

Self-direction Research Compendium

Home and Community-based Services (HCBS) Self-direction Series

HCBS Self-direction Series

This briefing paper series is designed for policymakers and stakeholders, to inform conversation and policy regarding HCBS self-direction and the direct service workforce. This brief is the final of four in the series and compiles the sources used to inform the briefs in this series.

Resource Websites

Website	Description
Administration for Community Living's (ACL) Veteran Directed Care (VDC) Program	<p>In 2008, ACL, on behalf of the Department of Health and Human Services (HHS), began a partnership with the Veteran's Health Administration to serve veterans of all ages at risk of nursing home placement through the VDC Program. Until 2018, this program was known as Veteran-Directed HCBS. The information provided on this website describes the purpose of the program and how it works and includes a list of the Veterans Affairs Medical Centers that have implemented VDC programs. Additional tools and resources are available here.</p>
Applied Self-Direction	<p>Applied Self-Direction provides practical expertise intended to create and operate self-directed programs that run effectively and efficiently for individuals, states, managed care plans, financial management services providers, and other stakeholders. Applied Self-Direction was previously the National Resource Center for Participant-Directed Services, which served as the National Program Office for the Cash and Counseling demonstration and evaluation from 1998 to 2009.</p>
HCBS Clearinghouse: Participant-Directed Services	<p>The HCBS Clearinghouse website, managed and housed by ADvancing States, includes a section with specific resources on self-directed services.</p>
HCBS Technical Assistance Website	<p>CMS funds technical assistance to state agencies pursuing section 1915(c) waivers and section 1915(i), section 1915(j), and section 1915(k) state plan options. Technical assistance topics include:</p> <ul style="list-style-type: none"> ▪ HCBS waivers and state plan option [section 1915(c) and section 1915(i), respectively] ▪ Self-Directed Personal Assistance Services state plan option [section 1915(j)] ▪ Community First Choice option [section 1915(k) state plan option] ▪ Expanding mental health services under waiver programs ▪ Self-directed services ▪ Systemic approaches to person-centered planning ▪ Supported employment ▪ Individual budgeting ▪ Need assessments ▪ Positive behavioral supports ▪ Community integration ▪ Mortality and morbidity data collection and analysis

Website	Description
Medicaid.gov Self-Directed Services	This website provides an overview of self-directed services, including self-directed service options under Medicaid, self-directed guidelines (e.g., common characteristics by Medicaid authority, support guidelines, financial management services), and a history of self-directed options.
National Center on Advancing Person-Centered Practices and Systems (NCAPPS)	NCAPPS is a technical assistance initiative funded by ACL and CMS to support states, tribes, and territories to implement person-centered thinking, planning, and practices that align with HHS policies. NCAPPS conducts learning collaboratives and monthly webinars to promote learning and sharing of best practices and maintains a national clearinghouse of actionable and updated resources.

Handbooks and Toolkits

Handbook or Toolkit	Description
CMS Long-Term Services and Supports (LTSS) Rebalancing Toolkit	This toolkit was developed by CMS for state Medicaid agency staff and provides background information, resources, and promising practices to support state efforts to rebalance Medicaid LTSS in favor of HCBS. It also describes self-directed options and authorities under Medicaid and how self-directed services can support states' rebalancing strategies.
Developing and Implementing Self-Direction Programs and Policies: A Handbook	This National Resource Center for Participant-Directed Services handbook was developed as a useful tool to provide state staff, policymakers, service providers, program participants, and other stakeholders with a single comprehensive source of information about self-directed services and policies. It describes how states can increase participants' choice and control over their services and supports through expanding existing or creating new options for self-directed services.
Matching Service Registries	This registry resource tool, developed by PHI, includes general resources on worker registries and challenges and lessons learned from many states that have implemented worker registries.

Papers and Reports

Paper or Report	Description
Bogenschutz, M. D., DeCarlo, M., Hall-Lande, J., and Hewitt, A. (2019). Fiscal Stewardship, Choice, and Control: The Context of Self-Directed Services for People with Intellectual and Developmental Disabilities in the United States. <i>Intellectual and Developmental Disabilities</i>, 57(2), pp. 158-171.	This study reports on perspectives of state-level intellectual and developmental disability (I/DD) program administrators who are charged with implementing self-directed services and supports in the U.S. regarding three questions: (1) How do state-level I/DD program administrators perceive the balance between fostering self-determination and stewardship of public funds in self-direction? (2) What are the primary drivers behind the expansion of self-direction for people with I/DD? and (3) How do administrators perceive the roles and responsibilities of people with I/DD and their families as participants in self-directed services and supports?

