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An Inventory of Publicly Funded Participant-Directed Long-Term Services and Supports Programs in the United States

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Abstract

After a decade of changes in federal law, regulation, and policy designed to promote the growth of publicly funded participant-directed long-term services and supports (PD-LTSS) programs, the number of these programs has grown considerably. The National Resource Center for Participant-Directed Services (NRCPPDS) at Boston College started developing an inventory of these programs in 2010-2011 to determine the number and characteristics of publicly funded PD-LTSS programs in the United States. The 2010-2011 NRCPPDS inventory provides baseline data for future research efforts in gauging the growth and expansion of this service delivery model. This article details the process for developing this data resource, some of the major characteristics of PD-LTSS programs in the United States, and discusses possible implications and areas for future research.

Keywords

Self-direction; Medicaid; Long-Term Services and Supports

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The District of Columbia has a §1915(c) Medicaid waiver approved for an employer authority PD-LTSS but the program was not implemented in 2010-2011.

Introduction

The idea that participants receiving services from publically funded long-term services and support (LTSS) programs comes out of the independent living and disability rights movements of the 1970s and 1980s (Litvak, Zukas, & Heumann 1987; Simon-Rusinowitz & Hofland 1993; DeJong, Batavia, & McKnew 1992). Participant-directed long-term services and supports (PD-LTSS) recognize that individuals should be able to determine for themselves the types of services and supports they need to remain independent and reside in their community. While a small number of publically funded PD-LTSS programs have existed since the 1970s, the majority of home and community-based LTSS participants have traditionally received their services from programs managed by an agency.

From the establishment of the Medicaid Home and Community Based Waiver program in the early 1980s through the mid-1990s, policies at the federal level and within the majority of states did not support publically funded PD-LTSS. According to Doty (2010), this was “likely due to the widely prevalent view that professional oversight was required to protect persons with chronic illnesses and disabilities” (p. 3). Policy maker attitudes begin to change in the 1990s due to the positive findings of research studies comparing PD-LTSS with agency-managed services

Research on the Effectiveness of PD-LTSS

In the early 1990s, Doty, Kasper, and Litvak (1996) examined data collected by the 50 World Institute on Disability (WID) on Medicaid Personal Care Service (PCS) programs to understand differences between participant-directed elements versus traditional agency management and the viewpoints of participants and administrators concerning these models. The data were collected by WID from surveys of PCS programs in all 50 states in 1984 and 1988. The 1988 WID 50-state survey provided the basis for selecting six state programs for in-depth examination in 1990 and 1991.

Doty, Kasper, and Litvak (1996) report strong preferences for PCS programs with participant-directed options among both participants and program administrators. Satisfaction with their worker and care received was higher among individuals receiving care by programs that included elements of participant direction. Among administrators a common thread of support for participant direction was the potential cost savings associated with the model.

Later in the 1990s, Doty, Benjamin, Matthias, and Franke (1999) completed an evaluation of participant direction and agency-managed service options in California's In-Home Support Services (IHSS) program. IHSS was examined partly because it includes both participant direction and agency program options (Doty et al., 1999). This study also found IHSS users preferred a participant directed program to professional management models (PMM). Compared with PMM clients, self-directing participants reported greater choice in handling their services and supports had higher emotional and social well-being, and were more satisfied with their worker and the services provided.

In the mid-1990s a three-state demonstration was conducted to compare a budget authority participant-directed model with the traditional agency-directed approach to delivering LTSS. The Cash & Counseling Demonstration and Evaluation (CCDE) occurred in Arkansas, Florida, and New Jersey and involved 7,500 participants. CCDE was the first large-scale demonstration offering budget authority to be evaluated with controlled experimental design methods (Kemper, 2007). As a result, the CCDE has both the largest research base and the strongest evidence of efficacy of any PD-LTSS program.

The CCDE showed significant differences between participants who were randomly selected to manage their services and service budgets and their peers who were selected to receive agency-managed services. The persons randomly selected for participant direction reported fewer unmet personal care needs and improvement in a number of health outcomes and were more likely to be satisfied with the quality of their care and their caregivers than their peers receiving agency-based services (Brown, Carlson, Dale, & Foster, 2007).

