

Advancing Self-Direction in LTSS: Empowering Individuals and Mitigating the Direct Care Workforce Crisis

Webinar

July 16, 2024

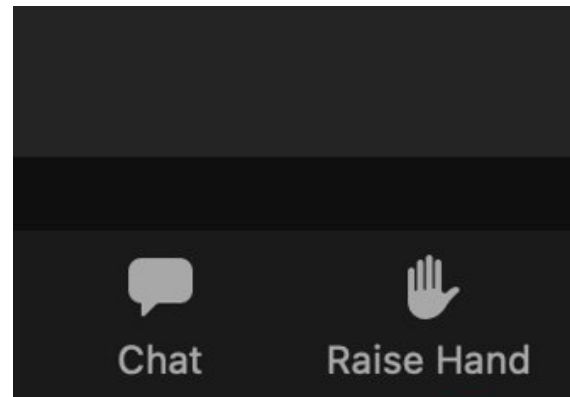




Event Logistics

Please use the following buttons at the bottom of your screen:

- **Chat box** to ask questions, make comments, and share resources
- **Raise hand** if you have a comment during the discussion portion



Please chat your name, organization, and location now!

About Long-Term Quality Alliance



- LTQA is a 501(c)3 membership organization aimed at improving outcomes and quality of life for people who need long-term services and supports (LTSS), and their families.
- LTQA advances person- and family-centered, integrated LTSS through research, education, and advocacy.

For more information:



www.ltqa.org



[LinkedIn](#)

LTQA Members



AARP
ADvancing States
Aetna
AlohaCare
Altarum
AmeriHealth Caritas
American Network of Community Options and Resources (ANCOR)
Applied Self-Direction
Association of University Centers on Disabilities (AUCD)
Autistic Self Advocacy Network (ASAN)
CareSource
Catholic Health Association of the United States
Centene
Commonwealth Care Alliance
Community Catalyst
Elevance Health
Humana
Independent Living Systems/Florida Community Care
The John A. Hartford Foundation

Justice in Aging
LA Care
LeadingAge
Meals on Wheels America
Molina Healthcare
National Alliance for Caregiving
National Adult Day Services Association (NADSA)
National Association of State Directors of Developmental Disabilities Services (NASDDDS)
National Council on Independent Living (NCIL)
National PACE Association
Neighborhood Health Plan of Rhode Island
The SCAN Foundation
1199SEIU
UnitedHealthcare
UPMC Health Plan
USAgings
VNS Health
Volunteers of America National Services (VOA)

Our Speakers



Molly Morris
Vice President



Brendan Flinn
Director, LTSS



Kris Kubnick
Senior Director, Product
Management



Talking Points at a Glance

- Quick background on Applied Self-Direction
- Introduction to self-direction and key concepts
- Recent research findings on self-direction developed in partnership with AARP and Elevance Health

