Applied Self-Direction

Self-Direction on the Rise: The Past, Present, and Future of the Self-Direction National Inventory

April 12, 2022

Setting the Stage

- Today's Speakers:
  - Merle Edwards-Orr, Applied Self-Direction
  - Molly Morris, Applied Self-Direction
  - Carrie Amero, AARP

- Agenda
  - A look back at the findings from past iterations of the National Inventory
  - Pandemic-related changes to self-direction
  - New approach for the forthcoming AARP LTSS State Scorecard
  - Questions

A Look Back at the National Inventory

History of the Inventory

- 4 Inventories since 2011
  - 2011, 2013, 2106, 2019
- Many (many!) thanks to AARP who has partnered with us

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NATIONAL RESOURCE CENTER *for* PARTICIPANT-DIRECTED SERVICES

Applied Self-Direction

How did we get the information?

- For program information
  - Reviewed waivers on CMS website
  - Reviewed state program websites
- Spoke with program staff
  - To confirm program information
  - To collect participant numbers
  - To learn about hot topics
- Spoke with FMS members
  - To confirm program and number information

What did we do with the information?

- Report published as part of the Long-Term Services and Supports Scorecard
- Published report on ASD website
- Used data for other interim reports
  - e.g., Appendix K and other COVID responses

So, What Did We Find Out?

Numbers have gone up year-to-year

Year	Participants
2002	496,000
2011	739,711
2013	811,218
2016	1,058,889
2019	1,234,214

But growth rates have been inconsistent

Years	Increase in number of Participants	Percentage increase in number
2011 - 2013	71,507	10%
2013 - 2106	247,671	31%
2016 - 2019	175,325	17%

Number of programs has been flat

Year	Programs
2011	233
2013	261
2016	253
2019	267

- In 2019, we changed how we counted programs, so this comparison in imperfect
- There is considerable program churn
  - Between 2016 and 2019, 43 programs closed or were consolidated while 70 new programs started

What else have we learned

- Some form of Medicaid remains the primary funding source
  - 2011 - 62% were Medicaid funded
  - 2013 – 81% were Medicaid funded
  - 2016 – 72% were Medicaid funded
  - 2019 – 66% were Medicaid funded
- While people over 65, adults with physical disabilities, and people with intellectual and physical disabilities remain the core populations, new populations are emerging.
  - People with behavioral health diagnoses
    - Small but growing
  - Children with physical disabilities
- Veteran-Directed Care grows slowly but steadily

More things we have learned

- More programs are using budget authority
  - 44% in 2011
  - 75% in 2019
- Fiscal/Employer Agent remains the predominant FMS model but the rate is steady
  - 76% vs 26% Agency with Choice in 2013
  - 77% vs 24% Agency with Choice in 2019
- Hiring family and friends has always been important but restrictions remain on hiring responsible relatives
  - 60% restricted in 2011
  - 54% restricted in 2019

How Did the Pandemic Affect Self-Direction Programs?

Overview

- COVID pandemic was declared a national public health emergency (PHE) on March 13, 2020
- CMS released guidelines for states to implement temporary waiver flexibilities
- American Rescue Plan Act was passed by Congress on March 11, 2021

Appendix K Flexibilities

- Appendix K may be utilized by states during emergencies to temporarily amend an approved 1915(c) waiver
- Numerous states adopted temporary flexibilities that expanded or strengthened self-direction programs, including:
  - Permit payment for family members or legally responsible individuals not already permitted by the waiver
  - Lift or loosen worker requirements (ex. reduce eligibility age, suspend criminal background checks, waive training requirements)
  - Lift or loosen settings requirements (ex. allow for SD services during a hospital stay)
  - Increased pay (ex. higher pay for workers, hazard pay, retainer payments, increase FMS rates, exceed budget caps)

Source: https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html

Appendix K State Examples: Colorado

- Notable examples of temporary changes made across various waivers include:
  - Relatives may provide over 40 hours of care over 7-days, up to 48 hours
  - Requirements will be waived for a client to switch to agency-based care if a CDASS attendant cannot be in found. A client may receive both CDASS services and agency-based services if a CDASS attendant cannot be found.
  - Waive training requirements for new CDASS Authorized Representatives
  - Reduce minimum caregiver age from 18 to 16

Source: https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html

Appendix K State Examples: Georgia

- Notable examples of temporary changes made across various waivers include:
  - Financial Management Services- temporarily increases rate from $70-$75 per month to $95.00 per month.
    - Rate increase is in response to expected temporary increase in consumer directed work-load related to shift in members hiring new staff and family caregivers. There is an expectation that some members may shift from traditional models of delivery to consumer directed as workforce shortage issues present.
  - Services may be delivered on a temporary basis in alternative settings including extended family home, hotel, shelter, or other emergency placement.
  - Services may be delivered out of state

Source: https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html

Appendix K State Examples: Maryland

- Notable examples of temporary changes made across various waivers include:
  - Current certification in CPR and First Aid can be temporarily waived with respect to legally responsible family members
  - FMS can authorize up to $2000 above the authorized budget to support any of the following:
    - (1) increased need in services
    - (2) increase Support Broker hours,
    - (3) Staff Recruitment; and
    - (4) Personal Protective Equipment/Supplies
  - The Support Broker may be paid to provide other Waiver program services (beyond Support Broker services) to the participant at the rate applicable to that other Waiver program service

Source: https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html

Will states maintain flexibilities after the pandemic?