The CCDE required Arkansas, Florida, and New Jersey to operate their programs under a Centers for Medicare and Medicaid Services (CMS) approved research and demonstration waivers and the evaluation was co-sponsored by The Office of the Assistant Secretary for Planning and Evaluation (ASPE). The involvement of CMS and ASPE as well as CCDE's status as a randomized controlled experimental design with large numbers of participants resulted in its findings proving influential in bringing about changes in federal law, regulation, and policy that encouraged and facilitated the growth of PD-LTSS.

Federal Activity Promoting PD-LTSS in the 2000s

In 2001, CMS revised the §1915(c) Home and Community-Based Services (HCBS) waiver application to include participant direction options. In early 2006, Congress passed the Deficit Reduction Act of 2005, which created several new Medicaid statutory authorities for participant direction, including §1915(j) that allows states to offer budget authority to Medicaid State Plan personal care services participants without having to operate under the §1115 demonstration authority.

In 2007, the Administration on Aging (AoA) initiated the Nursing Home Diversion Modernization Grants Program (later the Community Living Program), which represented a significant non-Medicaid effort to encourage states to consider participant-directed services using the Cash and & Counseling design. The Veterans Health Administration (VHA) and the AoA partnered in late 2008 to develop a Cash & Counseling program called Veteran-Directed Home and Community-Based Services (VD-HCBS) to meet the needs of the growing numbers of veterans with service-related and/or chronic disabilities.

The 2010 Patient Protection and Affordable Care Act (ACA) also included a number of reforms supporting the development of PD-LTSS. The ACA expanded Medicaid funding authorities encouraging participant direction including Community First Choice (§1915(k) and revised the §1915(i) authority). Section 2402(a) of the ACA calls on the Secretary of the Department of Health and Human Services to develop a common framework establishing principles and process elements supporting participant direction across the whole department and all of its programs.

With these changes, Federal Medicaid officials report that states are increasingly offering PD-LTSS alternatives to professionally managed services (Greene, 2007). CMS currently recognizes two basic models of PD-LTSS. Employer authority gives participants the ability to employ workers directly; participants are responsible for selecting, hiring, training, scheduling, managing, and discharging workers. Budget authority gives participants the ability to manage an individual budget that can be used to hire a worker and purchase other permissible goods and services.

The first comprehensive inventory of PD-LTSS programs was completed in 2001 (Doty & Flanagan, 2002). However, almost ten years after Doty and Flanagan's (2002) inventory, little was known about the actual number of participant-directed service programs, the populations that they serve, their size, or their policies and procedures. To fill this gap, the National Resource Center for Participant-Directed Services (NRCPDS) sought to create an inventory of publicly funded PD-LTSS program

Method

Data for the 2010 – 2011 NRCPDS inventory was collected from PD-LTSS program administrators. The 2001 Doty and Flanagan inventory identified 138 PD-LTSS programs (Doty & Flanagan, 2002). Using these programs as a starting point, the NRCPDS research team reviewed state program websites and state Medicaid waivers and requested a listing of known Medicaid PD-LTSS programs from CMS. This initial process yielded 333 potential PD-LTSS programs to be surveyed for inclusion in the inventory.

NRCPDS staff developed a 10-item mail survey to collect information regarding program characteristics (e.g. number of people served, covered populations, etc.), funding mechanisms, financial management services (FMS), program restrictions on hiring workers and/or the use of individual budgets, amounts and types of participant involvement, and program services and supports. The team also prepared a four-item questionnaire on program procedures to be covered as part of a telephone follow-up interview. A summary of the data points collected is included in Table 1. An advisory committee of national experts and members of the National Participant Network (a national advocacy group for individuals who self-direct their LTSS) reviewed the survey and telephone questions.