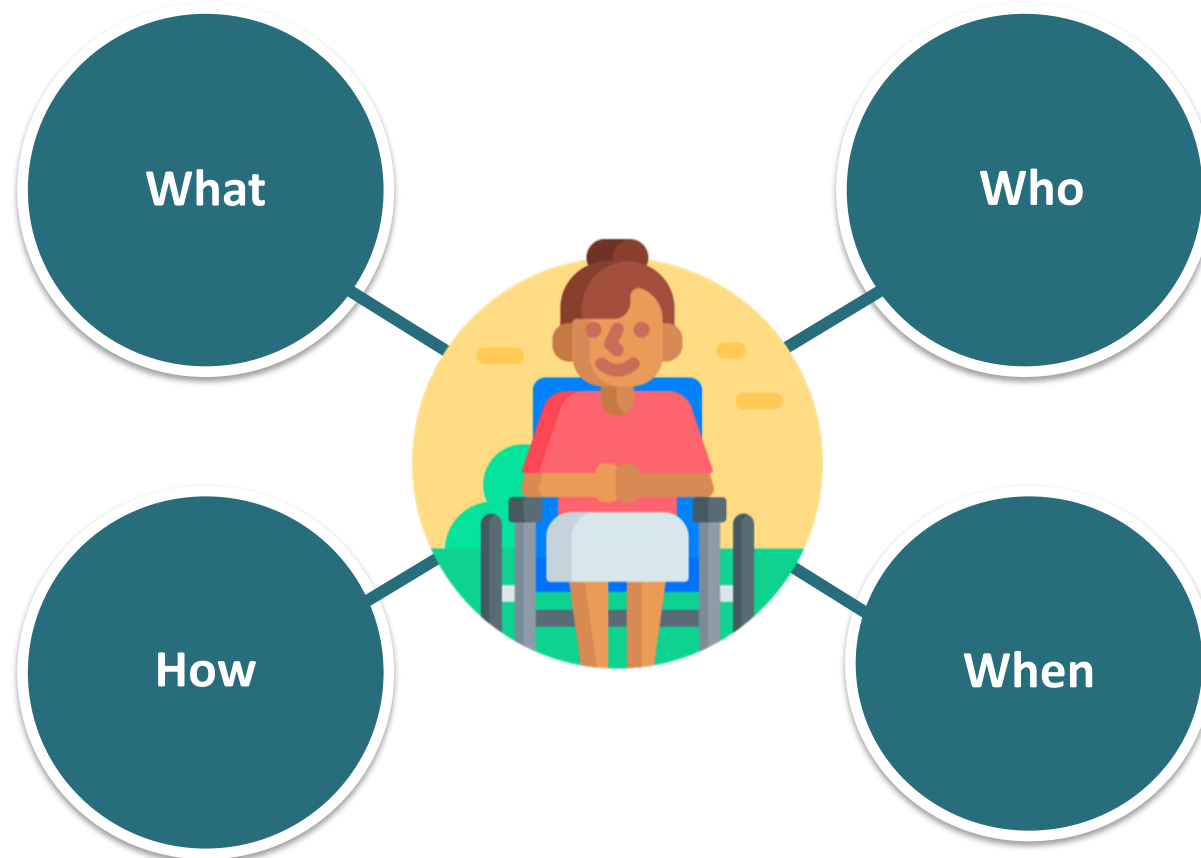
Applied Self-Direction



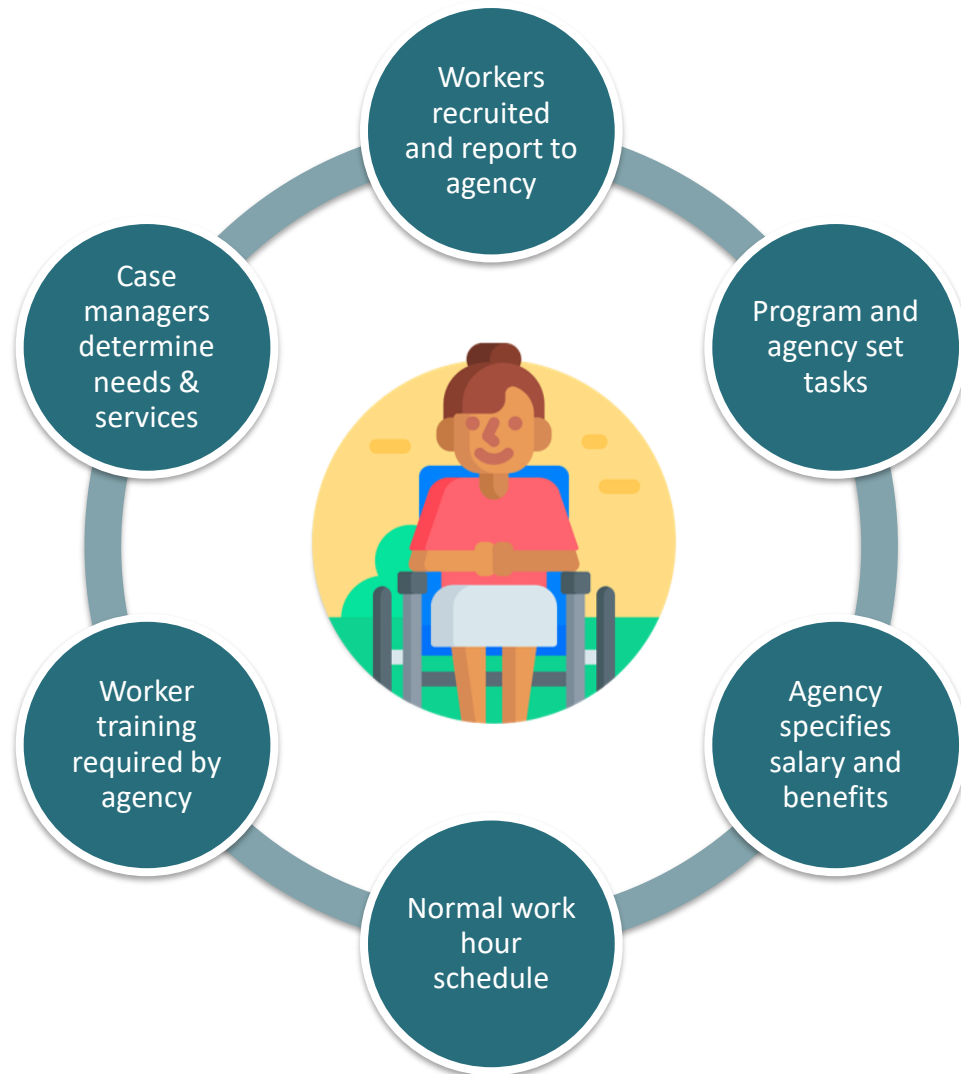
- Mission-driven organization advancing self-direction across the U.S. since 2015
- A national hub providing technical assistance, training, and community-building
- Stakeholders served include State Agencies, FMS providers, MCOs, Participant & Advocacy Groups, Support Brokers, and more

What is Self-Direction?

**Participant has
choice and control**



Traditional Services



Self-Directed Services



Common Misconceptions of Self-Direction

~~Lots of fraud~~

~~Only for those with
lots of natural
support~~

~~Only a “Plan B” or
when other
services aren’t
successful~~

~~Only for “high-
functioning”
individuals~~

Self-Direction Programs



Most basic: Sharing preferences with an agency

Employer Authority

The participant:

- Recruits, hires, and manages workers
- Sets the schedule for the workers
- Provides training for the workers, in addition to any agency or state-specific requirements
- Disciplines and terminates workers

Budget Authority



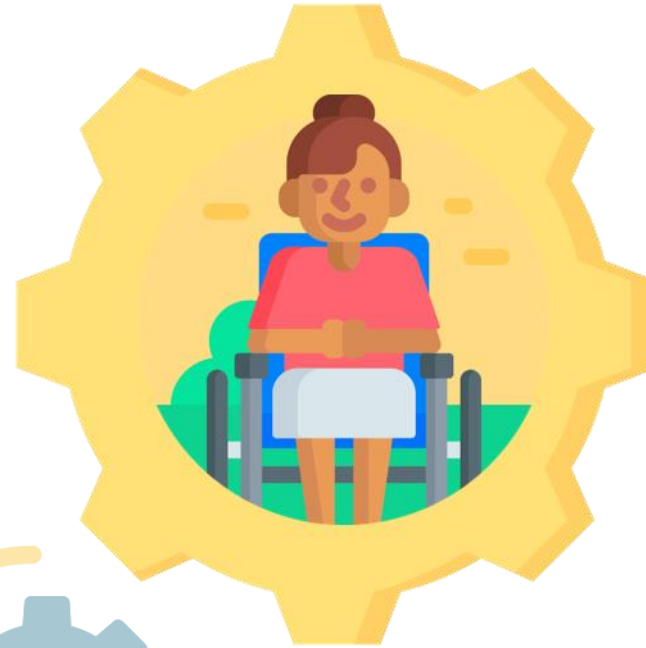
The participant:

- Has an individual budget
- Sets the hourly wage for workers
- Determines the worker's training requirements beyond any state requirements
- Decides how much of the budget is used for each service
- Can purchase individual-directed goods and services

