Facts and Figures: 2013 National Inventory Survey on Participant Direction

Acknowledgements:

We gratefully acknowledge NRCPDS staff at the Boston College (BC) Graduate School of Social Work and the Connell School of Nursing, Chestnut Hill, MA. We would like to especially thank Ruth Fleischer for her dedication to and orchestration of this project as well as the many BC graduate students for their significant contributions with the data collection process.

The creation of the 2013 NRCPDS NI was made possible with support from the AARP, Atlantic Philanthropies, and Robert Wood Johnson Foundation. The results of the Inventory were used for the AARP’s recently published Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers (http://www.longtermscorecard.org/).

Follow this and other works at: participantdirection.org

©2014 by Trustees of Boston College, National Resource Center for Participant-Directed Services. All rights reserved. Short sections of text, not to exceed two paragraphs may be quoted without explicit permission provided that the authors are identified and full credit, including copyright notice, is given to Trustees of Boston College, National Resource Center for Participant-Directed Services.

The opinions and conclusions expressed in this brief are solely those of the authors and do not represent the opinions of the funders of the National Resource Center for Participant-Directed Services.

The content in this brief is for informational purposes only and not for the purpose of providing legal advice. Contact the NRCPDS for permission to redistribute at info@participantdirection.org.
Table of Contents

Table of Contents ........................................................................................................................................ 1

I. Overview ................................................................................................................................................. 3

II. Methodology ............................................................................................................................................ 3

III. General Findings ................................................................................................................................. 4

   Figure 1: Participant Direction Enrollment by State .............................................................................. 4

   Figure 2: Ratio of Participant Direction Enrollment to Income-Based Government Assistance Recipients with a Disability by State ................................................................. 5

   Table 1: Programs by Service System/Delivery Type .......................................................................... 6

   Table 2: Enrollment of Participants by Service System/Delivery Type .............................................. 6

IV. Program Characteristics ...................................................................................................................... 7

   Figure 3: Number of PD-LTSS Programs by Funding Source ............................................................... 7

   Figure 4: Number of PD-LTSS Programs by Population Served ......................................................... 7

   Figure 5: Roles Case Manager Plays in Delivery and Management of PD-LTSS Programs Nationwide ........................................................................................................................................ 8

   Figure 6: Number of PD-LTSS Programs by Party Responsible for Measuring Outcomes ............ 9

   Figure 7: Number of PD-LTSS Programs by Type of Outcome Measured ........................................ 10

V. Employer Authority ............................................................................................................................... 10

   Figure 8: Number of PD-LTSS Programs by Allowable Providers of Direct Support Services 11

   Figure 9: Number of PD-LTSS Programs by Hiring Restrictions ...................................................... 12

VI. Budget Authority .................................................................................................................................. 12

VII. Financial Management Services ....................................................................................................... 13

VIII. Participant Involvement in Management of Program ......................................................................... 14

   Figure 10: Number of PD-LTSS Programs by Participant Involvement Mechanism ........................ 14

IX. Conclusion ............................................................................................................................................. 14
I. Overview

The National Resource Center for Participant-Directed Services (NRCPDS) designed this survey to capture program characteristics of participant-directed long-term services and supports (PD-LTSS)\(^1\) programs across the United States. Based on survey responses and supplementary sources of data, a national database, the 2013 NRCPDS National Inventory (NI), was created. The 2013 NRCPDS NI\(^2\) aims to address stakeholder queries and identify best practices, challenges, and future directions. The Facts and Figures report is the first of multiple publications to be released on the findings of the 2013 NRCPDS NI.

II. Methodology

Data were collected from June 2013 to April 2014. Sources of data included:

1. Surveys from state administrators of PD-LTSS programs;
2. The Medicaid waiver database (http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html);
3. Program websites, including online manuals, pamphlets, and fact sheets;
4. A program’s financial management services (FMS) provider; and
5. Data/information requests to state agencies (in line with the federal Freedom of Information Act [FOIA] which allows individuals to request documents and public records from state and local government bodies).

Percentages are reported throughout this report. These percentages are rounded to the nearest whole number and based on the number of programs with data for a particular question and not on the percentage of the total number of programs in the 2013 NRCPDS NI. This is referred to as the “valid” percentage. As a result, sample sizes (n) varied for different analyses and are noted for each of the analyses presented in this report.