The Pennsylvania State University's Survey Research Center (SRC) was contracted to conduct both the survey and telephone interviews. The SRC designed a traditional paper survey using Cardiff's TeleForm® software and an identical web survey using Perseus SurveySolutions® software. Both options were created and presented to program respondents to provide them with greater response flexibility. Each potential respondent received three contact mailings. First, potential respondents received an initial mailing packet that included an individualized cover letter, a paper survey, and a postage-paid return envelope. The cover letter included a suggestion that respondents could complete the same survey online. An individualized URL was printed in the letter to guide the respondent to that option. Two weeks after the initial mailing packet, each potential respondent received a reminder via the mail. Finally, four weeks after the initial mailing, an additional mailing of the initial packet survey was sent to all non- respondents. This final mailing included a follow-up letter and the contents of the initial packet.

A phone follow-up to all potential respondents began in late 2010. For those who completed the mail or web survey, this follow-up consisted of clarifying questions (if needed) and the four program process questions. In addition, all nonrespondents were contacted to either recruit them to participate or ascertain that the program either no longer existed or was not participant-directed. Through this process the 2010-2011 inventory eliminated programs incorrectly identified or not previously identified as PD-LTSS programs. As a result of this process, 212 programs funded by either Medicaid or state revenues were identified, representing 80% of the PD-LTSS programs operating in 2010-2011. The 2010-2011 inventory does not include 43 VD-HCBS programs that were operating at this time. The decision not to include these programs in the survey was made because the policies and procedures for these programs were still being formed.

The 2010-2011 inventory includes information on enrollment totals, funding source, and population served for all 212 programs. The inventory incorporates programmatic information for 186 programs (87% of the sample), while 23% had at least one missing item. A missing data analysis did not identify any questions missing more than 5% of the requested information nor a consistent pattern of missing data. The nonresponsive programs were all Medicaid funded with small enrollments. Despite these program gaps, the information from the 186 programs provides a basic overview of the state of PD-LTSS in 2010 – 2011.

Results

Programmatic Growth

Number of PD-LTSS programs has grown substantially since 2000—The majority (66%; n=139) of PD-LTSS programs started since 2000. Of the PD-LTSS programs that started operations in the 2000s, 58% (n=82) began between 2005-2010. There is at least one PD-LTSS employer authority program in each state and the District of Columbia (see Note) and 43 states also have at least one PD-LTSS budget authority program. While often started as demonstration projects serving only selected areas within a state, 79% (n=106) of the 212 PD-LTSS programs reported operating statewide.

The number of PD-LTSS program participants is growing—Doty and Flanagan (2002) reported 486,000 participants in PD-LTSS. In 2010-2011 there were approximately 750,00 individuals enrolled in the 212 PD-LTSS programs. Approximately 60% (n=450,000), however, were enrolled in California's In-Home Supportive Services program. The next five (n=5) largest programs accounted for 18% (n=132,611) of PD-LTSS participants. The majority of PD-LTSS programs (57%; n=120) reported enrollments of less than 500.

General Program Characteristics

Medicaid is the major funding source for PD-LTSS—Among the 212 programs, Medicaid was the major funding source for PD-LTSS (n=160). Seventy-three (n=73) programs reported using state revenues to fund PD-LTSS programs. Eleven PD-LTSS

programs reported being funded through “other” sources including funds from the Tobacco Master Settlement Agreement and gaming revenues.

PD-LTSS programs serve individuals of all ages and with all types of disabilities—Approximately 60% (n=129) of the 212 serve two or more populations including elders and adults with physical disabilities, persons with intellectual disability, children with special health care needs, and so forth. Few programs reported targeting single populations such as elders (n=19), children with special health care needs (n=16), or persons with physical disabilities only (n=16) or intellectual disability only (n=14). Eighteen (n=18) programs reported serving populations outside of the above categories.

PD-LTSS programs possess a range of participant supports—Programs reported a variety ways of supporting the efforts of participants to self-direct their services. The majority of programs (n=173) allow for representatives. A representative is someone selected by the participant to assist them in making LTSS decisions (or in some instances making LTSS decisions on the participant's behalf). Likewise a majority (n=179) require participants to use Financial Management Services (FMS). FMS are a support function that provides participants and their representatives with fiscal protections and safeguards. FMS providers typically complete financial transactions such as issuing worker paychecks; filing and depositing federal, state, and local taxes on behalf of the participant in accordance with spending plan authorizations and/or program rules; and generating reports for the participant and the program regarding these transactions. However, only 52 respondents reported knowledge of registries of workers that PDLTSS participants could use to identify potential persons who could be hired to assist them.