Self-Direction Program Components Summary

Person Self-Directing (Participant)

Manages and directs services and supports, including being the employer



Information & Assistance (I&A)

Provides guidance and resources on all aspects of self-direction, including support and encouragement



Financial Management Services (FMS) Entity

Supporting the regulatory and financial responsibilities of the self-directing participant

Recent Research

- Applied Self-Direction published two major reports on self-direction in 2023
 - The **2023 Self-Direction National Inventory** funded by the AARP Foundation, The Commonwealth Fund, the SCAN Foundation, and AARP as part of the AARP State Scorecard
 - **Bridging the Gap: Insights Into Strengthening the Self-Directed Workforce Paper** funded by Elevance Healthcare



Background: Inventory

Purpose of the Self-Direction National Inventory

- To provide an overview of all publicly funded self-directed LTSS nationwide

History of the Inventory

- Previous Inventories were completed in 2011, 2013, 2016, & 2019

What is notable about 2023?

- The first Inventory conducted since the COVID pandemic emerged in 2020
- Coincided with a huge wave of new interest in self-direction at the participant and program level
- While the number of people self-directing has grown in every Inventory, there was a sharper rate of enrollment growth in 2023
- States were now implementing more new programs and program expansions than at any point in the previous decade



Methods

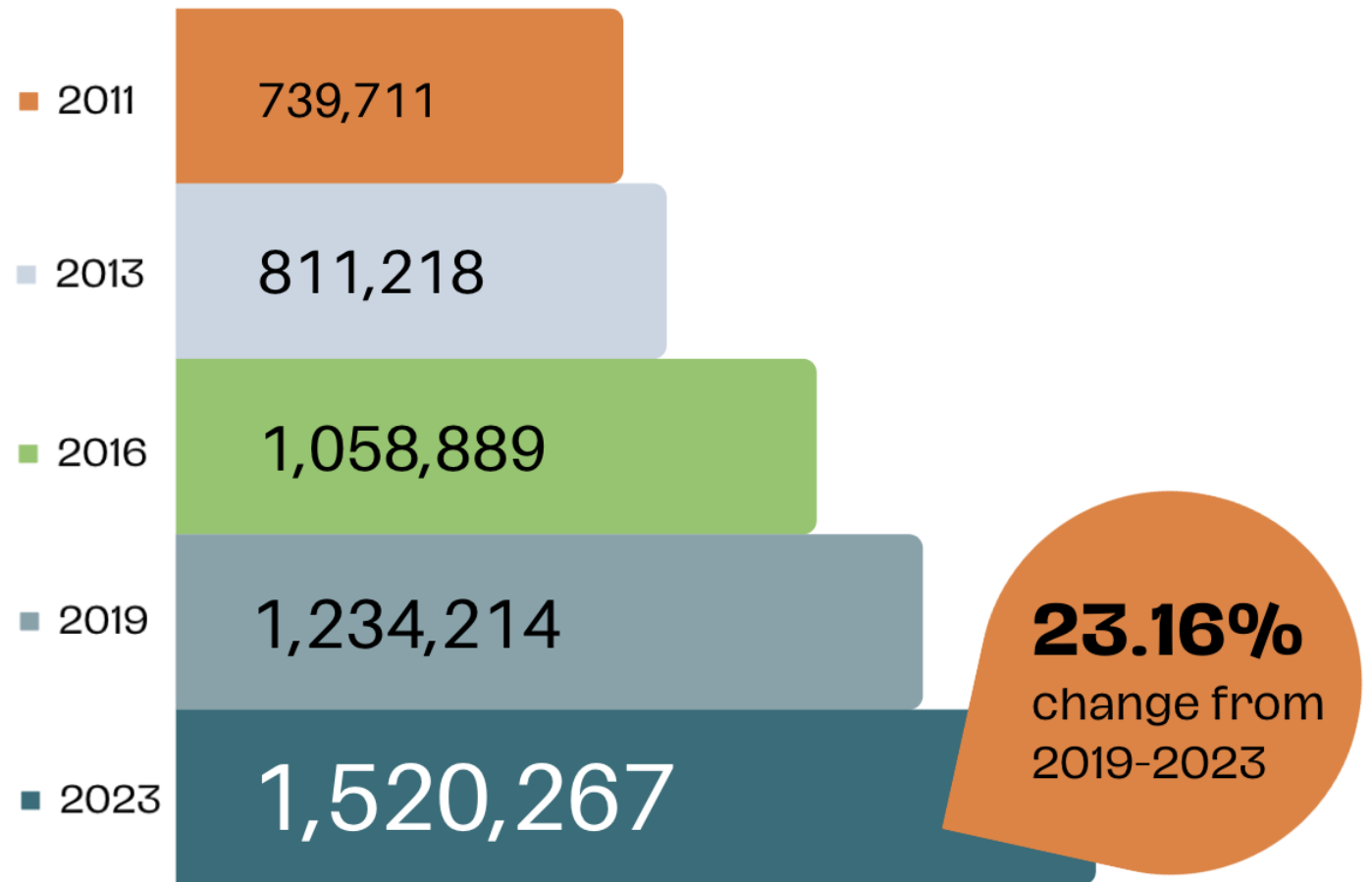
- Program data were collected from October 2022 through February 2023
- Data collection process included the following steps:
 1. Comprehensive review of publicly available information via state Medicaid waiver applications, Medicaid state plan documentation, and state websites across all 50 states and DC.
 2. Conducted 65 interviews with state staff from 43 states and had correspondence with administrators in every state.
 3. In a few cases when enrollment data was not available from state administrators, program data was provided by FMS entities or we used enrollment estimates from Medicaid documentation
 4. Enrollment findings were shared with ASD state and FMS members for final review



Self-Direction Enrollment (1/2)

Self-direction enrollment has increased by 23% since 2019

- 1,520,267 people self-directing nationwide
- By comparison, enrollment grew by 17% from 2016 to 2019