- It is not yet known when the PHE will officially end, but states will be given at least 60 days notice, experts expect it may end as early as mid-July*
  - Most states have indicated flexibilities will remain in place until 6 months after the end of the PHE

- CMS has provided guidance on how to make certain Appendix K flexibilities permanent by submitting an amendment to the state's 1915(c) waiver:
  - https://www.medicaid.gov/federal-policy-guidance/downloads/sho20004.pdf
  - "Examples of common changes in Appendix Ks that may be approved in a standard 1915(c) waiver application include the use of telehealth for certain services, addition of home-delivered meals and other services, rate increases for waiver services, retainer payments up to 30 days, and increased ability to pay family caregivers."

Source: https://www.dailycitizen.news/covid-pandemics-end-may-bring-turbulence-for-us-health-care/article_71da2108-b1cc-11ec-8a2d-fb86b72c0fb9.html

American Rescue Plan Act (ARPA)

- ARPA added a temporary 10 percent FMAP increase for Medicaid-funded HCBS effective April 1, 2021 through March 31, 2024
- This increase adds onto a service's existing FMAP
  - It does NOT cancel out other enhanced FMAP, like Community First Choice
- Estimated to add approximately $12.7 billion in additional HCBS funding
  - This structure rewards states that have already chosen to invest more in LTSS rebalancing
- Many states are still awaiting approval from CMS to utilize their funds

Source: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html

How Can States Use ARPA Funds?

- States must use the enhanced funds to "implement, or supplement the implementation of, one or more activities to enhance, expand, or strengthen" HCBS
- Applies to all Medicaid HCBS authorities, including 1915(c) waivers, 1915(k) Community First Choice State Plan Amendments, and PACE programs
- States *cannot*:
  - Use the money for non-HCBS Medicaid spending
  - Use the money to offset state's existing Medicaid spending
    - States must maintain their current Medicaid spending as of April 1, 2021 to receive the enhanced match

Source: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html

ARPA State Examples: Illinois

- Plans for self-direction in the state spending plan include:
  - Expand self-direction to medically fragile children and allow un-licensed parents to be able to become paid caregivers, in response to feedback from numerous stakeholders
  - Improved nurse training for those providing self-directed care

Source: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html

ARPA State Examples: Maine

- Plans for self-direction in the state spending plan include:
  - Expand self-direction options in the state to include people with intellectual disabilities and explore the feasibility of offering self-direction to adults with serious mental illness and substance use disorders

Source: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html

ARPA State Examples: Rhode Island

- Plans for self-direction in the state spending plan include:
  - Hiring incentives that will be paid after six months of employment as an incentive to new hires, including PCAs in self-directed programs, to compete in a tight labor market
  - Funding for technology training for people who self-direct
  - Increase the number of service advisory agencies and fiscal intermediaries available for the self-directed programs.
  - Increase the number of PCAs enrolled in the worker registry to be accessible by people who self-direct
  - Increase percentage of overall clients receiving self-directed services as their HCBS service.
  - Increase number of clients of color receiving self-directed services as their HCBS service.
  - Clear information on website and available to community explaining array of self-directed services and clear steps on how to access these services.
  - Greater support in empowering individuals to manage services for Self Directed

Source: https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html

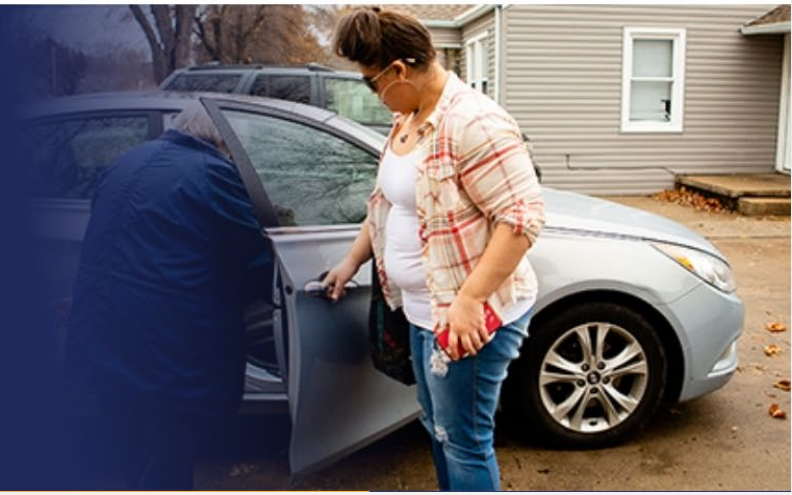
A Quick Recap

- Promising indicators that self-direction has grown significantly:
  - Numerous states implemented temporary flexibilities that expanded self-direction. Some states may choose to make certain flexibilities permanent.
  - Anecdotal reports suggest that many switched to self-direction during the pandemic to flexibly receive care at home.
  - Numerous states plan to use ARPA funds to specifically invest in self-direction programs and/or HCBS initiatives that will benefit self-direction programs

What's Next for the AARP LTSS State Scorecard?

