

Advocacy opportunities for promoting self-direction



Presented by Optum and the Spark Initiative

The Spark Initiative, developed by Optum®, brings together experts to spark new thinking on major health and human service issues. This white paper identifies opportunities for advocates and advocacy groups whose efforts primarily focus on improving the lives of individuals with intellectual and/or developmental disabilities (I/DD). It is one of a series of four Spark white papers, and its purpose is to describe the self-directed service delivery model, explain why it works, identify barriers and outline strategies for advocates and advocacy groups.

Advocacy groups provide support for individuals with I/DD. By engaging communities, advocates work tirelessly to improve public perception and drive beneficial policies at the local, state and national levels. Their achievements have realized greater equality and an enhanced quality of life for millions of Americans.

For example, state-based initiatives in the past 30 years have resulted in regulations ensuring individuals with I/DD can join the workforce, be paid fair wages and be protected from workplace discrimination. Major national milestones that advocacy efforts have influenced include policies such as the Americans with Disabilities Act of 1990 and the Olmstead decision of 1999.¹



Guiding principles of self-direction

- Dignity and respect
- Freedom
- Authority
- Responsibility
- Choice and control
- Relationships
- Vision
- Contribution and community

Knowing that individuals with I/DD are often underserved, their allies continue to seek practical improvements in access to and funding for a variety of services, ranging from health care and housing to education and community living supports.²

In 2016, among the 4.7 million Americans who had intellectual and/or developmental disabilities, 1.4 million were known to or were served by state I/DD agencies. Only 17% of individuals were utilizing long-term supports. This demonstrates a significant gap in services.³ Caregivers, families, friends, advocacy groups and the individuals themselves remain eager to elevate more far-reaching solutions. The self-directed service model is one such solution.

What is self-directed service delivery?

The self-directed service delivery model has grown in acceptance as an alternative to traditionally managed services. First tested in the 1990s, the model allows the person maximum control over helpful supports in the context of preferences, personal goals and individual aspirations. Self-directed programs now operate in every state.

As a concept, self-direction is the idea that individuals (and those who support them) should decide on the types and levels of supports that will work best for their needs.⁴ With self-direction, the person acts on his or her own behalf to:⁵

- Decide what services or purchases are needed
- Make sure services and purchases are funded
- Schedule the services
- Hire, fire and manage people
- Manage the self-directed services

The defining element of the self-directed approach is the shifting of decision-making authority from a state agency or provider organization to the individual who actually receives the supports.

From the individual's perspective, self-direction translates into selecting the supports he or she needs to meet preferred goals. Individuals are afforded more opportunities to live a values-driven life of their choosing, which might include independent living, education and training, employment, community involvement, self-advocacy and leisure activities. Through the empowerment of such decision making, individuals can realize greater happiness, satisfaction and confidence.

From the policy perspective, the Centers for Medicare and Medicaid Services (CMS) has designed self-directed Medicaid services so participants or their applicable representatives have decision-making authority over most, if not all, services and take direct responsibility to manage them. A system of complementary supports also helps to facilitate the management aspects of the model.

Person-centered planning provides the basis for self-directed arrangements. For example, participants are afforded "employer authority," which allows them to recruit, hire, train and supervise the individuals who furnish their supportive services. Some participants may also have "budget authority," which allows them decision-making authority over how their Medicaid funds are spent.



Supported decision-making authority agreements

In a supported decision-making model, individuals with I/DD make and communicate their own decisions in any number of informal arrangements, with support from trusted family and friends. A growing number of advocacy groups, social services organizations and state agencies assist with implementing these arrangements by documenting and formalizing the process with supported decision-making agreements.

As of this writing, there are nine states with supported decision-making authority laws in place. While many individuals will continue to engage in an informal supported decision-making arrangement, others are documenting various provisions in a formal agreement. This document would include the names and roles of all supporters, as well as details about the scope of their assistance, authority and duties. These agreements may also include whether the supporter has access to confidential information pertaining to the decision maker. They also typically outline the terms of revocation or termination of a supporter.

The advantages of having legally recognized supported decision-making agreements include:

- They help ensure the individual's decision-making autonomy, which might otherwise be limited or removed
- They provide structure and accountability
- They specify the duties and authority of supporters, as well as prohibit them from making decisions on behalf of the individual
- They can indemnify third parties such as financial and health care institutions from any liability for relying on a supported decision-making agreement, as well as require them to honor that agreement



States have several options under the Medicaid State Plan and Medicaid waivers for providing enrollees with the opportunity to self-direct their Medicaid services:⁶

- Home and Community-Based Services State Plan Option – 1915(i)
- Community First Choice State Plan Option – 1915(k)
- Self-Directed Personal Assistance Services State Plan Option – 1915(j)
- Home and Community-Based Services Waivers – 1915(b)/(c)
- Experimental, pilot or demonstration waiver of the Social Security Act – Section 1115

According to a 2016 scan of self-directed programs by OPEN MINDS⁷:

- Forty-six states had at least one 1915(c) waiver that allows self-direction.
- Nine states used 1115 demonstration waivers.
- Four states had a 1915(i) State Plan Option, at least six states had a 1915(j) State Plan Option and five states had a 1915(k) State Plan Option.
- Two states (Alaska and Nevada) had only a state plan amendment that allows individuals to self-direct personal care services.