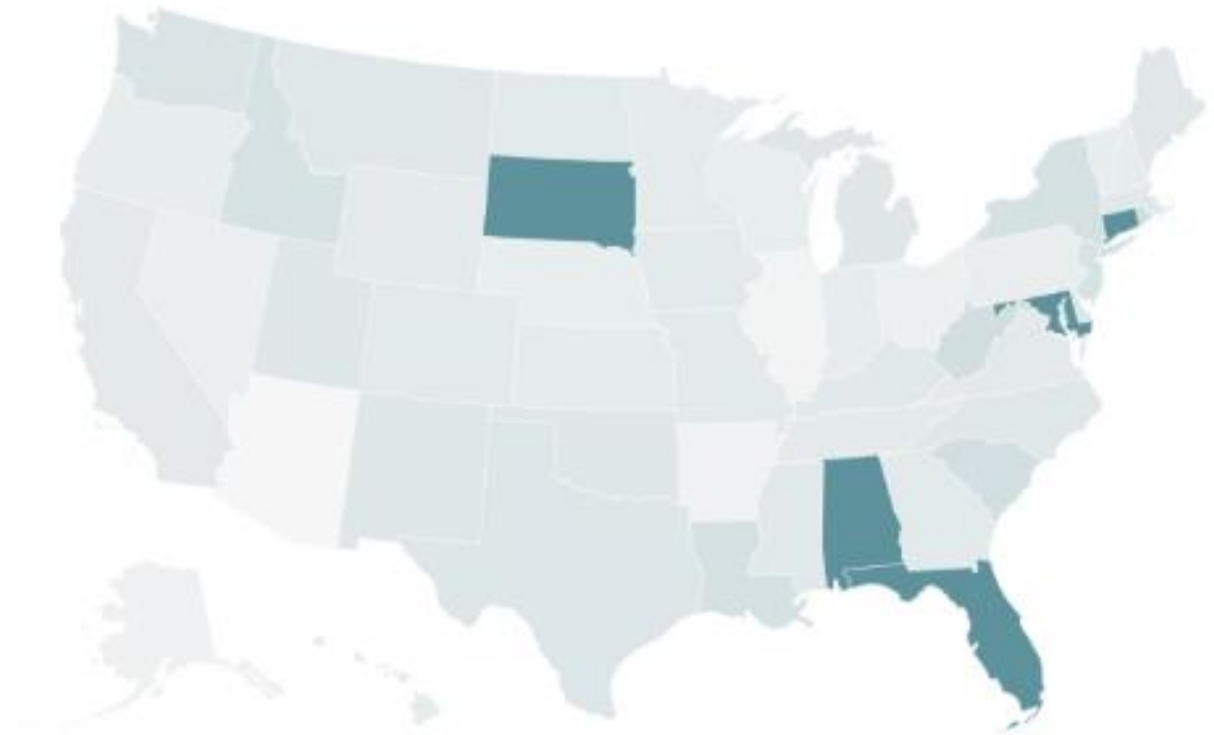
Self-Direction Enrollment (2/2)

State-by-state self-direction enrollment

- Most states (44) reported an increase in SD enrollment
- A few states (7) reported a decrease
- California continues to account for a significant share (48%) of total national enrollment, but this percentage continues to trend downward since 2011

Notably, six states have more than doubled self-direction enrollment since 2019

- Alabama
- Connecticut
- District of Columbia
- Florida
- Maryland
- South Dakota



Availability of Self-Direction by Population

- Almost all states provide at least one Medicaid-funded self-direction offering for adults over age 65, adults with physical disabilities, and adults with intellectual and developmental disabilities.
- Self-direction is less widely available for other populations (e.g., people with behavioral health needs; children who are medically fragile)
- In general, though, states are signaling more interest in expanding self-directed options to these populations

Impact of the COVID Pandemic

The pandemic accelerated the expansion of self-direction nationwide



A majority of states created a **temporary emergency option via Appendix K** to allow legally responsible individuals, such as spouses and parents of minor children, to serve as paid caregivers, in addition to other options to expand family caregiving.



States reported that **self-direction was critical in filling a void** left by the widespread closure of day services across the country.



The pandemic **galvanized federal investment** in Medicaid, and particularly HCBS

Interviews with state administrators suggested more research is needed to examine:

How worsening workforce shortages have impacted reliance on self-direction and family caregiving

How self-direction can scale to support historically marginalized and underserved communities

Levels of unmet need among people who self-direct vs. people who use traditional services

Whether EVV and/or cumbersome enrollment processes have been driving factors in states reporting a decline

Self-Direction Workforce

For the first time, AARP requested research on the self-direction workforce as part of the 2023 National Inventory

The report includes findings on:

- The impact of national workforce shortages on self-direction from the state administrator perspective
- State efforts to recruit and support family caregivers to join the direct care workforce or pursue related fields
- Recommendations for further research and policy development
- Strategies states are using to address workforce shortages in self-direction

Background: Bridging the Gap

Purpose of the Bridging the Gap report

- To provide clarity and understanding regarding the state of the self-direction workforce from the perspective of key stakeholders

What is notable about 2023?

- Features feedback from a diverse cross-section of stakeholders on the state of the self-direction workforce
 - State, MCO, and FMS representatives
 - Self-direction participants, family members who support someone with self-direction, and paid workers
- Engagement from 691 participants, representatives and their workers
- Findings include stakeholder perspectives on self-direction, the benefits and challenges of the model, concrete advice for participant employers on recruitment and retention, and policy recommendations

Methods

- Program data were collected from May through September 2023
- Data collection process included the following steps:
 1. Two virtual focus group style roundtable discussions
 2. National survey of self-direction participants, representatives, and their workers



Bridging the Gap: Policy Recommendations (1/2)



Bridging the Gap:
Insights into
Strengthening the
Self-Directed Workforce

October 2023

This initiative was sponsored by Elevance Health



- Lessen onboarding requirements and let participants decide what is needed
 - Background check requirements
 - Certification requirements
 - Training requirements
- Ensure workers don't incur costs associated with employment
- Streamline paperwork
- Allow participants to budget for hiring expenses
- Lessen hiring restrictions
 - Allow legally responsible individuals to be hired
 - Allow family members 16 and over to be hired

