 2016 to 2019 as discussed in item 3 under "Emerging Trends".

5. **The majority of publicly funded self-direction programs have flexible program features that provide enrollees greater choice and control over their services and supports.** The 2019 Inventory collected information on whether self-direction programs placed restrictions on hiring relatives, offered respite services, and whether programs allowed enrollees to manage their service budget.

   - *Hiring Restrictions:* Slightly more than half of programs (n=144) have specific restrictions on who the enrollee can hire. Of those with restrictions, 25 indicated that exceptions could be made on a case-by-case basis. In 2019, hiring restrictions included:
     - Spouses (n=122)
     - Legal guardians (n=110)
     - Parents (n=107)
     - Adult children (n=6)
   - *Respite Services:* In 2019 the majority of programs (n=213) either reported that respite was a waiver service (n=143), or, in the case of Veterans Health Administration's Veteran-Directed Care (VDC) programs, that funds could be used to purchase respite services (n=71). Although respite is not explicitly built into the VDC program plan of care, program rules do not include restrictions that would prohibit participants from using allotted staff time to provide respite services.
   - *Budget Authority:* The majority of programs (n=201 or 75%) reported using a budget authority model of self-direction. Budget authority provides participants with a flexible budget, which includes the ability to set the wage rates of service workers and facilitates creative usage of care resources. Of those 201 programs, however, only 166 allow participants to purchase a wide range of goods and services to meet their needs beyond hiring a service worker. The other budget authority programs generally allow participants flexibility in hiring and wage setting but either prohibit or place restrictions on purchasing goods and services.

Emerging Trends

The 2019 SD-LTSS survey has identified several notable trends, which include:

1. **The number of self-direction "feeder programs"[4] has increased sharply since the 2016 Inventory.** Not included in the 2019 Inventory program count (n=267) are 42 waivers that allow self-direction but do not provide self-direction as a service option. ASD refers to these 42 programs as "feeder" programs. In a feeder program, waiver recipients who opt to receive self-directed LTSS services are referred by their primary HCBS waiver (i.e., the feeder program) to an appropriate self-direction program to receive self-directed services. Waiver recipients continue to remain enrolled in the primary HCBS waiver to receive non-self-directed services. For example, participants in any of Colorado's five home and community-based services waivers who want to self-direct are referred for enrollment in either the state's In-Home Supportive Services or Consumer-Directed Attendant Support Services programs to access self-directed services. However, participants continue to remain enrolled in their respective "primary HCBS waiver" for other services (e.g., case management). In this example, the two self-direction programs were counted in the 2019 Inventory and the other five HCBS waiver programs were classified separately as "feeder programs."

   Several of these types of programs were identified in 2016 but were still counted as self-direction programs. To obtain a more precise count in 2019, however, the ASD project team formally recognized this type of program design and created the self-direction "feeder program" classification. In 2019 the project team identified 42 feeder programs across 10 states. These programs are currently in the following states: Alabama (4), Alaska (1), Colorado (5), Connecticut (8), Iowa (6), Massachusetts (3), Oregon (4), Texas (8), Vermont (1) and Wisconsin (2).

   The growing number of these feeder programs may reflect state efforts to eliminate barriers to individuals who may not elect self-direction upon initial receipt of LTSS, but who over time may want to do so. Further research is needed to understand state motivations to develop "feeder" programs, their design and structure, and how these programs may contribute to increased enrollment in self-directed service programs.

2. **In some states, managed long-term services and supports (MLTSS) may be promoting increased use of self-direction**. States that contract all or some of their LTSS program administration were identified using information from the National Association of States United for Aging and Disabilities (NASUAD) State Medicaid Integration Tracker© published on May 7, 2019.[5] NASUAD reported 23 states contracting with managed care entities to administer all or some of their LTSS programs (MLTSS states are reported in Table 2 above). In five MLTSS states (IL, MN, NY, VA, and WI), the 2019 Inventory found large increases in self-direction enrollment. In New York, the number of individuals self-directing increased by more than 50,000. Anecdotal information from Fiscal Intermediary entities that are responsible for providing FMS in New York, suggests that this

4 During the 2019 Inventory, ASD developed the term "feeder program" to define waivers that allow self-direction but do not provide self-direction as a service option. In a feeder program, individuals receiving waiver services who choose to self-direct are referred to the appropriate state self-direction program. This categorization was developed during the 2019 Inventory and the state may not use this term.

5 In August 2019, NASUAD changed its name to ADvancing States. The State Medicaid Integration Tracker© is published each month by ADvancing States, formerly known as NASUAD and is available at http://www.advancingstates.org/publications/state-medicaid-integration-tracker.

growth strongly correlated with the statewide rollout of a MLTSS option. In Wisconsin, the number grew by almost 20,000 since 2016. Virginia recorded an increase of approximately 7,000 since 2016. Looking farther back, Illinois and Minnesota reported increases of nearly 60,000 and 20,000 respectively since the 2013 Inventory, around the time that states began to rapidly adopt MLTSS.