Employer Authority

Majority of PD-LTSS programs have restrictions on who can be hired—Of the 212 programs, 73% (n=155) have some restriction regarding paid workers. Restrictions included not hiring a spouse (n=75), a parent and/or legal guardian (n=64), and persons who have previous criminal convictions (n=37). The majority of programs (n=158) require workers to have criminal background checks.

Participant sets the rate of pay in the majority of PD-LTSS programs—. In 79% (n=169) of the surveyed programs, the participant is responsible for setting the rate of pay with an additional 4% (n=9) reporting that the participant does this in consultation with the program. The remaining programs reported the worker's rate of pay is determined in a variety of ways— by the program itself, through a collective bargaining agreement, or in a few instances some other entity (e.g., county government).

Budget Authority

Majority of budget authority PD-LTSS programs base individual budgets upon individual need—Among the 102 programs offering the participant the option of managing an individual budget and make purchases related to personal care, the size of the participant's budget is determined by a professional needs assessment. These programs described a process that uses the needs assessment to create a traditional care plan and then

converting this number into a monthly budget allocation. A subset of programs then described a variety of factors for finalizing the participant's budget including need for specific services (n=39) and an individual's existing available resources (n=6).

Majority of budget authority PD-LTSS programs have purchasing restrictions

—None of the budget authority PD-LTSS programs report allowing participants to exceed their annual budgets. Few (n=14) reported allowing PD-LTSS participants to carry forward funds into a new fiscal year. Of those programs offering budget authority, the majority (n=98) specified the existence of categorical purchasing restrictions including limits to specific services such as respite or transportation, limits to the number of hours per month a caregiver can be paid, and overall monthly or weekly limits among others.

Discussion

The purpose of the NRCPPDS inventory of publicly funded PD-LTSS programs is to create the most complete national dataset on PD-LTSS that would be useful for participants, program administrators, researchers, and policy makers in understanding the development and features of these programs. While the process of developing this inventory has its limitations, it has sufficient information to make the following general observations:

1. PD-LTSS is a growing service option designed for persons of all ages and across different disability types.
2. While there has been extensive growth in the number of programs, the majority of the PD-LTSS programs are very small.
3. The Medicaid program has largely driven the growth of PD-LTSS but its role is unknown as more states contract with managed care entities to administer their LTSS services.

PD-LTSS as a Growing Service Option

The information in the 2010-2011 NRCPPDS inventory shows that all states have at least one LTSS program offering participants the opportunity to select and manage individuals who help them with activities of daily living (employer authority) and the majority of states have at least one program that allows individuals to manage their LTSS budgets to purchase any combination of goods, services, and human assistance that meets their needs and helps them stay in dependent in the community (budget authority). Furthermore, the 2010 -2011 inventory shows that PD-LTSS programs have been developed for all age groups and a variety of disability types. With the passage of the ACA and its various provisions directed towards promoting PD-LTSS, we can expect continued support for the expansion of service option in the years to come.

The 2010-2011 inventory information provides a basic outline of how the participant direction service option has been developed. In keeping with the general philosophy of participant direction, the majority of programs have been developed in ways to promote the participant's autonomy and choice. The majority of programs provide participants with supports (e.g. representatives, FMS, etc.) to facilitate the individual's ability to self-direct. In

the majority of programs, the participant can set the rate of pay for the person they hire. Such ability reflects tangible support for the individual's autonomy and choice. At the same time, the majority of programs have taken care to minimize potential fraud and abuse through hiring and purchasing restrictions. While 2010-2011 inventory cannot inform beyond basic program descriptions, its utility lies in its ability to inform and guide future researchers to programs with certain characteristics so that the effectiveness of these characteristics can be tested.