Bridging the Gap: Policy Recommendations (2/2)

- Make budget authority a requirement
- Increase the availability of information and assistance
- Raise wages
- Allow bonuses for recruitment and retention
- Allow benefits to be offered
- Ensure workers in self-direction are treated equally to agency workers
- Remove caps on hours for workers for emergencies
- Improve FMS provider responsiveness
- Reconsider Electronic Visit Verification (EVV) requirement
- Hold listening sessions



Bridging the Gap:
Insights into
Strengthening the
Self-Directed Workforce

October 2023

This initiative was sponsored by Elevance Health





Advancing Self-Direction in LTSS: Empowering Individuals and Mitigating the Direct Care Workforce Crisis

July 15, 2024

About the AARP Public Policy Institute



- ❑ The AARP Public Policy Institute (PPI) is the focal point of public policy research, analysis and development at AARP.
- ❑ “Think and do tank” - identify and help advance solutions to critical policy problems
- ❑ Within PPI, our LTSS Choices initiative seeks to spark and help spread innovation in LTSS and to support family caregivers.
- ❑ Key websites:

www.AARP.org/PPI

LTSSChoices.AARP.org (do not include www prefix)

AARP PPI's Self-Direction Work

- ❑ LTSS Scorecard Indicator
- ❑ Inventory of Self-Directed Programs
- ❑ COVID-19 report (both with Applied Self-Direction)
- ❑ Family caregiving research and data
- ❑ More to come...



Paying Family Caregivers to Provide Care during the Pandemic—and Beyond

Kate Murray, Merle Edwards-Orr, Highsmith Rich, and Molly Morris
Kathleen Ujvari
AARP Public Policy Institute
Applied Self-Direction

LTSS CHOICES

About this Series
This Spotlight is part of the AARP Public Policy Institute's LTSS Choices initiative. This initiative includes a series of reports, blogs, videos, podcasts, and virtual convenings that seeks to spark ideas for immediate, intermediate, and long-term options for transforming long-term services and supports (LTSS). We will explore a growing list of innovative models and evidence-based solutions—at both the national and international levels—to achieve system-wide LTSS reform.

We recognize the importance of collaborating and partnering with others across the array of sectors, disciplines, and diverse populations to truly transform and modernize the LTSS system. We invite new ideas and look forward to opportunities for collaboration.

For all questions and inquiries, please contact Susan or LTSSchoices@aarp.org.

Introduction
As the COVID-19 pandemic reshapes long-term care in America, an increasing number of older Americans are relying on family members to provide the care they need, allowing them to live safely at home. While this shift offers an option for families, it also puts households under financial, emotional, time-related, and other types of strain. In essence, these family caregivers are often performing the tasks of paid professionals who work both in nursing facilities and through in-home visits. Paying family members to provide care is a cost-effective option with unique advantages that help ensure a rapidly aging American population can receive the care needed to live at home.

Background
Family caregivers' value in terms of dollars has been well documented. The total economic value of unpaid family caregiving was estimated at approximately \$470 billion in of 2017, and this number will only increase as more Americans than ever are turning 65 and older.^{1,2} And now, as the COVID-19

¹Susan Reinhardt et al., "Valuing the Invisible: 2018 Update," AARP Public Policy Institute, Washington, DC, November 2018, <https://www.aarp.org/issuebriefers/files/2018/11/valuing-the-invisible-2018-update-chinese.aspx>.
²Mark Hori et al., "The Value of Family Caregiving."

¹Mark Hori et al., Paula Scaramanga, and Lillian Kibuff, "Fact Sheet: Aging in the United States—Population Reference Bureau," Population Reference Bureau, Washington, DC, July 11, 2018, <https://www.aarp.org/issuebriefers/files/2018/07/fact-sheet-aging-in-the-united-states-population-reference-bureau.aspx>.

What do we know about family caregivers?

□ As of 2020:

48 million unpaid family caregivers (both relatives and nonrelatives) who provide on average 18 hours of care per week.

Most support an adult 50+

More than 6 in 10 are women, more than 6 in 10 balance work and caregiving

Family caregivers are more diverse by race/ethnicity compared to the general population.

Economic Value of Family Caregiving

❑ In 2021, family caregivers provided \$600 billion worth of unpaid care to people they support.

AARP provides estimates for each state

❑ Exceeds total US (including out-of-pocket) spending on LTSS including post-acute care.

❑ Reinforces the need for robust supports including self-directed models that include family caregivers.

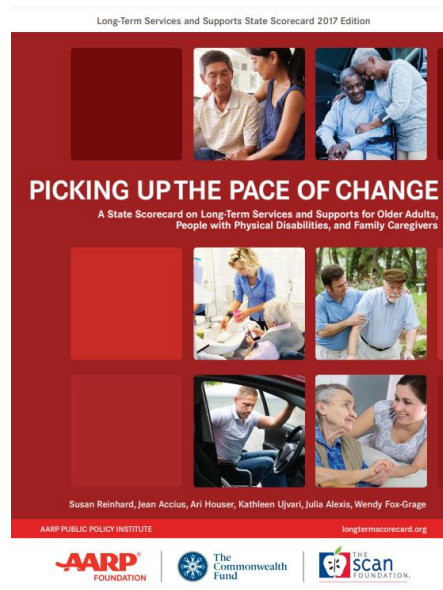
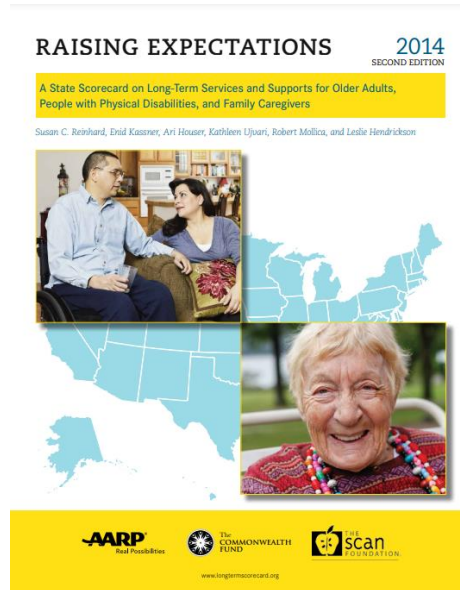
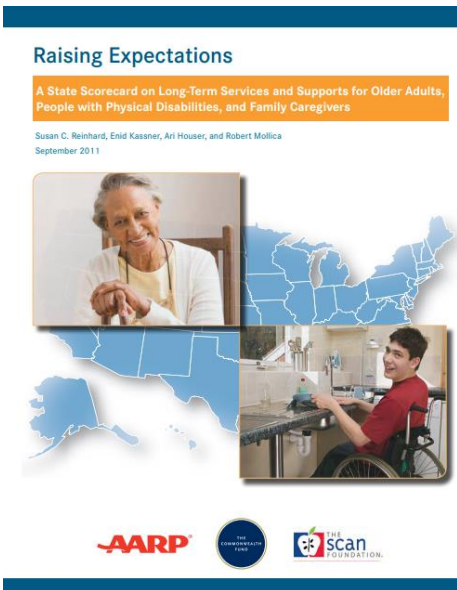
❑ Key webpage: www.aarp.org/valuing