While further research is needed to understand what factors contributed to these large enrollment increases, it does not appear from data collected in the 2019 inventory that MLTSS is having a negative impact on the growth of self-direction. Comparisons between 2016 and 2019 state enrollments show that self-directed LTSS program enrollment increased in 16 MLTSS states and decreased in the other seven states, but five of those seven states had either low enrollment or a decline in enrollment of less than 8 percent.

3. **The Veteran-Directed Care (VDC) program is showing promising growth.** The VDC program, formerly called the Veteran-Directed Home and Community-Based Services (VD-HCBS) program, continued to show growth from 2016 to 2019 – expanding from 60 programs in 31 states serving 1,572 Veterans to 71 programs in 41 states serving 2,048 Veterans. VDC program growth of 18 percent and an enrollment increase of 30 percent far exceeds the overall national rate of growth of self-directed LTSS programs (7 percent) and enrollment (18 percent) from 2016 to 2019. With less than one-half of VA Medical Centers offering self-directed services through VDC programs, there is considerable room for further growth to meet demand for these services.

4. **More states are offering self-direction to individuals with serious mental illness.** While the number of self-direction programs for individuals with serious mental illness remains small (19 programs for adults nationally), this nonetheless demonstrates significant growth from four programs identified in the 2016 Inventory. These programs tend to be small, usually well under 100 people each, and are generally structured as pilot or experimental programs. Texas, for example, is operating an experimental program with significant financial support from its managed care entities. Despite the small number of programs and number of people served, these programs show promise to be an area of continued growth in self-direction.

5. **States are concerned about implementing Electronic Visit Verification (EVV).** Use of EVV in all Medicaid-funded personal care was mandated by the 21st Century Cures Act, passed in 2016. Deadlines for state compliance have been pushed back one year, and EVV is now scheduled to go into effect January 2020. During interviews with state officials, the ASD team consistently found that states reported moving forward with implementation. Most states reported that they expected to meet the January 2020 deadline. States are using a variety of ways to address EVV implementation but, in almost every case, officials stated that implementing EVV in a self-direction context is challenging. The employer-related roles and responsibilities that are managed exclusively by an agency in a traditional service delivery model are instead diffused across the participant or representative, FMS entity, and potentially other parties in a self-direction model. This creates technical, operational, and philosophical complexities that are difficult for many EVV products which were designed for traditional home care service models.

Appendix 1: Definitions for 2019 Self-Direction Inventory

SELF-DIRECTION

For the Inventory to count a program as a "self-direction" program, the program must:

- Allow for basic employer authority, including the ability for the participant or representative to hire, schedule, and dismiss workers; and
- Provide sufficient support to assist the participant in a regular and continuous manner (i.e., providing services several times per week), rather than occasionally or in a situationally specific manner.

An exception to this definition will be made for programs that provide self-direction opportunities to people with serious mental illness. This exception will allow the Inventory to count programs that serve this population, even though program budgets are frequently small, and participants may not necessarily use their budget to hire a worker.

DEFINITION OF A PROGRAM

In recognition that waivers may include more than one self-direction program and that a program may serve multiple populations, a clear definition of a self-direction "program" was established to obtain a more precise program count for the 2019 Inventory. For the 2019 Inventory, a "program" is defined as a self-direction opportunity that has its own rules that differentiate it from other self-direction opportunities in the state. "Rules" are defined as program processes that do *at least one* of the following:

- Define who may receive services;
- Determine the approach for calculating the budget amount;
  - Note: "Budget" in this context refers to resources available to participants for their care. Some programs refer to available resources using other terms such as allocation and authorization. Therefore, employer authority-only programs, in which resources are distributed in forms other than dollars (e.g., hours of service), are included in this definition.
- Specify the prerogatives of the employer along the continuum of self-direction; or
- Identify what services are available to be self-directed.

DEFINITION OF RESPITE

Respite is an intermittent service that is designed to give the primary caregiver a reprieve from her or his caregiving duties while assuring the health, well-being, and life quality of the care recipient. While respite may be regularly scheduled and may extend as long as several days at a time, it remains a secondary caregiving strategy aimed at allowing the primary caregiver to remain in that role and not become exhausted. For purposes of the Inventory, only non-institutional respite services were counted.

DEFINITION OF FEEDER PROGRAM

During the 2019 Inventory, ASD developed the term "feeder program" to define waivers that allow self-direction but do not provide self-direction as a service option. In a feeder program, waiver recipients who opt to receive self-directed LTSS services are referred by their primary HCBS waiver (i.e., the feeder program) to an appropriate self-direction program to receive self-directed services. Waiver recipients continue to remain enrolled in the primary HCBS waiver to receive non-self-directed services. This categorization was developed during the 2019 Inventory and states may not use this term.

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