Background
Why the Inventory?

- Is self-direction growing more prevalent over time?
- Are there common trends across states?
- How are programs changing, evolving, and expanding?
- What are the challenges facing self-direction?
Lead Contributors

- Project Management - Applied Self-Direction
- Sponsorship - AARP
- Lead Authorship - Penn State

Our heartfelt thanks to Kathleen Ujvari at AARP and Mark Sciegaj at Penn State for your leadership, indispensable contributions, and years long dedication!
Key Contributors

▪ State Program Administrators
▪ FMS Entities
▪ Managed Care Organizations

▪ If you contributed or reviewed data for the inventory, we thank you for volunteering your time and expertise for this effort!
Definitions

A more concise definition of self-direction

Introducing the concept of ‘feeder’ programs

What is a program?

Respite
Methods

- Initial review of waiver applications and program websites
- 61 Interviews with state staff from 44 states
- Written correspondence with program staff in every state
- Enrollment data from state program administrators
- Enrollment data from FMS entities
- Data audit with ASD members
Key Findings
New Growth Overall & Consolidation

- 262 self-direction programs
- 70 new self-direction programs
- 43 programs discontinued or consolidated
- 1,234,214 enrolled
Self-Direction Continues to Grow

Self-Direction National Enrollment Over Time

Participant Enrollment

- 2011: 700,000
- 2013: 800,000
- 2016: 1,000,000
- 2019: 1,200,000
A Snapshot of the States

Top 5 Largest: CA, NY, IL, MO, WI

Top 5 Smallest: SD, IN, ND, DC, NV

Top 5 for Growth: DC, AL, NY, CO, MN
Mostly Medicaid

Number of Self-Direction Programs by Funding Source

- Medicaid: 66%
- VHA: 23%
- State Funds Only: 4%
- Other: 7%

Legend:
- Green: Medicaid
- Red: VHA
- Blue: State Funds Only
- Yellow: Other
Serving Many Populations

Number of Programs by Population in 2016 & 2019

- Adults 65+
- Adults ID/DD
- Adults PD
- Adults SMI
- Children ID/DD
- Children PD
- TBI
- Veterans
- Other

# of Programs in 2016  # of Programs in 2019
More than half of programs have specific hiring restrictions

Majority of programs offer respite options

77% of programs use a budget authority model

83% of budget authority programs allow a wide range of goods & services
Emerging Trends
Emerging Trends for Self-Direction in 2019

1. The number of self-direction “feeder programs” has increased sharply since the 2016 Inventory.
2. In some states, MLTSS may be promoting increased use of self-direction.
3. The Veteran-Directed Care program is showing promising growth.
4. More states are offering self-direction to individuals with serious mental illness.
5. States are concerned about implementing EVV.
Which Emerging Trends Interest You Most?
Feeder Programs
A New Phenomenon: Feeder Programs

47 Feeder Programs

AL, AK, CO, CT, IA, MA, MN, OR, TX, VT, WI
A New Phenomenon: Feeder Programs

HCBS Feeder Waiver

SD Program

HCBS Feeder Waiver

HCBS Feeder Waiver
MLTSS & Program Growth?
Could MLTSS be spurring program growth?

- **NY**: Increase by more than 50,000
- **WI**: Increase by almost 20,000
- **VA**: Increase of approx. 7,000
- **IL & MN**: Since 2013, IL up by 60,000 & MN up by 20,000
Could MLTSS be spurring program growth?

MLTSS States

- SD Enrollment Increased: 70%
- SD Enrollment Decreased: 30%
Veteran-Directed Care
Veteran-Directed Care (VDC) Programs are Showing Promising Growth

- Number of states with VDC programs
- Veteran participants (ages 65+, physical disability)
- Program count
- States with multiple programs
States with Veteran-Directed Care (VDC) Programs, 2016 and 2019

## Trends: 2016 - 2019

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>State Count</td>
<td>31</td>
<td>41</td>
<td>32% increase</td>
</tr>
<tr>
<td>Veteran Participants</td>
<td>1,572</td>
<td>2,048</td>
<td>30% increase</td>
</tr>
<tr>
<td>Program Count</td>
<td>60</td>
<td>71</td>
<td>18% increase</td>
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<tr>
<td>Multiple Programs</td>
<td>12</td>
<td>15</td>
<td>25% increase</td>
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### States with 100 or More Veteran Participants in 2019

<table>
<thead>
<tr>
<th>State</th>
<th>Number of Participants</th>
<th>Number of Programs</th>
<th>% Change in Number of Participants (2016 to 2019)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Florida **</td>
<td>373</td>
<td>6</td>
<td>58%</td>
</tr>
<tr>
<td>Missouri **</td>
<td>279</td>
<td>2</td>
<td>417%</td>
</tr>
<tr>
<td>Virginia *</td>
<td>211</td>
<td>3</td>
<td>220%</td>
</tr>
<tr>
<td>Colorado</td>
<td>206</td>
<td>2</td>
<td>N/A – new programs since 2016</td>
</tr>
<tr>
<td>Montana</td>
<td>194</td>
<td>1</td>
<td>362%</td>
</tr>
<tr>
<td>Texas *</td>
<td>148</td>
<td>4</td>
<td>244%</td>
</tr>
<tr>
<td>Illinois *</td>
<td>134</td>
<td>5</td>
<td>No change</td>
</tr>
<tr>
<td>Michigan *</td>
<td>113</td>
<td>5</td>
<td>20%</td>
</tr>
<tr>
<td>Utah</td>
<td>108</td>
<td>1</td>
<td>39%</td>
</tr>
</tbody>
</table>

* VDC program began in 2009-10
** State added additional VDC programs since 2016
Self-Direction for Individuals with SMI
More Self-Direction for Individuals with SMI

Small, under 100

19 Programs Nationally in 2019

Only 4 Programs in 2016

Pilot programs

TX pilot with MCO support

Potential for growth!
Electronic Visit Verification
States are Uneasy about EVV

States are moving forward with EVV implementation

EVV in self-direction is especially challenging

January 2020 deadline

Diffusion of responsibility in self-direction

EVV products designed for traditional programs
Questions?

www.appliedselfdirection.com

membership@appliedselfdirection.com