Paper or Report	Description
<p>Brown, R., Lepidus Carlson, B., Dale, S., Foster, L., Phillips, B., and Schore, J. (2007). <i>Cash and Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and Community-Based Services</i>. Mathematica Policy Research.</p>	<p>Although dated, this report summarizes the independent evaluation findings from data collected and reports prepared since the inception of the Cash and Counseling demonstration. These analyses examine how each of the three demonstration states implemented its program, how the programs affected the consumers who participated as well as their paid and unpaid caregivers, and the costs to Medicaid. The study findings are robust as they are drawn from a randomized experimental design with adequate sample sizes in three different settings.</p>
<p>Cook, J. A., Shore, S., Burke-Miller, J. K., Jonikas, J. A., Hamilton, M., Ruckdeschel, B., Norris, W.... Bhaumik, D. (2019). <i>Mental Health Self-Directed Care Financing: Efficacy in Improving Outcomes and Controlling Costs for Adults With Serious Mental Illness. Psychiatric Services, 70(3), pp. 191-201.</i></p>	<p>This paper (1) reports on results of a comparative analysis of self-directed care and traditionally-delivered services, (2) evaluates the self-directed services effect on budget neutrality, and (3) evaluates self-directed care participants’ satisfaction with mental health services under self-direction compared to traditionally-delivered services.</p>
<p>DeCarlo, M.P., Bogenschultz, M.D., Hall-Lande, J.A., and Hewit, A.S. (2019). <i>Implementation of Self-Directed Supports for People with Intellectual and Developmental Disabilities in the United States. Journal of Disability Policy Studies, 30(1), pp. 11-21.</i></p>	<p>This study examines the implementation of self-directed supports for individuals with I/DD. Researchers interviewed state developmental disabilities administrators in 34 of 42 states that currently operate self-directed service options and used qualitative analysis to arrive at a thematic map of the strengths and challenges currently experienced by state administrators. Common strengths identified by state administrators were increased opportunities for participant self-determination and improved relationships with support staff. Common challenges included restructuring case management relationships as well as rulemaking and enforcement. Administrators’ suggestions for the future of self-direction focused on increasing program size and streamlining services using technology.</p>
<p>Doty, P. J., Squillace, M. R., and Kako, E. (2020). <i>Analysis of State Efforts to Comply with Fair Labor Standards Act Protections to Home Care Workers</i>. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.</p>	<p>This report describes changes states have made to their Medicaid and other publicly funded self-directed home care programs for older adults and individuals with disabilities to comply with the 2013 update to the U.S. Department of Labor Fair Labor Standard Act regulations.</p>
<p>Edwards-Orr, M., Morris, M., DeLuca, C., Sciegaj, M., and Ujvari, K. (2020). <i>National Inventory of Self-Directed Long-Term Services and Supports Programs</i>. AARP Public Policy Institute.</p>	<p>This report summarizes the key findings of the 2019 National Inventory of Self-Directed LTSS Programs conducted by Applied Self-Direction. The Inventory builds on the 2011, 2013, and 2016 inventories conducted by the National Resource Center for Participant-Directed Services at Boston College and reflects the impact of changes in federal policy designed to promote the growth of self-directed LTSS programs as well as changes in Medicaid programs across the U.S.</p>
<p>Edwards-Orr, M. & Ujvari, K. (2018). <i>Taking it to the Next Level: Using Innovative Strategies to Expand Options for Self-Direction</i>. AARP Public Policy Institute.</p>	<p>This paper describes how four states (Texas, Iowa, Wisconsin, and Florida) used innovative strategies to develop and expand options for self-direction, coordinate and personalize service options, promote stakeholder engagement and outreach, and implement training programs to expand opportunities for individuals to self-direct their LTSS. This paper also includes a toolkit of self-direction resources that can be used for training, education, collaboration, and replication. These tools are offered as a guide for states seeking to develop, improve, or expand their own self-directed LTSS programs.</p>

