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Long-Term Services and Supports Scorecard
Innovative and Promising Practices

Taking It to the Next Level: Using Innovative Strategies to Expand Options for Self-Direction

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Having Choice and Control My Way

Rita knows what she wants from her personal care workers. As a 73-year-old former college English teacher and phlebotomist, she wants them to be on time, do the work she hired them to do, and do it well. Because she lives in a small apartment, Rita wants her employees to be people she can get along with, yet she also desires a basic mutual understanding with them: "I don't pay them to visit; I pay them to work."

RITA WITH HER DOG SANDY

Fortunately, Rita is a participant in the Texas STAR+ PLUS, Consumer Directed Services (CDS) program, which allows her to find workers that meet her expectations. Rita selects her employees carefully and is willing to pay them more than they might make elsewhere. Her reputation for being a good employer enables Rita to find personal care workers through word of mouth, rather than through local advertising.

Having the kind of workers she wants and needs has not always been the case for Rita. Before enrolling in CDS in 2010, Rita used an agency to provide workers, but she found the arrangement unsatisfactory. Frustrated that she wasn't in charge of her workers, Rita found herself, in her words, "negotiating" her care with the agency care manager–especially when workers were frequently late or did not show up and did not call.

Now that Rita is in control, her employees know her expectations early on. Using a flexible and creative team approach that works for everyone, Rita has workers who enjoy cooking to prepare her meals (she eats vegan) and those who are good housekeepers to do housekeeping. At any given time, Rita has about four employees on her payroll to support her needs, which also allows workers to have flexibility in their schedules.

Rita recommends CDS to anyone who qualifies for the program. Paperwork can be daunting, especially for some older adults, but she points out that participants can appoint a family member or a friend as their representative to help with that task. What is important is that program participants can hire the workers they want.

Rita revels in having choice and control over managing her workers, but she knows that she and they form a team: she has to care for them so they can care for her. Being able to pay her workers adequately, assigning them to the tasks they like, and scheduling them flexibly, Rita has developed for her employees a support structure that keeps them happy and for herself, a safe and healthy home.

About This Paper

In 2016, roughly 1 million people were enrolled in Medicaid-funded and Veteran-Directed Home- and Community-Based Services (VD-HCBS) self-directed programs. While the number of people self-directing their services nationally has increased by more than 40 percent since 2011, in 2016 fewer than 27 out of every 1,000 people with any disability were self-directing their long-term services and supports (LTSS). That said, counts vary widely across states, with California reporting 132 out of every 1,000 people with disabilities (about 1 in 8) received self-directed services, while in several states, fewer than 1 out of every 1,000 people with disabilities received self-directed services.

This is all in spite of studies consistently showing that people who self-direct their services are more satisfied with them, experiencing equal or improved outcomes than people whose services are directed by an agency. Nonetheless, the highly individualized nature of each service plan and concerns about the ability of plan participants to manage their services effectively can create barriers that hinder states to take their programs to the next level.

This paper describes programs in four states—Texas, Iowa, Wisconsin, and Florida—that take innovative approaches to self-direction. It discusses the strategies these states used to develop and expand their programs, coordinate and personalize services, promote stakeholder engagement and outreach, and implement effective training.

Using interviews with leaders and participants, this paper highlights some innovative and promising practices along with a sample of self-directed program resources that can be used for training, education, collaboration, and replication. These tools are offered as a guide for states seeking to develop, improve, or expand their own self-directed LTSS programs. Finally, for each program, we offer a point of contact for additional information and guidance.

Acknowledgments

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Introduction

HISTORY OF SELF-DIRECTION

While self-direction has been around in one form or another since the 1970s, it has only been since the Cash and Counseling Demonstration and Evaluation (CCDE) near the turn of the 21st century that self-direction has become a fundamental program element for home- and community-based services (HCBS). A random control trial experiment looking at over 6,500 Medicaid-eligible individuals with long-term services and supports (LTSS) needs in three states, the CCDE showed that when compared with people receiving traditional agency-based services, self-directed LTSS programs allowed participants to receive more services—and be more satisfied with those services—while experiencing equally good or better outcomes.[1] Since then, the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration (VHA) have worked to expand available self-direction options for the older adults and people with disabilities they serve.

What Is Self-Direction?

Built on the premise that people receiving LTSS know their needs best, self-direction—also known as participant direction or consumer direction—is an approach to home- and community-based services that maximizes the degree of choice and control that participants have over what services they receive, who provides the services, and when, where, and how services are provided. This is usually accomplished by program participants receiving a budget for services and having control over how that budget is spent.