Self-Direction in the LTSS State Scorecard

Our Fifth Scorecard!

Published every 3 years since 2011!



LTSS State *Scorecard* Framework



The Self-Direction Enrollment Indicator

- ❑ Part of the Scorecard for several editions.
- ❑ Categorized as part of the Choice of Setting and Provider dimension.
- ❑ Measures enrollment indexed to population (enrollment per 1,000 adults with a self-care/ADL disability).
- ❑ Significant growth since the beginning (2009) and since the most recent Scorecard edition's data (2019).

The Self-Direction Enrollment Indicator

- ❑ Across the United States, indexed enrollment increased from 30 to 36 enrollees per 1,000 adults with a self-care/ADL disability.
- ❑ Top performing states: California (1), Minnesota (64), Wisconsin (62).
- ❑ Among indicators most correlated with better overall Scorecard performance.

Additional key *Scorecard* findings

- ❑ For the first time, more than half of Medicaid LTSS dollars for older adults and people with physical disabilities went to HCBS—including respite.
- ❑ Availability of services remains a concern, especially for settings like home-based care and adult day services.
- ❑ Cost for services of all sorts increased across states and are largely unaffordable to most families.
- ❑ States with more robust supports for family caregivers (including respite) were the states that performed best overall for system performance.



Impact of Self- Direction on Older Adults and Family Caregivers

Upcoming Report Highlights Self-Direction's Success

- ❑ Forthcoming PPI report will put further spotlight on the self-direction model.
- ❑ Looks beyond current and recent data and examines the existing literature.
- ❑ Identifies impact on consumers as well as family caregivers.



Impact on Consumers



- ❑ Self-direction enhances control, self-determination, and goal achievement for consumers.
- ❑ It leads to higher satisfaction with services, better health outcomes, and reduced unmet care needs.
- ❑ Better outcomes and satisfaction compared to agency-based/non-self directed services.
- ❑ Age trends exist.

Impact on Family Caregivers

- ❑ Well-being and met needs
- ❑ Likelihood to remain caregiving
- ❑ Training and preparation
- ❑ Role as representatives of care recipient
- ❑ COVID-19 implications

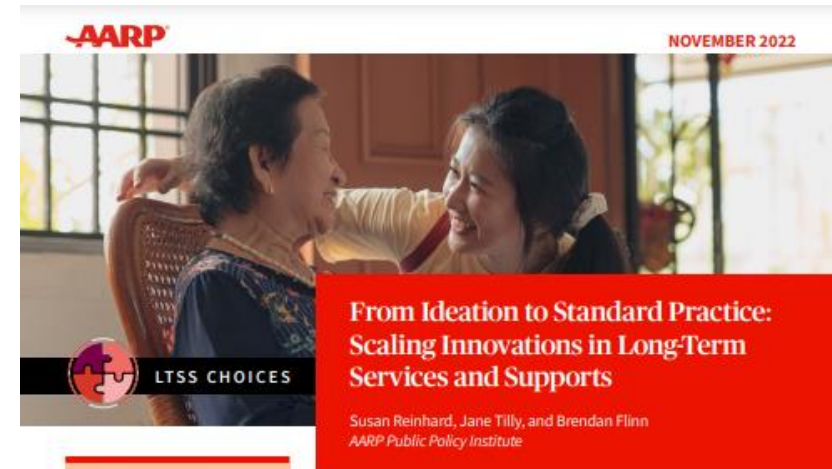




Diffusion of Innovation Across LTSS and in Self- Direction

Diffusion of Innovation Across LTSS

- ❑ Through five models of delivery that have shown scale, AARP PPI studied how to best diffuse innovation specifically in LTSS.
- ❑ Employed the Rogers Model:
 - Relative advantage
 - Compatibility
 - Complexity
 - Trialability
 - Observability



About this Series

This Spotlight is part of the AARP Public Policy Institute's LTSS Choices initiative. This initiative includes a series of reports, blogs, videos, podcasts, and virtual convenings that seeks to spark ideas for immediate, intermediate, and long-term options for transforming long-term services and supports (LTSS). We will explore a growing list of innovative models and evidence-based solutions—at both the national and international levels—to achieve system-wide LTSS reform.

We recognize the importance of collaborating and partnering with others across the array of sectors, disciplines, and diverse populations to truly transform and modernize the LTSS system. We invite new ideas and look forward to opportunities for collaboration.

For all questions and inquiries, please contact Susan at LTSSchoices@aarp.org.

Introduction

Over the past few decades in the United States, much of the innovation in the long-term services and supports (LTSS) system has originated at the state or local levels, only to be elevated to the national level after much experience and testing of new concepts. Such evolution—and subsequent expansion—has involved federal government and foundation support, along with changes in federal Medicare, Medicaid, and housing policies. Most innovations take a long time to diffuse or fail to do so.¹ For example, in health care, the average time it takes for an evidence-based practice to make its way into general practice is 17 years, and half of all new practices never become widespread.² However, five promising innovations currently in the LTSS system are becoming more commonplace. This paper discusses these innovative programs and the diffusion³ of innovation,⁴

¹ J. W. Dearing and J. G. Cox, "Diffusion of Innovations Theory, Principles, and Practice," *Health Affairs* 37, no. 2 (2018): 183–90.

