

**Long-Term Services and Supports Scorecard
Innovative and Promising Practices**

**Appendix:
National Inventory of
Self-Directed Programs for the
2017 State Long-Term Services and
Supports Scorecard**

Publicly Funded Self-Directed Long-Term Services and Supports Programs in the United States

Final Report, December 6, 2016

INTRODUCTION

The National Resource Center for Participant-Directed Services (NRCPDS) completed a National Inventory (NI) of self-directed programs in the United States on behalf of the *2017 State Long-Term Services and Supports Scorecard*. This inventory builds on the NRCPDS’ 2011 and 2013 NIs to reflect the impact of changes in federal law, regulation, and policy designed to promote growth of self-directed long-term support services (SD-LTSS), as well as the expanding number of state Medicaid programs contracting with managed care entities to administer their LTSS services. The following sections describe the state of SD-LTSS and changes or trends from earlier NRCPDS NI findings on SD-LTSS. The 2016 NI was conducted to support the development of the *2017 State Long-Term Services and Supports Scorecard*, which was produced

with support from the AARP Foundation, The Commonwealth Fund, and The SCAN Foundation.

METHODS

Data were collected from April to September 2016. Sources of data included state Medicaid waiver information, information from financial management services (FMS) providers, and telephone interviews with SD-LTSS program administrators.

FINDINGS

The number of SD-LTSS programs nationally remains stable: The 2016 NRCPDS Inventory is reporting 253 SD-LTSS programs nationally (Table 1). The 2016 NI counted all “programs” operating under a single Medicaid 1915© waiver and all Veteran-Directed Home- and Community-

TABLE 1
National Inventory of State Self-Directed Program Comparisons 2011–2016

	2011 STATE LTSS SCORECARD DATA SOURCE ¹	2013 NRCPDS INVENTORY	2016 NRCPDS INVENTORY
Total Program Count	233	261	253
TOTAL SD PARTICIPANT ENROLLMENT BY STATE			
Alabama	89	79	260
Alaska	3,688	4,601	3,802
Arizona*	2,140	1,466	4,000
Arkansas	4,928	4,465	3,661
California*	480,000	450,374	540,190
Colorado	19,550	2,660	4,355
Connecticut	2,429	4,809	3,650
Delaware*	35	1,042	1,407
District of Columbia	1	2	33
Florida*	1,984	4,880	3,196
Georgia	2,849	2,008	3,769
Hawaii*	2,271	2,424	2,959
Idaho	1,178	640	2,170
Illinois*	8,327	5,689	**35,434
Indiana	905	762	375

INNOVATIVE AND PROMISING PRACTICES

	2011 STATE LTSS SCORECARD DATA SOURCE ¹	2013 NRCPPS INVENTORY	2016 NRCPPS INVENTORY
Iowa*	3,095	2,193	8,430
Kansas*	3,416	14,073	10,333
Kentucky	4,332	3,228	10,676
Louisiana*	2,235	3,833	4,875
Maine	930	1,292	1,076
Maryland	7,175	273	583
Massachusetts*	19,460	13,254	41,590
Michigan*	9,355	60,939	72,192
Minnesota*	5,736	18,653	** 17,878
Mississippi	3,750	600	3,457
Missouri	15,270	25,921	29,205
Montana	4,832	1,956	3,399
Nebraska	2,346	4,729	3,550
Nevada	1,238	436	572
New Hampshire	1,770	1,508	1,444
New Jersey*	2,587	7,264	15,415
New Mexico*	4,400	4,700	2,535
New York*	10,252	10,372	30,759
North Carolina*	70	1,426	1,856
North Dakota	432	701	1,239
Ohio	1,082	962	1,433
Oklahoma	953	865	1,235
Oregon	23,512	18,340	30,012
Pennsylvania*	19,157	22,958	20,018
Rhode Island*	1,642	1,961	2,102
South Carolina	1,786	2,323	3,442
South Dakota	1,036	925	98
Tennessee*	1,186	2,046	2,852
Texas*	7,964	11,744	24,677
Utah	2,875	1,682	** 2,072
Vermont	4,310	5,956	5,074
Virginia	7,809	10,885	19,582
Washington	22,585	44,150	48,540
West Virginia	690	1,236	2,250
Wisconsin*	9,563	20,784	24,258
Wyoming	506	1,149	929
TOTAL SD Enrollment	739,711	811,218	1,058,889

¹ M. Murphy, I. Selkow, and K. Mahoney, *Financial Management Services in Participant Direction Programs* (Long Beach, CA: The SCAN Foundation, 2011), http://www.thescanfoundation.org/sites/default/files/TSF_CLASS_TA_No_10_Financial_Management_Services_FINAL.pdf.

* Managed-Long-Term Services and Supports states.

**Missing one or more program enrollment counts and using 2013 enrollment counts where possible.

Based Services (VD-HCBS) programs operating in a state as a single program (previous NRCPPDS NIs generally counted these programs separately). Despite this change, the 2016 program count is an increase of 20 programs from the 2011 inventory used in the 2011 edition of the *Scorecard*, which estimated the number of SD-LTSS programs to be 233, and a slight drop from the 2013 NI, which estimated the total number of programs to be 261 (Table 1). The more conservative counting of programs in 2016 explains the drop in the total number of programs nationally from 2013.