RECENT STUDY FINDINGS

Self-directed program enrollment is on the rise. A 2016 National Inventory of self-directed programs conducted by the National Resource Center for Participant-Directed Services for the 2017 *State Long-Term Services and Supports Scorecard* (*"Scorecard"*) reported that there were 253 self-directed LTSS programs nationally, operating in every state and the District of Columbia, representing an 8 percent increase since 2011 (Appendix).[2] Despite low growth in the number of self-directed LTSS programs, enrollment in Medicaid-funded and Veteran-Directed Home- and Community-Based Services self-directed programs has increased 43 percent from 2011 to 2016, to just over 1 million people. The number of programs that offer self-directed services on a statewide basis is also increasing. Specifically, of the 253 self-directed LTSS programs, 229 (91 percent) reported on whether the program was offered statewide. Of those responding, 189 programs (75 percent of all programs) reported that they offer self-directed services statewide. In 2013, only 116 programs (44 percent of all programs) reported operating statewide.[3]

The availability of programs offering self-directed services on a statewide basis is increasing throughout the United States.

1 R. Brown, B.L. Carlson, S. Dale, L. Foster, B. Phillips, and J. Shore, *Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community Based Services* (Princeton, NJ: Mathematica Policy Research, 2007).

2 National Resource Center for Participant-Directed Services, "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" (unpublished), National Resource Center for Participant-Directed Services, Boston College, Boston, December 2016.

3 Ibid.

The 2016 National Inventory survey also found that the growth in Medicaid-managed long-term services and supports (MLTSS) does not appear to have had much impact on self-directed LTSS program enrollments.[4] Specifically, in August 2016, the National Association of States United for Aging and Disabilities (NASUAD) State Medicaid Integration Tracker© reported that 21 states were either operating or implementing MLTSS.[5] Comparisons between 2013 and 2016 state enrollments show that of the 21 MLTSS states, self-directed LTSS program enrollment increased in 16 states (76 percent of states) and declined in 5 states (24 percent). Overall, MLTSS states saw enrollment grow, on average, by over 80 percent. Of the 30 non-MLTSS states, 20 states (67 percent) showed an increase in program enrollment and 10 states (33 percent) a decrease. Overall, non-MLTSS states increased program enrollment by 110 percent.[6]

PROGRAM BENEFITS

Although self-directed LTSS benefits vary by state and program, they always include either a service hour or dollar budget that can be used at the discretion of the participant to purchase a range of services. Generally, budgets are used to hire staff or a family member, if permitted by the state, to provide personal assistance; in some cases, funds can also be used to purchase goods and services to help participants maintain their independence. Almost all programs offer participants supports to develop and manage their LTSS spending plan. For example, participants are offered information and assistance services (sometimes called support brokerage, case management, or consultation services) that can help them develop their service plans. They are also offered financial management services (FMS), which are used to manage the payroll of their direct care workers, including ensuring that taxes are paid and applicable hiring rules are followed.

Evidence shows that self-direction is an effective way to provide LTSS.[7,8] However, the highly individualized nature of each service plan and concerns about participants' ability to manage these services effectively can create barriers that prevent states from taking their programs to the next level. Careful planning, thoughtful use of support services, and sound feedback—or feedback and improvement loops, which include both participants and their support services—can ease complexity and minimize risk. Outreach is equally important, as usually people who need LTSS and their caregivers need to know that self-directed program options are an alternative to traditional HCBS programs and that these alternative options may be available.

Growth in MLTSS does not appear to have had much impact on self-directed LTSS program enrollments.

By highlighting how four successful self-direction programs have implemented strategies to address these issues, this paper can inform programmatic and policy development in states seeking to expand self-directed service options. It can also help state administrators by providing strategies, tools, and the names of experts and their contact information.

4 Ibid.

5 Ibid.

6 Ibid.

7 Self-direction contributes to increased HCBS utilization, lower per person cost of providing LTSS, and reduced nursing home utilization.

8 Mark Sciegaj, Suzanne Crisp, Merle Edwards-Orr, and Casey DeLuca, "Three Emerging Themes from Implementing Self-Directed Long-Term Service and Support Programs Under Managed Care," *Public Policy & Aging Report* 26, no. 4 (2016): 134–37, https://doi.org/10.1093/ppar/prw019.

CHOICE AND CONTROL

Self-direction grew out of the independent living movement and shares many of its values, as self-direction seeks to maximize personal choice and control over the supports and services that work best for participants. Self-direction begins with a person-centered plan that is developed jointly by the participant and the program planning team (often referred to as the circle of support); this plan outlines the participant's goals and objectives. A person-centered plan can provide a level of autonomy many of us take for granted, as it gives participants in a self-directed program control over what services they receive, who provides the services, and when, where, and how these services are provided:

- ***What:*** The participant can choose what services to use to meet his or her needs or preferences. For example, does the participant want home-delivered meals, or would she or he rather pay an aide to cook?
- ***Who:*** The participant can elect service providers available in the state's self-direction program or hire his or her own staff or family member, if permitted by the state (an option that many participants choose).
- ***When:*** Participants can determine when they prefer to have services delivered. If they prefer to go to bed late, they can hire a family member, if permitted by the state, or a neighbor to come in and help with their evening routine whenever they like.
- ***Where:*** Participants can determine if they want their services at home or elsewhere (e.g., at work or at school, or to enable engaging in out-of-home activities such as grocery shopping or going to the local YMCA for exercise).
- ***How:*** Participants can choose how services are provided. For example, participants can make their own decisions over how funds in their self-directed services budget are spent.