Paper or Report	Description
<p>Kulchinsky, A., Winkler, S., Hallas L. J., Hall, S., Pettingell, S. L., Donaghy, T. J.... Hall-Lande, J. A. (2021). <i>2020 Evaluation of Experiences with Self Direction in New York State: A Focus on Sustainability</i>. Institute on Community Integration.</p>	<p>This study explores both the current benefits and challenges of self-directed supports as well as the sustainability of self-directed supports when a primary caregiver can no longer support the self-directed process. To the authors' knowledge, this evaluation is the first to explore the sustainability of self-directed supports across major life transitions. This evaluation holds important implications for the design, implementation, and sustainability of self-directed initiatives in the future.</p>
<p>Lewis, E., Eiken, S., Amos, A., and Saucier, P. (2018). <i>The Growth of Managed Long-Term Services and Supports Programs: 2017 Update</i>. Mathematica Policy Research and Truven Health Analytics.</p>	<p>This study reviewed available information about the status of Medicaid Managed Long-Term Services and Supports (MLTSS) programs as an update to an inventory completed for CMS in 2012. It provides updates on the prevalence of MLTSS programs, total enrollment, and specific program design elements as of August 2017.</p>
<p>McCall, S. (2019). <i>How Can Matching Service Registries Increase Their Impact?</i> PHI.</p>	<p>This article is the final installment in a three-part series highlighting online matching service registries around the country. It focuses on Minnesota's matching service registry, <i>Direct Support Connect</i>. This matching service registry was implemented in June 2017.</p>
<p>National Leadership Consortium on Developmental Disabilities of the University of Delaware. (2018). <i>Barriers and Catalysts to Self-Directed Services and Supports for Adults with Disabilities</i>.</p>	<p>This report discusses the key findings of the 2018 <i>Intellectual and Development Disabilities (I/DD) Provider Survey on Self-Directed Services and Supports</i> related to barriers and catalysts to self-directed services and supports.</p>
<p>National Resource Center for Participant-Directed Services. (2016). <i>2016 National Inventory of Self-Direction Programs</i>.</p>	<p>This report summarizes key findings of the 2016 National Inventory of Self-Directed Programs in the U.S. and describes the state of self-direction, as well as changes and trends in 2016 from earlier (2011 and 2013) National Resource Center for Participant-Directed Services' National Inventory findings.</p>
<p>Optum and the Spark Initiative. (2019). <i>Promoting Self-Direction in State and Local I/DD Programs</i>.</p>	<p>This report focuses on individuals with I/DD and is one of a series of four Spark white papers on this topic. Its purpose is to discuss the opportunities and challenges state and local government programs can consider regarding implementing self-directed plans for the individuals with I/DD that they serve.</p>
<p>Sciegaj, M., Mahoney, K. J., Schwartz, A. J., Simon-Rusinowitz, L., Selkow, I., and Loughlin, D. M. (2014). <i>An Inventory of Publicly Funded Participant-Directed Long-Term Services and Supports Programs in the United States</i>. <i>Journal of Disability Policy Studies</i>, 26(4), pp. 245-251.</p>	<p>This paper details how the National Resource Center for Participant-Directed Services inventory is compiled, some of the major characteristics of self-directed LTSS programs in the U.S., and possible implications and areas for future research.</p>
<p>Simon-Rusinowitz, L., Schwartz, A. J., Loughlin, D., Sciegaj, M., Mahoney, K. J., and Donkoh, Y. (2014). <i>Where Are They Now? Cash and Counseling Successes and Challenges Over Time</i>. <i>Care Management Journals</i>, 15(3), pp. 104-110.</p>	<p>This paper describes the findings of a 2011 study conducted by the National Resource Center for Participant-Directed Services concerning the challenges the original three Cash and Counseling demonstration states and the 12 replication states faced and can inform policymakers as they make program and budget decisions.</p>
<p>Spaulding-Givens, J., & Lacasse, Jeffrey R. (2015). <i>Self-Directed Care: Participants' Service Utilization and Outcomes</i>. <i>American Psychological Association</i>, Vol. 38, No. 1, 74-80.</p>	<p>This study examines the demographic characteristics, service utilization patterns, and outcomes of individuals enrolled in the Florida Self-Directed Care (FloridaSDC) program, which is the oldest and most established SDC program in the U.S. for individuals diagnosed with a severe and persistent mental illness.</p>

Paper or Report	Description
Veterans Health Administration. (2021). <i>Opportunities Exist to Improve Management of Noninstitutional Care Through the Veteran-Directed Care Program.</i> Office of Audits and Evaluations, report # 20-02828-174.	<p>The VDC program, one of the Veterans Health Administration’s (VHA) 12 noninstitutional care programs, provides veterans with a budget to hire caregivers and purchase the goods and services that will best meet their care needs and allow them to remain in their homes longer. The VA Office of Inspector General found that VHA provided VDC services to veterans that addressed their care needs. The report reflects opportunities for VHA to improve VDC policies and funding to ensure medical facilities can effectively implement and manage the program to help veterans stay in their homes.</p>

For more information, please view the other briefs in this HCBS self-direction series:

- Origins and Benefits of Self-direction*
- Key Components of Self-directed Services*
- Operational Considerations for Self-directed Service Delivery Models*

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