Program Enrollments Vary Considerably

In 2010-2011, a small number of programs accounted for approximately three quarters of the all persons enrolled in PD-LTSS. The majority of programs reported enrollments of 500 persons or less. There are a couple of explanations for this. First the California IHSS Program accounts for approximately 450,000 participants of the approximately 750,000 PD-LTSS enrollees. IHSS has over 30 years of experience with participant direction and since its inception participant direction has been the default service option presented to individuals upon program enrollment and as that program grows, the number of persons self-directing grows as well. Second, in 2010-2011, 89 of the 212 programs began operations after 2005. So small program size may be by design in some states—limiting enrollments as program policies and procedures are tested and improved. Small enrollments may suggest the program's need to demonstrate its effectiveness for state policy makers who may be hesitant regarding participant direction

Suggestions regarding possible explanations for small program size from potential bias within the LTSS networks toward agency-based delivery have been provided previously (San Antonio, Simon-Rusinowitz, Loughlin, Eckert, Mahoney, & Ruben, 2010; Doty, Mahoney, & Sciegaj, 2010; Simon-Rusinowitz, Mahoney, Marks, Zacharias, & Loughlin, 2005; Simon-Rusinowitz, Mahoney, Simone, & Zacharias, 2009). Whether this bias is due to a lack of understanding about what PD-LTSS is and is not, the lack of familiarity with PD-LTSS, or greater comfort with a professional decision-making culture, it is an area for ongoing investigation.

The 2012 establishment by the Administration for Community Living (ACL) of Options Counselor competencies for participant direction may serve as a blueprint for addressing potential work force biases towards agency-based care. This document states options counseling “should include discussion of available options without the personal bias of the Options Counselor” (ACL, 2012, p.10). As this was incorporated into the occupation competencies, it suggests some concern regarding bias toward service options exist. Because PD-LTSS is seen as an important dimension for LTSS, re-balancing efforts from institutional to community-based care, identifying ways to optimize PD-LTSS operations and enrollments will only grow in the years to come (Miller, Clark, & Mor, 2008).

The reasons for larger or smaller sized programs cannot be explained by the 2010-2011 NRCPS inventory data alone. Understanding the reasons for small program size should be of concern, as program size may reflect program underutilization, the expression of professional bias, or state policy maker opinions regarding participant direction. However, such conclusions cannot be made based on the inventory; therefore, future research efforts

using NRCPS inventory data to target small programs and exploring these possible reasons are necessary.

Medicaid's Role in Future Growth is Unknown

The 2010-2011 inventory illustrates how Medicaid funding has supported the expansion of PD-LTSS. However, with growing concerns regarding state budgets, Medicaid programs have started to contract with managed care organizations (MCOs) to administer their long-term services and support programs. In 2013, 16 state Medicaid programs moved towards such managed long-term services and support arrangements (MLTSS) (Saucier, Kasten, Burwell, & Gold, 2012). Medicaid requires that programs offering PD-LTSS continue to do so under MLTSS. Of the 16 states with MLTSS, 12 offered PD-LTSS. How PD-LTSS is supported in these configurations is largely unknown.

The compatibility of managed care and participant direction has been debated since 1997. Kodner, Mahoney, and Raphael (1997) concluded that MCOs were driven by the very characteristics compatible for participant direction, such as flexible service delivery. Stone (1997) also believed that managed care and participant direction could be compatible but pointed to potential challenges associated with how a MCO implemented the model. Early studies of MCO administrator attitudes towards participant direction provided mixed results. One early study reporting very positive attitudes regarding participant direction's contribution to high quality and improved service satisfaction (Meiners, Mahoney, Shoop, & Squillace, 2002) while another by the same research team (Mahoney, Meiners, Shoop, & Squillace, 2003) reported concerns regarding the participant's ability to effectively self-direct their services.