People without disabilities can routinely make these decisions. Self-direction helps ensure that having a disability does not limit a person's control over daily life choices.

Key Principles of Self-Direction

1) People who receive services know best what services they need and how they should receive them.
2) When given the opportunity to manage their services, they will do so efficiently and effectively.
3) Supports in such areas as service planning and resource management should be flexible and available, to enable participants to manage their services when needed.

SELF-DIRECTED SERVICES: A KEY PART OF A HIGH-FUNCTIONING LTSS SYSTEM

The *Scorecard* identifies self-direction as a key component of a high-performing LTSS system.[9] In a high-performing system, a person-centered approach allows people with LTSS needs to receive services in the setting of their choice and from the providers they choose. Because of the importance of giving people who receive publicly funded HCBS choice and autonomy over directing their own services and care arrangements, the *Scorecard*, since 2011, has included a self-direction indicator. Data for the indicator were based on a national inventory of self-directed programs in the United States conducted by the National Resource Center for Participant Directed Services.[10]

9 Susan C. Reinhard, et al., *Picking up the Pace of Change: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, June 2017). Prior editions (2011 and 2014) of the *Scorecard* are available at http://www.longtermscorecard.org/.

10 The 2013 and 2016 National Inventories were conducted to support the development of the 2014 and 2017 *State LTSS Scorecards*.

In 2016, roughly 1 million people were enrolled in self-directed programs nationally.[11] While the number of people self-directing services nationally has increased by more than 40 percent since 2011, in 2016, fewer than 27 out of 1,000 people with any disability received self-directed services through a publicly funded program.[12] This is not for lack of demand, as most self-direction programs report having waiting lists. Programs that do not have enrollment limits continue to show significant growth. Many stakeholders—including state and federal officials, advocates, and consumers of HCBS—want to develop self-direction programs, expand capacity, establish and implement service coordination, and roll out training and quality monitoring.

IDENTIFYING INNOVATIVE AND PROMISING PRACTICES

Using information from the 2016 National Inventory and feedback from state program leaders, Applied Self Direction and the *Scorecard* team identified programs in four states with innovative self-directed program approaches and strategies to develop and expand programs, coordinate and personalize services, engage stakeholders, and implement training programs. These programs are:

STAR+ PLUS Consumer Directed Services (CDS) (Texas). This MLTSS program requires managed care providers to offer service coordination as a basic service. The program emphasizes quality and has robust participant and stakeholder involvement.

Consumer Choices Option (CCO) (Iowa). A single self-direction program founded on person-centered principles, CCO serves six of the state's seven LTSS populations. It uses budget and employer authority to maximize participant choice and has developed a strong support network around its FMS provider.

Include, Respect, I Self-Direct (IRIS) (Wisconsin). A self-directed services program where the participant's needs and goals are the principal focus, IRIS maximizes choice from the beginning of the participant's experience by using shared decision making instead of bureaucratic rules to resolve difficult issues and by offering strong support to enable the participant to be in charge.

Veteran-Directed Home- and Community-Based Services (VD-HCBS) (Florida). VD-HCBS is a self-directed services program formed through a partnership between the local Veterans Affairs Medical Center and its neighboring aging and disability network agency. Factors contributing to the program's startup success include the partners promptly acting on an opportunity, developing and trusting in the partnership, and quickly proving the program's value.

The authors of this paper interviewed officials from the four programs for details on issues that cut across self-direction programs, including:

- Program development and growth;
- Program support and expansion in an environment where MLTSS has increasing influence;
- Effective coordination of all program components, including participants, case managers/support brokers, and FMS providers, to ensure quality;
- Participant and stakeholder engagement in the development and oversight of self-direction programs; and
- Developing LTSS options tailored to meet participant and family member needs.

11 National Resource Center for Participant-Directed Services, "National Inventory."

12 Note that not all people with disabilities have LTSS needs.

State Innovations in Self-Direction Programs and Practices

TEXAS: ACHIEVING SUCCESS IN A MANAGED CARE ENVIRONMENT

As states began to move increasingly toward MLTSS, many supporters of self-direction expressed concern that managed care plans lacked expertise in LTSS. This led to fears that the shift to MLTSS would give self-direction the short shrift.

Texas is a case in point. At the time the Lone Star State began a transition toward MLTSS, it already had in place a number of self-direction programs, known collectively as Consumer Directed Services (CDS), aimed at several populations. The concern was that moving them into a managed care structure would undermine the core principles of the self-direction model.

As it would turn out, however, Texas's experience demonstrates that this need not be the case: virtually all of Texas's LTSS population of older adults and people with disabilities is now covered under the state's STAR+ PLUS MLTSS program, and, in fact, self-direction under this system is thriving, with over 17,000 Texans managing their own care.[13]

While there have been many reasons for this successful transition, four offer particular guidance:

- Slow and methodical statewide rollout,
- Strong service coordination,
- Emphasis on quality, and
- Robust participant and stakeholder involvement.