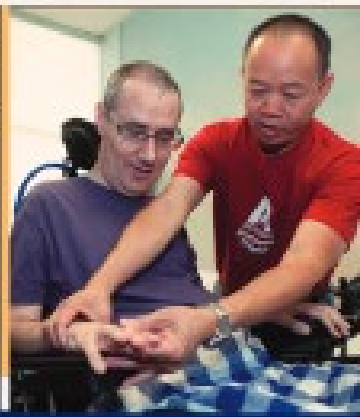
Long-Term Services & Supports State Scorecard

A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers



ADVANCING ACTION

A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers



AARP Public Policy Institute

longtermscorecard.org

AARP Foundation | The Commonwealth Fund | THE scan FOUNDATION.

What is the Scorecard?

- Multidimensional approach to comprehensively measure state LTSS system performance overall and within five different domains.
- Puts state LTSS policies and programs in context, stimulates dialogue, and prompts action.
- Funded with the support of The Commonwealth Fund and The SCAN Foundation.
- Updated every 3 years.

2020 Scorecard Conceptual Framework

HIGH-PERFORMING LTSS SYSTEM

Five dimensions of LTSS performance, constructed from 26 individual indicators.

AFFORDABILITY AND ACCESS

1. Nursing Home Cost
2. Home Care Cost
3. Long-Term Care Insurance
4. Low-Income PWD with Medicaid
5. PWD with Medicaid LTSS
6. ADRC/NWD Functions

CHOICE OF SETTING AND PROVIDER

1. Medicaid LTSS Balance: Spending
2. Medicaid LTSS Balance: Users
3. Self-Direction
4. Home Health Aide Supply
5. Assisted Living Supply
6. Adult Day Services Supply
7. Subsidized Housing Opportunities

QUALITY OF LIFE AND QUALITY OF CARE

1. PWD Rate of Employment
2. Nursing Home Residents with Pressure Sores
3. Nursing Home Antipsychotic Use
4. HCBS Quality Benchmarking

SUPPORT FOR FAMILY CAREGIVERS*

1. Supporting Working Family Caregivers
2. Person- and Family-Centered Care
3. Nurse Delegation and Scope of Practice
4. Transportation Policies

EFFECTIVE TRANSITIONS

1. Nursing Home Residents with Low Care Needs
2. Home Health Hospital Admissions
3. Nursing Home Hospital Admissions
4. Burdensome Transitions
5. Successful Discharge to Community

Reimagining the Scorecard for 2023

- The 2020 edition was released while the nation was in the midst of the pandemic based on pre-pandemic data
- State LTSS systems look very different in a post-pandemic world
- Some policies the *Scorecard* has been tracking for over a decade take on new importance during a pandemic
- Other important issues have been hard to address in past editions, but are top priorities now
  - Consumer experience/quality of life
  - Racial and ethnic disparities in access and utilization of LTSS
  - LTSS workforce strength and stability
  - Emergency preparedness, public health
  - State policy innovations

Self-Direction Indicator Definition

Number of People Self-Directing Services per 1,000 Population with Disabilities:

This is the number of people receiving self-directed services per 1,000 people with any disability in the state. Note that not all people with disabilities have LTSS needs. The number of people receiving self-directed services is from the National Inventory of Self-Directed Programs in the United States 2019 survey data. Data for the inventory were collected from April to August 2019. Sources of data included state Medicaid waiver information, information from Financial Management Services providers, and telephone interviews with self-directed LTSS program administrators. The number of people with disabilities is from the 2018 American Community Survey.

Applied Self-Direction, "National Inventory of Publicly Funded Self-Directed Long-Term Services and Supports Programs in the United States Survey" (unpublished, Boston, MA: Applied Self-Direction, 2019).
US Census Bureau, ACS, American Community Survey (Washington, DC: US Census Bureau, 2018). Census population data (all ages) from 2018 American Community Survey 1-Year Estimates, Table B18101, Sex by Age by Disability Status, available at https://data.census.gov/cedsci/.

Discussion: What should we add to the Scorecard for 2023?

- How else could we measure and recognize state performance in **self-direction**?
- What outcomes do we most want to see?
- What kinds of state policies would we like to see replicated in more states?
- What innovations should we look for?
- What about **equity** in access and utilization?
- What about **workforce**?
- Other areas?

Questions?

www.appliedselfdirection.com