² M. S. Bauer, L. Damschroder, H. Hagedorn, J. Smith, and A. M. Kilbourne, "An Introduction to Implementation Science for the Non-specialist," *BMC Psychology* 3, no. 1 (2015): 1–12.

³ According to Rogers (2003), diffusion occurs when an innovation that people perceive to be new is communicated among the members of a social system. E.M. Rogers, *Diffusion of Innovations*, 5th Edition (New York, NY: Simon and Schuster, 2003).

⁴ According to Rogers (2003), an innovation is "an idea, practice, or object that is perceived as new by an individual or other unit of adoption."

Diffusion of Innovation Across LTSS

- ❑ Innovators trying to solve problems with their state and local LTSS systems
- ❑ Innovations that are compatible with the ethics and needs of the innovators
- ❑ Local and state level experimentation that demonstrates the cost-effectiveness of the innovations
- ❑ All stakeholders considering equity as a key component across the scaling process.

<https://ltsschoices.aarp.org/resources-and-practices/ideation-standard-practice>

Diffusion of Innovation Across LTSS

- ❑ Foundations and government policy makers working together to test and refine the innovations and providing technical assistance to reduce complexity, costs, and risks for potential adopters
- ❑ Successful innovations, in terms of diffusion, that have backers who disseminate information about them
- ❑ Policy makers who alter policy, increase funding, and provide technical assistance to help states and localities expand the innovations

Thank you!

☐ www.aarp.org/ppi

☐ LTSSChoices.AARP.org

☐ [Email: bflinn@aarp.org](mailto:bflinn@aarp.org)

Advancing Self-Direction in LTSS: Empowering Individuals and Mitigating the Direct Care Workforce Crisis

July 16th, 2024

Kris Kubnick, MPA, CSW

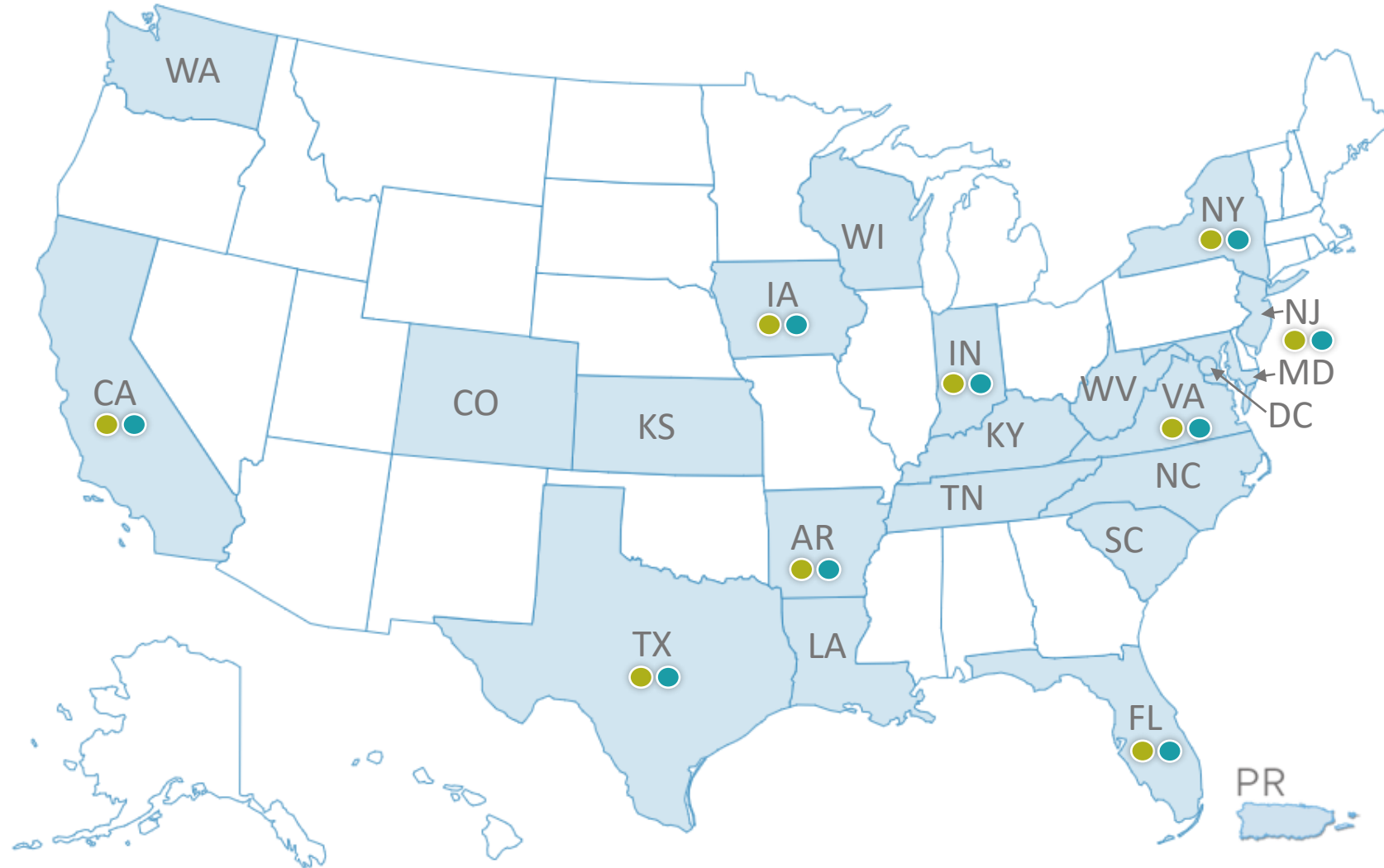
Elevance Health's LTSS Footprint

We coordinate care for 477,000 individuals across 27 markets, for 11 of which we manage their long-term services and supports. With 63,000 members Self-Directing one or more services.