Slow and Methodical Rollout

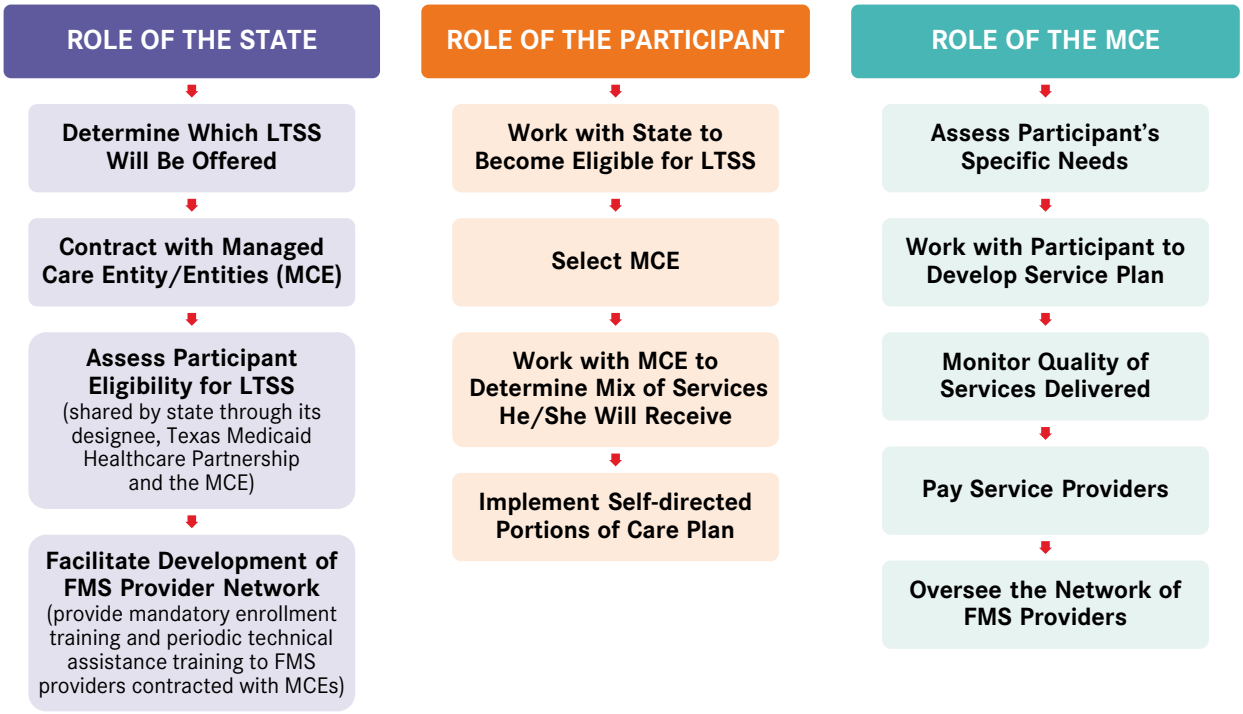
Texas began converting its Medicaid programs to managed care in the 1990s and completed the move to statewide coverage in 2014. This allowed the state to replicate the program from county to county and region to region, keeping and emphasizing program components that worked well and modifying those that needed improvement. Texas is a big state, both in population and in area, so a smaller state may not need to measure its rollout period in decades. However, Texas's do-no-harm approach allowed its self-direction programs to grow significantly while it was transitioning its population to MLTSS. Texas is currently working toward implementing MLTSS to serve individuals with intellectual and developmental disabilities, and will maintain its strong commitment to self-direction during these transitions. Texas has also started STAR Kids, a new MLTSS program for children.

Managed Long-Term Services and Supports

Beginning in the 1990s, states began experimenting with moving LTSS from a fee-for-service approach to a managed care approach. In MLTSS, the state determines which Medicaid LTSS it will provide, generally through a combination of state plan and waiver services, and then contracts with one or more Managed Care Entity (MCE) to provide and pay for those services. The state pays the MCE through some variation of a per member/per month rate. Participants, after going through a state eligibility process, select which MCE they want to receive their services through (assuming more than one is available) and work with MCE case managers to develop and implement their service plans. If self-direction is a state service, then participants would work with the MCE to set up their self-directed plan.

13 Enrollment count is based on 2016 program enrollment data collected for the National Inventory for the 2017 *State LTSS Scorecard*.

Who Does What in Texas STAR+ PLUS



Service Coordination

Years of work in the field have shown that the manner in which self-direction options are initially offered to a consumer is very influential to whether they ultimately choose to self-direct.[14] MLTSS service coordinators, therefore, are a key component to the success of self-direction programs.

As part of the move to MLTSS, Texas required its managed care providers to offer service coordination as a basic support service. This gives program participants a reliable point of contact who can answer questions, offer program options that meet their day-to-day needs, and help plan for future goals. Service coordinators are expected to be well-versed in self-direction and clearly offer the CDS option to consumers.