The 2013 National Inventory includes data from 277 programs from all 50 states and the District of Columbia.

---

\(^1\) For more background on participant direction and definitions of basic terms, refer to our website and online handbook (http://www.bc.edu/content/bc/schools/gssw/nrcpds/tools/handbook.html).


www.participantdirection.org
III. General Findings

Emerging Trends

Three overall trends emerged:

- Fifty-three new programs started since 2010.
- Moderate growth in PD-LTSS programs since 2010. (An increase of approximately 90,000 participants nationwide from 2010.)
- 18 states use managed care as a service delivery mechanism; a significant change since 2010.

Participant direction is available in every state and the District of Columbia. The majority of states have between 1,000 – 5,000 participants enrolled in PD-LTSS programs. Figure 1 shows the range of participant direction enrollment by state. However, when the number of participant-directing enrollees is adjusted to the state population that is potentially eligible, i.e. noninstitutionalized recipients of income-based assistance with a disability, a new picture emerges, as shown in Figure 2.

---

3Six programs do not track participant direction enrollment data. These programs are located in Iowa, Kansas, Michigan, Minnesota, Oregon, and Wyoming. One program in Minnesota reported estimated enrollment based on expressed interest. Figure 1 includes this estimated value.

www.participantdirection.org
Figure 2: Ratio of Participant Direction Enrollment to Income-Based Government Assistance Recipients with a Disability by State

There are 277 programs nationwide. Table 1 breaks down the number of specific system/delivery types of PD-LTSS programs in the 2013 NI.

### Table 1: Programs by Service System/Delivery Type

<table>
<thead>
<tr>
<th>Service System/Delivery Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD-LTSS Medicaid waiver(s) and state plan amendment programs</td>
<td>192</td>
<td>96</td>
</tr>
<tr>
<td>Veteran-directed home and community-based services (VD-HCBS)</td>
<td>43</td>
<td>16</td>
</tr>
<tr>
<td>Participant-directed managed long-term services and supports (PD-MLTSS)</td>
<td>31</td>
<td>11</td>
</tr>
</tbody>
</table>

1. Total n does not add up to 277 programs as not all system/delivery types are highlighted in this table.
2. PD-LTSS Medicaid waiver include: 1915(b) managed care waivers, 1915(c) HCBS waivers, 1915(b) & 1915(c) concurrent waivers, and 1115 research and demonstration project waivers.
3. State plan amendments include: Medicaid personal care and home health plans, 1915i, 1915j, and 1915k.

There are approximately 838,503 individuals enrolled in PD-LTSS programs nationwide. Table 2 breaks down the enrollment numbers of participants in programs by service system/delivery type. Of 838,503 individuals, 65,000 are in programs that only offer participant direction.

### Table 2: Enrollment of Participants by Service System/Delivery Type

<table>
<thead>
<tr>
<th>Service System/Delivery Type</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants enrolled in Medicaid waiver and state plan amendment programs</td>
<td>808,847</td>
<td>96</td>
</tr>
<tr>
<td>Participants enrolled in PD-MLTSS programs</td>
<td>77,816</td>
<td>9</td>
</tr>
<tr>
<td>Participants enrolled in VD-HCBS programs</td>
<td>831</td>
<td>0.1</td>
</tr>
</tbody>
</table>

1. Total n exceeds 838,503 (i.e., total enrollees nationwide) as the service system/delivery types listed are not mutually exclusive. For example, an individual may be enrolled in a Medicaid waiver program that is delivered through managed care and, thus, is accounted for in two service system types.
IV. Program Characteristics

The first question asked in the survey was about geographic availability.
- Of 241 programs, 73% offered participant direction statewide.\(^5\)

The survey asked what the funding mechanism(s) is/are for the participant direction program. Eleven options were provided. Respondents were able to choose more than one option as a program may have more than a single funding mechanism. For the breakdown of number of PD-LTSS programs by funding source, see Figure 3.

![Figure 3: Number of PD-LTSS Programs (n = 272) by Funding Source](image)

The survey asked what population was served by the program. Six options were provided. More than one option could be selected. For the breakdown of number of PD-LTSS programs by populations served, see Figure 4.

![Figure 4: Number of PD-LTSS Programs (n = 276) by Population Served](image)

*Of the 59 programs, 43 are VD-HCBS programs; while, only 3 of the 59 programs are exclusively designed for adults with behavioral health disabilities.