Those markets that have SD include:

Florida, New York, Virginia, Texas, Tennessee, Iowa, Indiana, New Jersey, and Kansas

Elevance supports more individuals in MLTSS programs than any other MCO in the country



KEY

- I/DD with MLTSS
- ABD/SSI with MLTSS carve-in



MCO Best Practices to Advance Self-Direction - Internal

Education and Accountability for Care Coordination

- Foundation of Person-Centered Planning processes
- Informed Choice
- Program knowledge

Building Internal Resources

- Systems focused development
- Subject Matter Expert roles
- National Center of Excellence with a team dedicated to advancing Self-Direction
- On the ground resources

Support of Self-Direction Across Senior Leadership and Organizational Priorities



MCO Best Practices to Advance Self-Direction: Caregiver Support

Caregiver Support

- Building broad library of resources to be leveraged proactively and reactively

Real-time Resources

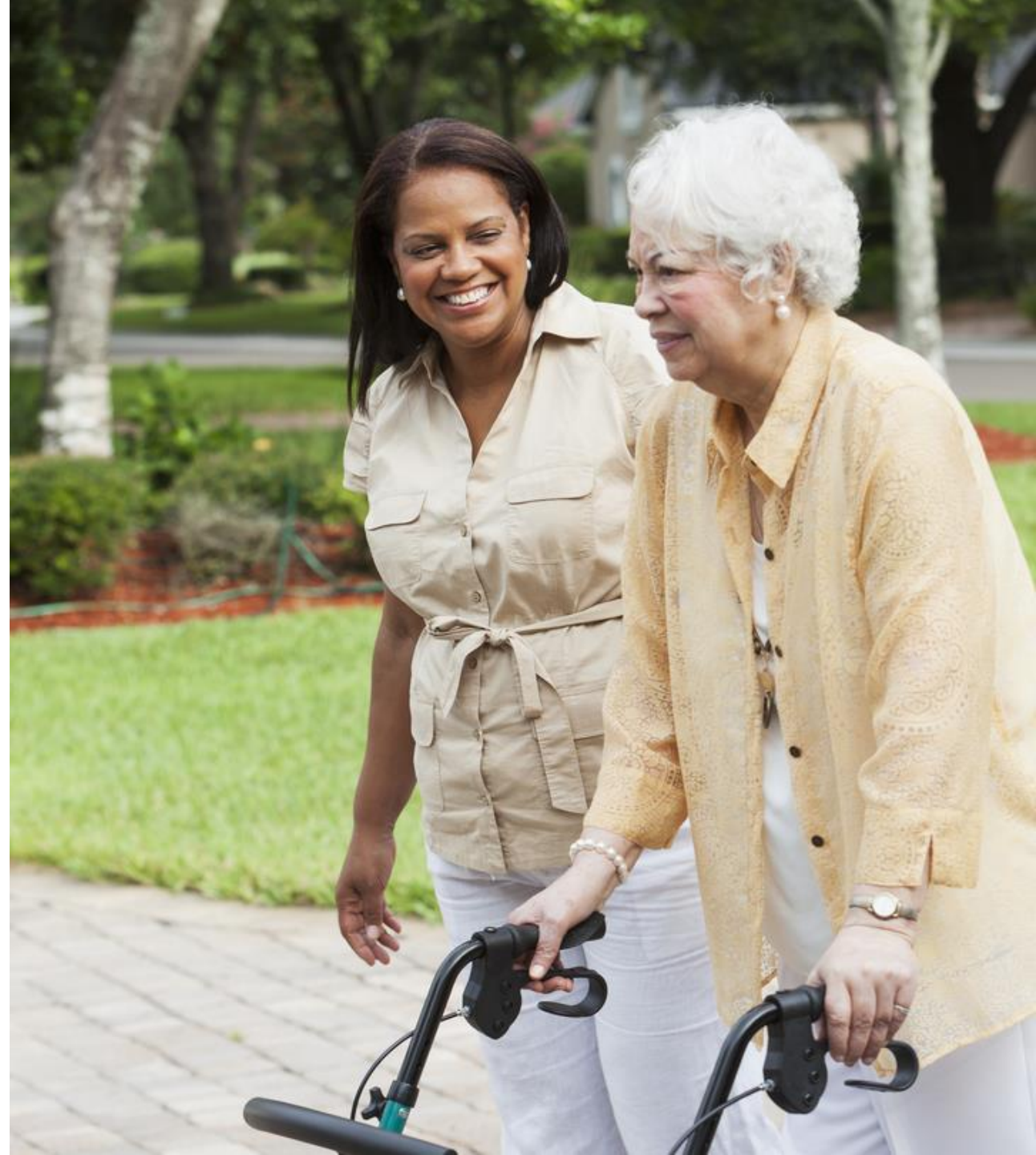
- Use of Caregiver assessments
- Rapid response to connect Caregivers to resources

Ongoing Monitoring

- At the member/caregiver level
- At the Market level
- Global level

Workforce Development Strategy

- Building workforce strategy for SD aligned with Provider agency strategy



MCO Best Practices to Advance Self-Direction: Fiscal Management Services

FMS Partnership

- Actively building and maintaining strong partnerships with FMS providers

Clear and Defined Expectations

- Outline key roles and responsibilities
- Reciprocal accountability
- EVV
- Quality metrics

Invest in Value

- Incentive based contracts/SOW
- Models that manage the fiscal risks

Ongoing Process Improvement

- Transparency in outcomes/metrics
- Trust in relationships
- Partnership in changes



State Program Structures

1

Full Budget Authority

Allows for greater flexibility for members.

Creates some additional complexities that need to have strong support through education, and MCO/FMS resources.

2

Expanded Services Options

Increases the types of services that can be self-directed.

Look to include Goods and Services as options.

3

Flexibility in Workforce

Open options for Family Caregivers and Legal Representatives to provide services.

Allow for changes to criteria for workers to provide supports, i.e. levels of criminal background checks, finger printing, etc.



Panel Discussion



Thank you!