Texas Star+ PLUS and CDS Toolkit:

- STAR+ PLUS Handbook with CDS Overview
- STAR+ PLUS FAQs
- CDS Option Website - General Information
- CDS FAQs
- CDS Option Roles and Responsibilities
- CDS Option Website - Detailed Information
- CDS Forms and Handbooks
- CDS Option Technical Assistance Webinars
- Texas Council on Consumer Direction Website with Archived Webcasts
- Video of December 2017 Texas Council on Consumer Direction Meeting
- Council on Consumer Direction Videos of Archived Meetings

14 Frank Thompson, Pamela Nadash, Michael K. Gusmano, and Edward Alan Miller, "Federalism and the Growth of Self-Directed Long-Term Services and Supports," *Public Policy & Aging Report* 26, no. 4 (2016): 123–28, https://doi.org/10.1093/ppar/prw020.

Emphasis on Quality

With participants in self-direction programs in control of services they receive, achieving and maintaining a quality program begins with the participant. In Texas, the role of support services, including those of service coordinators and FMS providers, is to ensure that participants have the knowledge and skills they need to effectively manage their services. At a minimum, participants are expected to be able to manage a budget and hire and supervise staff. Texas has dedicated state staff resources that are essential to ensuring that its FMS providers can support participants appropriately. The state operates an "all qualified providers" FMS system with a three-pronged approach to ensure that providers meet standards. All new FMS providers are required to take a two-day new-provider training course and pass a competency test. Providers are also required to attend quarterly and annual training that addresses program changes and systemic issues arising from complaints.

Robust Participant and Stakeholder Involvement

In general, participant involvement in program and policy decisions is often lacking in self-direction programs. The statewide Texas Council on Consumer Direction (TCCD), an influential stakeholder advisory committee established through Texas Government Code,[15] provides sound input on all aspects of the state's self-direction options. Two examples of this influence include TCCD's role in supporting the development of the new STAR Kids program, recommending topics for periodic FMS provider training, and providing feedback on CDS training and outreach materials. The TCCD is required to report any recommendations to the Health and Human Services executive commissioner and submit an annual report to the legislature of policy recommendations made to the executive commissioner. Annual reports keep the participant voice in front of state lawmakers. Council meetings are open to the public and webcasted live to facilitate statewide engagement; videos of archived meetings are publicly available.

IOWA: EXPANDING ACCESS TO SELF-DIRECTION ACROSS POPULATIONS USING A FLEXIBLE APPROACH

Iowa effectively addresses a common shortcoming among self-direction programs. Nearly all self-direction programs are population-specific—that is, there is a self-direction option for older adults and people with physical disabilities (both populations are often included in the same program), another for people with intellectual and developmental disabilities, and yet another for people with traumatic brain injuries. While this approach allows states to have increased control over their programs and to easily fit them into Medicaid 1915(c) HCBS waivers, it can simultaneously leave out populations that would benefit from self-direction and limit what services are available for each population. Iowa has worked to maximize access and choice for participants by

- Developing a single self-direction option that serves nearly all populations,
- Using budget authority to maximize participant choice, and
- Developing a strong support network based around the FMS provider.

Developing One Self-Direction Option to Serve Many Populations

The Consumer Choices Option (CCO) is Iowa's self-direction program, available to six of the state's seven LTSS populations (children with behavioral health needs is the exception). Rather than establishing a one-size-fits-all program, Iowa uses a flexible approach based on person-centered

15 For more information about the Texas Government Code, see Texas Government Code 531.012 available at http://www.statutes.legis.state.tx.us/Docs/GV/htm/GV.531.htm#531.012

principles. This approach allows participants and program planners to build service plans based on the unique needs of the individual participant rather than bounding those plans by some notion of what a particular population needs. For example, many programs for people with developmental and intellectual disabilities allow for services that enhance employment opportunities, yet very few programs for older adults offer these services. In the Iowa model, service planners need not worry about whether certain services are available to a particular population; rather, they can focus on the goals and preferences of the individual, so that an older adult who wants to get back into the work force can build that into his or her program plan.[16]

Using Budget Authority to Maximize Participant Choice

CCO is a budget and employer authority program that allows participants to hire and manage their own workers, including setting pay rates, schedules, and tasks, and purchasing goods and services. Participants also may save up funds over the course of a year to purchase a good or service that would support the person's goals but that option is not available through the Medicaid program. For example, savings from reduced employee hourly wages can be used to purchase assistive devices, laundry, cooking, or handyman or cleaning services, or to make home modifications to help consumers live more independently. This budget flexibility is not uncommon in self-direction programs, but it is an essential element of Iowa's cross-population approach because participants' needs can vary widely. Advocates in Iowa supported a budget authority model because services are often hard to find in rural areas—and Iowa has many such areas. A highly flexible approach allows participants to develop services creatively where formal services may not exist. An example might be a participant paying a family member, if permitted by the state, or a friend to drive him or her to the grocery store or a medical appointment because public transportation is scarce or nonexistent. Such a flexible approach can also enhance efficiency by encouraging participants to use local community resources—such as health clubs or personal trainers to work on personal health activities—rather than hiring direct care workers.