\(^5\) Statewide availability does not denote program availability to all populations.
• Of 200 programs, 78% reported that traditional case management continues when the individual elects to participant-direct.

The survey asked about whose role it was to fulfill a number of different functions, including the explanation of the participant direction option, enrollment, and assessment of needs. For each function, several options were provided and are presented in Figure 5 below. Multiple options could be selected. Options included a case manager from the traditional program, new position hired to serve as the support function in PD-LTSS who works in concert with traditional case managers, contracted external entity, and/or an FMS provider. For the breakdown, see Figure 5. As presented in Figure 5, the traditional case manager clearly shoulders the majority of responsibilities in the management of PD-LTSS operations.

Figure 5: Roles Case Manager Plays in Delivery and Management of PD-LTSS Programs Nationwide
• Of 231 programs, 97% reported that participants are able to have a representative assist them in managing and directing their services and budgets.

• Of 134 programs, 64% reported a wait list.

• Based on 106 programs:
  ▪ 75% reported that the program has explicit policies or procedures requiring program staff to have knowledge of participant direction.
  ▪ Only 8% of the programs that do require program staff to have knowledge of participant direction have clear policies and procedures specific to participant direction.
  ▪ For the majority of these programs, review of a policy manual or awareness of participant direction will fulfill the requirement (i.e., few programs have policies and procedures, but most are expected to review a policy manual).

The survey asked whether individual outcomes were measured in the PD-LTSS program and by whom. Multiple options could be selected. Options included: the participant, administrating agency, case manager, and/or the managed care organization. There was also a response option available if outcomes are not measured. For the breakdown by party responsible for measuring health outcomes, see Figure 6.

**Figure 6: Number of PD-LTSS Programs (n = 115) by Party Responsible for Measuring Outcomes**

If individual outcomes were measured, the follow-up question asked what outcomes are measured. Multiple options could be selected. Options included: quality of life, participants’ level of choice and control, participants’ access to personal care, participants’ health status, and/or individual goals tracked as part of the participants’ service plans. For the breakdown by type of outcome measured, see Figure 7.
Of 108 programs, 86% reported that the priority level of participant direction for their agency was moderate to high.

- Of the surveys completed (n=134), 22% did not respond to this question.

V. **Employer Authority**

- Based on 192 programs:
  - 52% reported that the participant or the participant’s representative was the employer of record for tax purposes for workers who perform services for participants.
  - 18% reported that the participant was the employer of record for tax purposes for workers who perform services for participants.
  - 16% reported “other” (e.g., a combination of one or more of the survey options for this question) was the employer of record for tax purposes for workers who perform services for participants.
  - 13% reported that the Agency with Choice (AwC) was the employer of record for tax purposes for workers who perform services for participants.
  - 2% reported that a public authority was the employer of record for tax purposes for workers who perform services for participants.

- Based on 120 programs:
  - 47% reported that training was offered to, but not required for, the participant.
  - 33% reported that training was required for the participant as the employer.
  - 21% reported that training was not offered to the participant.

- Based on 191 programs:
  - 46% reported that the participant or representative sets the rate of pay for the worker.
  - 22% reported that the program sets the rate of pay for the worker.

---

20% reported that “other” (e.g., a combination of one or more of the survey options for this question) sets the rate of pay for the worker.
7% reported that the participant sets the rate of pay for the worker.
3% reported that the union contract sets the rate of pay for the worker.
1% reported that the care manager sets the rate of pay for the worker.

- Of 178 programs, 89% reported that the participant direction program requires background checks for paid caregivers.

The survey asked which organizations or individuals may be selected to provide direct support services. Response options included: certified home health agency, homecare services agency, friends or neighbors and/or non-legally responsible relatives (e.g., siblings, aunts, uncles). Multiple selections were allowed. For the breakdown of service providers, see Figure 8.