A recent study using the 2010-2011 inventory targeted five states to better understand how MLTSS programs have implemented participant direction (Sciegaj, Crisp, DeLuca, & Mahoney, 2013). The study selected the states of Arizona, Massachusetts, New Mexico, Tennessee, and Texas for examination because of their long histories of either offering PD-LTSS or contracting with managed care or both. The study reported a great deal of variation of state involvement in the design, implementation, and evaluation of participant-directed service options under managed care (Sciegaj, Crisp, DeLuca, & Mahoney, 2013). As MLTSS continues to expand, further research on its impact on PD-LTSS is needed. While the 2010-2011 inventory data lacks information on how MLTSS impacts PD-LTSS, as with the above two areas, it can guide and inform future research activities.

Limitations

The limitations of this study must be acknowledged. First, while the goal of the 2010-2011 was to be as comprehensive as possible, it is impossible to verify that it includes every PDLTSS program in the United States—even though the study team used multiple approaches to be as exhaustive as possible in identifying PD-LTSS programs. Second, the program information is self-reported by an administrator. While the project enlisted external reviewers to review the inventory information, it is likely that there are inaccuracies (despite the project's best efforts to correct inaccurate information) as states may overestimated or underestimated program size or provided inaccurate information regarding program policy

and procedures. A final limitation is that the inventory is a snapshot of one point in time of programs that are constantly evolving. For example, it is possible that in the future small programs will be discontinued, consolidated, or be subsumed by larger programs as states renew their Medicaid waiver applications.

Conclusion

After a decade of changes in federal law, regulation, and policy designed to promote the growth of PD-LTSS programs, the number of these programs has grown considerably. The 2010-2011 NRCPS inventory was created in an effort to provide a description of the major characteristics of these programs. This inventory is useful to future researchers as a guide to existing programs, and enables the exploration of remaining questions such as those posed above. Such future research efforts can inform and assist policy makers in further development of PD-LTSS in the United States.

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References

- Administration for Community Living. Draft national options counseling standards. 2012. Retrieved from <http://www.altsa.dshs.wa.gov/stakeholders/ADRC/documents/projectinfo/Draft%20National%20Options%20Counseling%20Standards.docx>
- Brown R, Carlson B, Dale S, Foster L. Effects of Cash and Counseling on personal care and well-being. *Health Services Research*. 2007; 42(1):467–487. [PubMed: 17244293]
- DeJong G, Batavia AI, McKnew LB. The independent living model of personal assistance in national long-term care policy. *Generations*. 1992; 16(1):89–95.
- Doty, P. O'Keeffe, J., editor. Appendix III: History of Self-Direction.; *Developing & Implementing Participant Direction Programs & Policies: A Handbook*. 2010. p. 1-7. Appendix III Retrieved from http://www.bc.edu/content/dam/files/schools/gssw_sites/nrcpds/cc-app3.pdf
- Doty, P.; Benjamin, A.; Matthias, R.; Franke, T. In-Home supportive services for the elderly and disabled: A comparison of client-directed and professional management of services delivery (Non-Technical Summary Report). Retrieved from Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; 1999. website: <http://aspe.hhs.gov/daltcp/reports/1999/ihss.htm>
- Doty, P.; Flanagan, S. Highlights: Inventory of consumer-directed support programs. Retrieved from Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services; 2002. website: <http://aspe.hhs.gov/daltcp/reports/2002/highlight.htm>
- Doty P, Kasper J, Litvak S. Consumer-directed models of personal care: lessons from Medicaid. *Milbank Quarterly*. 1996; 74(3):377–409. [PubMed: 8780640]
- Doty P, Mahoney K, Sciegaj M. New state strategies to meet long-term care needs. *Health Affairs*. 2010; 29(1):49–56. [PubMed: 20048360]
- Greene, J. State approaches to consumer direction in Medicaid (Issue Brief). Center for Health Care Strategies, Inc.; Jul. 2007 Retrieved from http://www.chcs.org/usr_doc/State_Approaches_to_Consumer_Direction.pdf
- Kemper P. Commentary: Social experimentation at its best: The Cash and Counseling Demonstration and its implications. (Commentary). *Health Services Research*. 2007; 42(1):577–586. [PubMed: 17244299]