Another aspect of this flexibility is that Iowa allows participants to self-direct as many or as few services as they wish. If a participant wishes to use a budget only to purchase goods and services but is happy to have an agency manage his or her personal care staff, then that arrangement is possible. Even with this high level of personal choice, Iowa has been able to maintain budget neutrality required in all Medicaid waiver programs.

Iowa also has a separate self-direction program that predates CCO; this separate program only allows participants to hire direct care workers and does not offer the option to purchase goods and services. While Iowa is working to transition participants in this separate program to the CCO program, there has been some resistance from participants. Program transitions can be stressful, and program changes of any kind need to be implemented slowly and with considerable communication with stakeholders.

A Program Cornerstone: Developing a Strong Support Network around the FMS Provider

Underpinning this flexible arrangement is a network of independent support brokers and an FMS provider that plays a large role in supporting both participants and support brokers. Currently, Iowa uses a state credit union, Veridian Credit Union, as its sole FMS provider. This unique arrangement is due to requirements in Iowa state statute, which specifies that FMS providers be a statewide financial institution that is insured by the National Credit Union Administration or the Federal Deposit Insurance Corporation. While relying on independent support brokers is somewhat

16 Enrollees in the Iowa CCO program maintain eligibility as long they are eligible to receive home- and community-based waiver services.

controversial in self-direction circles, Veridian and its FMS subsidiary, Veridian Fiscal Solutions (VFS), leads the charge in ensuring the quality of these services. In addition to all the required FMS employer functions, VFS also provides the state-approved training for independent support brokers and distributes regular, quarterly updates to both support brokers and participants. VFS maintains a self-direction website to help participants manage their services. In its more traditional FMS role, Veridian plays an important part by making sure that all payments, whether for personal care or for goods and services, follow the participant's self-direction budget and program rules. Veridian is also the first to see if participants are getting the care they need, by monitoring the hours of care that are being billed by the participant. VFS works closely with the state to identify and address any program or billing issues that may affect the provision of self-directed services.

These tasks support broker training,[17] regular program updates to program stakeholders, and quality assurance—all universal needs in self-direction programs. Who carries them out, however, can vary and be designed to meet the needs and culture of the particular state. Iowa's approach to Medicaid services in general has been to outsource as much as possible, leaving a small state staff whose role is primarily to monitor program contractors rather than operate the program directly. Iowa's approach vests considerable responsibility in the FMS provider. The logic behind this approach is twofold. First, FMS providers are most apt to have current contact information on participants and their direct care workers, given the importance to all parties that timesheets and paychecks are received in a timely fashion. Second, given the importance to FMS providers of keeping abreast of statutory, regulatory, and policy changes, they are often best equipped to track, understand, and disseminate program updates. Using FMS as this type of resource helps ensure that accurate and consistent information about both programs and individual participants goes to each member of the self-direction team.

Iowa Consumer Choices Option Toolkit:

- CCO Web Page
- CCO Brochure
- Informed Consent and Risk Agreement
- CCO Handbook for Consumers, Caregivers, and Advocates
- CCO Manual for Case Managers
- Support Broker Training developed by Public Partnerships, LLC and conducted by Veridian Financial Solutions
- Examples of Provider Training Programs

WISCONSIN: PUTTING THE PERSON AT THE CENTER

Person-centeredness—that is, keeping the participants' needs and goals at the center of services—is an essential component of self-directed LTSS. Wisconsin's IRIS (Include, Respect, I Self-Direct) program has succeeded remarkably well at focusing on the participant's needs and goals and, through several innovative elements, has become one of the country's strongest programs. Wisconsin developed the IRIS program in 2008 so that participants would have a choice of LTSS as the state was rolling out its Family Care (managed care) model. Now available almost statewide, IRIS serves approximately 16,000 people, of whom roughly 21 percent are older adults, across all disabilities. The program strives to help eligible persons stay in the community and avoid entering a nursing home or other institution. IRIS has grown organically and is strongly supported by the people it serves.

17 Included in the toolkit are publicly available training materials for support brokers, but users need to register to gain access. Because this is a training program, the materials cannot be readily browsed.

Even as program staff moves to clarify and formalize the rules for this far-from-small program, that process is being done with a clear mandate to maintain IRIS' person-centered culture. It maintains that culture through three methods:

- Maximizing choice from the beginning of the participant's experience,
- Using shared decision making instead of bureaucratic rules to resolve difficult issues, and
- Offering strong support that enables the participant to be in charge.