The number of participants enrolled in SD-LTSS has grown considerably:

The 2016 NRCPPDS Inventory is reporting 1,058,899 participants enrolled in SD-LTSS programs nationally (Table 1). This is an increase of 319,188 from 2011 and approximately 247,681 from what NRCPPDS reported in December 2013 for the 2014 edition of the *Scorecard*. California SD-LTSS enrollments ($n = 540,190$) still account for just over half (51 percent) of the national total. California represented 56 percent in 2013 and 65 percent in the 2011 NI.

The Growth in managed long-term services and supports (MLTSS) does not appear to have much impact on SD-LTSS enrollments:

MLTSS has grown since the 2011 NRCPPDS Inventory. According to the August 2016 National Association of States United for Aging and Disabilities (NASUAD) State Medicaid Integration Tracker, 21 states (Arizona, California, Delaware, Florida, Hawaii, Iowa, Illinois, Kansas, Louisiana, Massachusetts, Michigan, Minnesota, North Carolina, New Jersey, New Mexico, New York, Pennsylvania, Rhode Island, Tennessee, Texas, and Wisconsin) are currently implementing or operating MLTSS.²² Table 1 notes these states with an asterisk. Comparisons between 2013 and 2016 state enrollments show that SD-LTSS program

enrollments increased in 16 MLTSS states and decreased in the other 5 states. Overall, MLTSS states increased SD-LTSS program enrollment on average by over 80 percent. Of the 31 non-MLTSS states, 21 states increased SD-LTSS enrollment and the other 10 states decreased it. Overall SD-LTSS program enrollment in the non-MLTSS states increased 110 percent between 2013 and 2016.

More SD-LTSS programs are being offered statewide:

Of the 253 programs, 229 (91 percent) reported on whether the SD-LTSS program was offered statewide. Of those responding, 189 programs (75 percent of all programs) reported operating statewide. In 2013 only 116 programs (44 percent of all programs) reported operating statewide.

Medicaid remains the largest funding source for SD-LTSS:

This is not a surprising finding— from the earliest effort to inventory SD-LTSS by Doty and Flanagan in 2002,²³ Medicaid has been the primary funding source. Funding sources were identified for 240 (95 percent) of the 253 programs in 2016 and are reported in Table 2. Medicaid sources accounted for 78 percent of SD-LTSS program funding in 2016.

SD-LTSS programs serve people of all ages and all types of disability:

The 2016 Inventory has information on populations served by SD-LTSS from 208 programs (82 percent of all programs). As in previous iterations of the NI, almost half ($n = 93$ or 37 percent) of these state SD-LTSS programs serve multiple populations. Table 3 reports on the number of programs that serve different populations.

State Implementation of Fair Labor Standards Act (FLSA) Home Care Rule:

The revised FLSA Home Care Rule went into effect in 2015 and its full impact on SD-LTSS may not be fully realized as of this writing. Several states reported that responding to the Home Care Rule has been difficult and

22 NASUAD, *State Medicaid Integration Tracker*, accessed September 25, 2016, <http://www.nasuad.org/initiatives/tracking-state-activity/state-medicaid-integration-tracker>.

23 P. Doty and S. Flanagan, *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, 2002), accessed September 28, 2016, <https://aspe.hhs.gov/pdf-report/highlights-inventory-consumer-directed-support-programs>.

TABLE 2
Programs by Funding Source 2016

FUNDING SOURCE	NUMBER OF PROGRAMS	PERCENTAGE OF REPORTING PROGRAMS (n = 240)
Medicaid State Plan	17	7%
Medicaid 1115 Demonstration Waiver	13	5%
Medicaid 1915(b) Waiver	3	1%
Medicaid 1915(c) Waiver	145	60%
Medicaid 1915(i) State Plan Option	2	1%
Medicaid 1915(j) State Plan Option	5	2%
Medicaid 1915(k) State Plan Option	4	2%
Veterans' Administration	31	13%
State General Revenue	7	3%
Private Pay	0	0%
Other Funding Mechanisms	13	5%

time consuming. A couple of states reported an unwillingness to incur the increased expenditures for home- and community-based LTSS necessary to pay overtime and are avoiding minimizing such cost increases by limiting the number of weekly hours for which independent providers (self-directed workers) may bill Medicaid (or other public programs). One possible impact of the new FLSA rule may be that self-directed participants may be

required to recruit additional workers and might have trouble finding workers with the right amount of billable time available to work the necessary hours. Another possible implication of FLSA is that self-directing participants might also have difficulty finding additional workers who they think can do as good a job for them as would the workers they would choose to employ if those workers were not subject to the billable hours cap.

TABLE 3
Population Served by SD-LTSS Programs

POPULATION SERVED	NUMBER OF PROGRAMS	PERCENTAGE OF REPORTING PROGRAMS (n = 208)
Adults with Behavioral Health Issues	4	2%
Adults with Intellectual Disabilities/Developmental Disabilities (ID/DD)	88	42%
Adults with Physical Disabilities	70	34%
Children	69	33%
Elders	58	28%
Other (e.g., Traumatic Brain Injury, Autism, HIV)	13	6%
Veterans	31	15%