- Kodner D, Mahoney K, Raphael T. Managed care and consumer-directed care: Are they compatible? *Managed Care & Aging*. 1997; 4(4):3–4.
- Litvak, S.; Zukas, H.; Heumann, J. Attending to America: Personal assistance for independent living, Report of a survey of attendant service programs in the United States for people of all ages with disabilities. World Institute on Disability; Berkeley, CA: 1987. Retrieved from <http://files.eric.ed.gov/fulltext/ED297507.pdf>
- Mahoney K, Meiners M, Shoop D, Squillace M. Cash and Counseling and Managed Long-Term Care. *Case Management Journal*. 2003; 4(1):18–22.
- Meiners M, Mahoney K, Shoop D, Squillace M. Consumer Direction in Managed Long-Term Care: An Exploratory Survey of Practices and Perceptions. *The Gerontologist*. 2002; 42(1):32–38. [PubMed: 11815697]
- Miller E, Clark M, Mor V. The Commonwealth Fund Survey of Long-Term Care Opinion Leaders: Focus Group Report. Report for the Commonwealth Fund. 2008 (Contract No. 20060606).
- San Antonio P, Simon-Rusinowitz L, Loughlin D, Eckert JK, Mahoney KJ, Ruben KA. Lessons from the Arkansas Cash and Counseling program: how the experiences of diverse older consumers and their caregivers address family policy concerns. *Journal on Aging and Social Policy*. 2010; 22(1): 1–17.
- Saucier, P.; Kasten, J.; Burwell, B.; Gold, L. The growth of Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 update. 2012. Retrieved from Medicaid.gov website: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf
- Sciegaj, M.; Crisp, S.; DeLuca, C.; Mahoney, K. Participant-Directed Services in Managed Long-Term Services and Supports Programs: A five state comparison. Retrieved from U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation; 2013. <http://aspe.hhs.gov/daltcp/reports/2013/5LTSS.shtml>
- Simon-Rusinowitz L, Hofland B. Adopting a disability approach to home care services for older adults. *The Gerontologist*. 1993; 33(2):159–167. [PubMed: 8468008]
- Simon-Rusinowitz L, Mahoney K, Marks L, Zacharias B, Loughlin D. The Cash and Counseling Demonstration and Evaluation: focus groups inform design of a consumer-directed cash option. *Care Management Journals*. 2005; 6(2):56–65. [PubMed: 16544866]
- Simon-Rusinowitz L, Mahoney K, Marks L, Simone K, Zacharias B. Social marketing principles enhance enrollment in the cash and counseling demonstration and evaluation. *Care Management Journals*. 2009; 10(2):50–57. [PubMed: 19626978]
- Stone R. Consumer advocacy and managed care. *Managed Care and Aging*. 1997; 4(3):3–4.

Table 1**PD-LTSS Inventory Data Fields and Items**

Data Fields	Item
Program Characteristics	What year did this program begin? How many participants are self-directing in this program? What are the approximate program costs? Which population(s) does this program serve? Is this program available statewide?
Funding Mechanism	What is the funding mechanism(s) for this program?
Employer Authority	Who is the employer of record? Who sets the rate of pay? Does the program require background checks? Are there any restrictions on who may be hired? Does the state have a worker registry?
Budget Authority	What is the process for setting the participant's budget? Are there any restrictions on what may be purchased?
Representatives	Can the participant have a representative?
Financial Management Services (FMS)	Are participants required to use FMS? Is FMS provided as a service or as an administrative function? What type of FMS is used? How is the program select FMS provider(s)? What is the average cost per participant for FMS?
Program Services and Supports	Which of the following services and supports are available? <ul style="list-style-type: none"> • Adult day services • Assistance with medication • Assistive devices/home modifications • Case management • Companion services • Counseling (Social and Personal) • Emergency response services • Homemaker services • Overnight or respite services • Personal care services • Private duty nursing • Specialized healthcare • Training and educational supports • Transportation • Other
Participant Involvement	Describe ways participants are involved in the planning, implementation, and evaluation of this program.

Note. PD-LTSS = participant-directed long-term services and supports; FMS = financial management services.