Maximizing Choice

Wisconsin developed IRIS as an alternative for participants as the state rolled out its MLTSS program.[18] This is unusual in that self-direction usually occurs within an MLTSS offering, rather than as an alternative to it. Wisconsin's approach is also unusual because it informs participants of the monthly budget estimate available *before* they make the choice between managed care and self-direction. Specifically, Wisconsin uses its Aging and Disability Resource Center/No Wrong Door system, which exists independently of both IRIS and MLTSS providers, to provide enrollment counseling to participants as they enter the LTSS Medicaid system. It is with this information in hand that participants are offered the choice of self-directing or working with a managed care organization. As previously noted, the manner in which participants are offered the choice of self-direction appears to have a significant impact on whether they choose this option. Wisconsin's approach of having a conflict-free party offer the choice, along with a clear statement of the budget estimate, may have a significant impact on the IRIS program's growth.

Supporting Participant Decision-Making Instead of Bureaucratic Rules

Person-centeredness recognizes that each individual has unique needs and goals, and the pieces necessary to achieve those goals will be as different as each participant. States, however, have to operate fairly; each citizen should be treated equitably. Because individuals have different notions of a *need* versus a *want*, maintaining fairness within self-direction programs can be a challenge. Rather than rely on lists of rules that include services always covered or never covered, the Wisconsin IRIS program uses what is referred to as "kitchen table" decision making. This means that when deciding the most cost-effective ways to meet a participant's desired outcome or need, the program's approach is to support the participant being in charge of the decision. This is done by bringing the team together—including the participant and family members—around the kitchen table in the participant's home to decide the best way to help the participant achieve his or her goals. This method allows all perspectives to be discussed openly, and it supports the participant's role, which is to be in charge of his or her IRIS service plan. Also, this approach allows decision making to be transparent to the participant and the family members.

Offering Strong Supports

The IRIS program provides every participant with an IRIS consultant who is employed by an IRIS consultant agency. These consultants help the participant create a self-directed service plan, and they remain available to the participant following development of the service plan to help ensure that it is working as needed and that the participant remains in charge. Devolving decision making to the participant and his or her team requires that all members of that team be proficient in their roles. For many years, there was only one provider for consultant agency services in the state. A few years ago, however, the state realized that a program that emphasizes choice should offer a choice of consultant agency providers. As a result, Wisconsin now has six consultant agencies and four fiscal employer agent (FEA) providers. Offering participants a choice of

18 While the Family Care MLTSS program offers some opportunities for self-direction, IRIS is specifically designed as a self-directed services program.

consultant and FEA providers necessitated that Wisconsin increase its oversight and monitoring of these agencies. Program leaders point out that opening the door for choice has led to competition among the agencies, resulting in improved quality. Agencies strive to provide the best service possible so that individuals choose them and not a competitor. This history of helping the participant be in charge of his or her plan, strong state oversight, and recent history of increasing choice has helped make Wisconsin's IRIS program among the strongest in the country.

Wisconsin IRIS Toolkit:

IRIS Website
IRIS Participant Handbook
IRIS Brochure
IRIS Participant Responsibilities
IRIS Policy Manual
IRIS Work Instructions
IRIS Service Definitions

FLORIDA: GET GOING AND GET GROWING STRATEGY

James A. Haley Veterans Hospital and Senior Connection Center Inc. Tampa, Florida

Veteran-Directed Home- and Community-Based Services (VD-HCBS) offers veterans who need LTSS the opportunity to self-direct their services. It operates as a partnership between a local Veterans Affairs Medical Center (VAMC) and its neighboring aging and disability network agency.[19] Details of the unique VD-HCBS program design can be found in the AARP *No Wrong Door: Supporting Community Living for Veterans* promising practice paper published in November 2017.[20]

Because VD-HCBS is available at roughly only one-third of the VAMCs in the United States, the VD-HCBS Tampa, Florida, program description will focus on the startup phase of the self-direction program to assist VAMCs and No Wrong Door (NWD) agencies that do not currently offer a program. Three aspects of that process will be examined:

- Striking while the iron is hot: being ready when the opportunity arises;
- Developing and trusting the partnership: letting each party do what they do best; and
- Proving value: being able to show benefit in order to bolster leadership support.

Striking While the Iron Is Hot

Because each VAMC and NWD agency is different, every VD-HCBS program has a unique story of how it was established. In each case, however, when the opportunity to start the program arose, both partners were willing and able to take advantage of that opportunity. In Tampa, Florida, the leadership at the James A. Haley Veterans Hospital learned about VD-HCBS early in the 2008 national rollout and decided it would be a better way to serve veterans who needed LTSS. Through VD-HCBS, veterans would have greater choice and control over their LTSS and be able to continue to live in their home and community. The coordinator for the VD-HCBS program at the hospital seized this opportunity and moved quickly to solidify a relationship with the local Aging and Disability Resource Center/ NWD agency, the Senior Connection Center, Inc. (SCC) of Tampa. Leadership at SCC saw promise with the program and moved quickly to develop

19 Aging and disability network agencies that serve veterans can include Area Agencies on Aging, Centers for Independent Living, Aging and Disability Resource Centers that are sometimes called No Wrong Door (NWD) agencies, and State Units on Aging.