**Figure 8: Number of PD-LTSS Programs (n = 154) by Allowable Providers of Direct Support Services**

The survey asked whether there are any restrictions on who the participant may hire based on age and relationship to the participant. Response options included: age (i.e., younger than 18 years of age), spouse, parent or legal guardian of a minor child, and/or power of attorney. Multiple selections were allowed. For the breakdown of restrictions on who can be hired, see Figure 9. While hiring a legally responsible individual (i.e., spouse, parent or legal guardian of a minor child) as a paid caregiver is allowed in eleven-percent of the programs responding (n = 168), the majority of programs do not allow this option. VD-HCBS programs also have the option to allow hiring a legally responsible individual as a paid caregiver (data are not included).
VI. **Budget Authority**

- Of 252 programs, 63% reported having budget authority although its application is program specific and its flexibility is variable across programs.
- Of 96 programs, 90% reported having restrictions on the purchase of non-traditional goods and services.
- Based on 122 programs:
  - 53% reported the participant’s budget is calculated based on the assessed need or service plan.
  - 42% reported that the participant’s budget is calculated based on “other” (e.g., a combination of assessed need and historic utilization, State statute).
  - 4% reported that the participant’s budget is calculated based on historic utilization.

---

• Of 109 programs, 44% reported that the participant is allowed to carry over unexpended funds into a new fiscal year.

VII. Financial Management Services

Participant direction programs include additional responsibilities because of the decision-making authority afforded to the participant; responsibilities include those associated with being an employer. Financial Management Services (FMS)\(^8\) are one of the pillar supports for a participant direction program. FMS then, as defined by The Center for Medicare and Medicaid Services, helps individuals: (1) Understand billing and documentation responsibilities; (2) perform payroll and employer-related duties; (3) Purchase approved goods and services; (4) track and monitor individual budget expenditures; and (5) identify expenditures that are over or under budget\(^9\). There are five FMS models that states may use to implement participant direction programs; (1) Fiscal Conduit, (2) Government Fiscal/Employer Agent (F/EA), (3) Vendor F/EA, (4) Agency with Choice (AwC), and Public Authority/Workforce Council. The stats below indicate the FMS models implemented.

- Based on 136 programs:
  - 6% reported that participants are allowed to receive the value of their participant direction program benefit directly in cash to manage and pay for selected services.

- Based on 198 programs:
  - 75% reported offering an F/EA as the FMS model.
  - 12% reported offering Agency with Choice as the FMS model.
  - 11% reported offering both AwC and F/EA FMS models
  - 2% reported offering more than two types of FMS models (i.e., F/EA, AwC and a fiscal conduit as the FMS).

- Based on 143 programs:
  - 84% reported offering a vendor F/EA model
  - 13% reported offering a government F/EA model.
  - 4% reported offering both a vendor and government F/EA model.

---

\(^8\) For more information about FMS roles, responsibilities, and models of FMS refer to chapter 7 of the NRCPDS Handbook Developing and Implementing Participant Direction Programs & Policies: A Handbook (http://www.bc.edu/content/dam/files/schools/gssw_sites/nrcpds/cc-07.pdf).

VIII. Participant Involvement in Management of Program

- Of 163 programs, 83% reported that the participant direction program involved participants in the design, implementation, or improvement of the program.

The survey asked if participants are involved in the design, implementation, or improvement of the PD-LTSS program, then what type of involvement mechanisms are employed. Multiple selections were allowed and included: advisory group, advocate meeting, committee of participants, focus group, individual interview, public forum/hearing, and/or survey. For the breakdown of involvement mechanisms, see Figure 10.

**Figure 10:** Number of PD-LTSS Programs (n = 110) by Participant Involvement Mechanism

- If participants are not involved in the design, implementation, or improvement of the program, the survey asked why participants are not involved. Multiple selections were permitted and included: difficulty finding participants, inadequate resources, limited staff time, not required, and/or previous negative experiences.

- Based on 23 programs who reported that they did not involve participants in these functions:
  - 44% reported that it is not required to involve participants in the design, implementation, or improvement of the program.
  - 9% reported that limited staff time was the reason for not involving participants in the design, implementation, or improvement of the program.

IX. Conclusion

The 2013 NRCPODS NI captures emerging trends, including new program development, growth in enrollment, and the use of managed care as a service delivery system, all of which are expected to continue to play an important role in the reshaping of the current landscape of participant direction. While the data indicate moderate growth in participant direction nationwide compared to 2010, less than six-percent of Medicaid eligible individuals nationwide are enrolled in participant direction programs. With enhanced efforts toward rebalancing, we expect this percentage to increase in the coming years. As this report serves as a summary of the NI data, we foresee future reports/publications offering higher level analysis, interpretation, and recommendations. For future updates or to join our mailing list, please contact us at info@participantdirection.org.