20 Christina Neill Bowen, Wendy Fox-Grage, Kali Thomas, and James Rudolph, *No Wrong Door: Supporting Community Living for Veterans* (Washington, DC: AARP Public Policy Institute, November 2017).

the necessary materials to serve veterans. With this rapid response, the James A. Haley Veterans Hospital became one of the first VAMCs in the country to offer the VD-HCBS program.

Developing and Trusting the Partnership

It is important to understand that the VAMC and NWD agency each bring knowledge and resources to VD-HCBS that the other does not have. VAMCs have veterans who need LTSS and some level of funding to buy those services; NWD agencies have an understanding of community resources in general and self-directed services in particular. SCC had extensive knowledge of self-direction because it had already been serving people who were self-directing through a Florida Medicaid program. As a result, SCC was readily able to modify its procedures to meet the needs of the VD-HCBS program. The toolkit shown here includes several SCC VD-HCBS program documents that could be used by other states and localities as a guide in developing, operating, and enhancing a VD-HCBS program.

Tampa Florida VD-HCBS Toolkit

Senior Connection Center, Inc. documents:

Program Operating Materials

Program Satisfaction Materials

Beyond the procedural level, building trust was an integral part of forging the partnership between the Haley Veterans Hospital and SCC. It was essential to establish trust at both the organizational and the personal level. Building trust involved sharing a common vision and purpose, coming to agreement on the meaning of giving veterans an opportunity to self-direct their services, and having open and regular communication during program development, implementation, and expansion. Ongoing dialogue has allowed issues, whether pertaining to individual veterans or to operation of the program, to be discussed and resolved in a collective manner.

Proving Value

All new VD-HCBS programs must demonstrate that they are achieving intended goals, doing it well, and operating at a reasonable cost. As the VD-HCBS program in Tampa expanded, VAMC leadership became concerned that the program was too expensive. The program's expense, however, can be attributed to it serving a high-needs population; it may actually save money because it helps limit costly nursing home admissions. Even though VAMC had proposed the program, VD-HCBS program leadership worked with SCC partners to provide evidence of the value of sustaining and growing the program. This was accomplished by demonstrating the following three factors:

- Veterans liked the program.
  - Veterans have reiterated their satisfaction with VD-HCBS services, as reported in satisfaction surveys. Toolkit materials from SCC include examples of these surveys.
- Veterans were getting good care.
  - While Veterans Affairs staff continues to monitor veterans through routine Veterans Affairs clinic visits, NWD agency staff also monitors veterans' care through regular required visits with VD-HCBS participants in their home and even more frequent phone contact. (The independent consultant contact requirements can be found in the VD-HCBS toolkit SCC program operating materials.) In their regular meetings, VAMC and SCC staff can share this enhanced information about veterans' care. The VAMC can also learn a great deal about the care veterans are receiving from the spending reports generated by the FMS provider. The Veterans Affairs and the NWD agency can, therefore, work together to paint a complete picture of the care each veteran is receiving.

- The program has been cost-effective.
  - A recent report prepared by The Lewin Group for the Veterans Health Administration showed that VD-HCBS recipients experienced utilization declines in both inpatient and nursing home lengths of stay.[21] Other smaller studies have shown savings in acute care costs, such as decreased emergency room use and hospital admissions. *No Wrong Door: Supporting Community Living for Veterans* addresses this issue. The *VD-HCBS Local Sustainability Guidance* report (see textbox) looks at cost and other evidence that local programs can use to demonstrate the positive impact of their programs.

VD-HCBS Local Sustainability Guidance

VD-HCBS Local Sustainability Guidance

In 2014, at the request of the Veterans Administration, the National Resource Center for Participant-Directed Services published a guide on how to make a case for sustaining the ongoing importance of the VD-HCBS program. The report addresses several ways that sites can create value in maintaining a program as well as the ways in which its importance can be conveyed to organizational leadership.

21 The Lewin Group, Inc., "VD-HCBS & H/HHA Demographics and Utilization," report created for the Veterans Health Administration, Office of Geriatrics and Extended Care, Washington, DC, October 2017.

Conclusion

Evidence shows that self-direction is an effective way to provide LTSS. Although all states have LTSS program options that offer self-directed services, how these services are structured and administered, as well as the number of people served, varies widely across states. Many stakeholders want more programs developed to increase opportunities for individuals to self-direct. Expanded capacity, improved service coordination, and training programs for individuals and providers are also critical. Although some states have increased opportunities for consumers to self-direct their LTSS, perceived barriers hinder many states to take their programs to the next level.

The innovative practices and strategies highlighted in this paper—program development and growth, expansion in an MLTSS environment, effective coordination, participant and stakeholder engagement, and tailored program options—are helping to expand opportunities for individuals in four state programs to self-direct their care. This information, along with toolkit resources and contact information for experts in the four states can help to encourage and guide other states, with the ultimate goal of increasing opportunities for individuals to self-direct.

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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

	2011 STATE LTSS SCORECARD DATA SOURCE[1]	2013 NRCPDS INVENTORY	2016 NRCPDS 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 NRCPDS 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 NRCPDS 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 NRCPDS 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 NRCPDS 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%

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