Why self-direction works

In the real-world application of self-directed programs, individuals feel empowered to have control of their lives and make their own decisions, such as where to live and who to be friends with.⁸ Many individuals are able to live more independently and with greater satisfaction when self-directed supports are available.



From the individual’s point of view, self-direction translates into selecting the supports needed to meet their goals.

For example, in an interview for Optum's Spark Initiative, a woman who lives in Las Vegas, Nevada, and utilizes self-directed services through a Medicaid waiver, explained that the model has allowed her to maintain her quality of life because she's able to choose her personal care assistants. The decision-making authority ensures she's able to hire and manage the assistants whom she prefers to provide for her most delicate service needs.

And the benefits have a spillover effect on the loved ones of those with I/DD. Researchers examining a Cash and Counseling program in three states found statistically significant, positive effects on unmet needs, satisfaction with care, and quality of life for adults with I/DD. Additionally, family caregivers of program participants likewise experienced much higher quality of life and lower levels of physical, emotional and financial stress than control group caregivers.⁹

Beyond satisfaction, the value of the self-directed approach can also be captured with budgetary savings. Researchers reported in the 2005 book, "Outcomes of Self-Determination in Michigan: Quality and Costs," a median reduction of 8% in service costs associated with 70 participants in a self-determination demonstration project. The savings increased to 14% when expenditures were adjusted for inflation over a three-year period, with the median public cost per participant declining from \$67,322 to \$56,778 in inflation-adjusted dollars. The small study also found that participants reported they had more and better choices, less professional domination and a higher overall quality of life.¹⁰

Barriers to self-direction

Unfortunately, there are barriers unique to individuals that continue to forestall greater adoption of self-direction within service systems. What's more, barriers can be more or less significant based on an individual's needs, the state in which he or she lives, and the natural supports available. Common barriers include, but are not limited to, the list below.

Attitudes and assumptions: The American Association on Intellectual and Developmental Disabilities states that individuals are "entitled to the freedom, authority and supports to exercise control over their lives."¹¹ However, those unfamiliar with the abilities and opportunities for individuals with I/DD might incorrectly assume these individuals are unable or unwilling to self-direct services.

In addition, there is a need to overcome the assumption that people who do not communicate verbally can not communicate in another way (and therefore are unable to self-direct).⁸ Assistive communication devices, including those operated with smartphones or tablets, provide a means for many individuals with I/DD to communicate by typing, pointing or touching a screen with a stylus. The advancements of the digital era indicate that future devices will make assisted communication even more effective, enabling more individuals to convey their thoughts and preferences in the context of self-direction.

Dignity of risk: Everyone has the right to take risks when engaging in life experiences and the right to fail in those activities. As an individual with I/DD becomes an adult, those risks may involve employment and living independently. However, some family members and caregivers believe they should protect the individual from the consequences of failed endeavors. In doing so, however, they may severely limit the person's ability to make choices, to risk failure and to grow. For many, the absence of the dignity of risk and opportunities to make choices has impeded individuals with I/DD from exercising their right of self-determination and has inhibited their ability to live the lives of their own choosing.



Individuals with I/DD and their families, friends and caregivers would benefit from understanding the principles and advantages of self-direction.

Low adoption: Data demonstrates that adoption of the self-directed model is increasing, although its use is still quite low. Without deliberate design, programs too often default to models that do not support self-direction.

When looking at National Core Indicators (NCI) data showing percentages of individuals who are using self-directed service options, only 4% were doing so in 2008/2009, growing to a modest 10% in 2015/2016, the most recent data available.¹²

Yet, among those participating, use of decision-making authority is quite high. In 2015/2016, 70% of those self-directing participated in decisions about how their budget is used and 77% hired and managed staff to provide services.¹³

Funding difficulties: Various funding streams that support individuals with I/DD are usually not integrated. Programs often include tight spending caps or waiting lists, reducing access to helpful services. In fact, in an interview for the Optum Spark Initiative, the mother of an individual in Atlanta, Georgia, recalled that her son waited 10 years to obtain a Medicaid waiver allowing him to self-direct services.

Federal regulations: The federal approval process for waivers and waiver amendments can be excessively long, and the actions of states tend to occur in a context of uncertainty and inconsistent support. Service definitions can also be limiting, further hampering state efforts to gain federal support of self-directed programs.



State regulations: Unless state policies are established to embed self-direction in managed long-term services and support (MLTSS) programs with I/DD, their opportunities to self-direct their supports could be significantly curtailed. A legacy of outdated regulations too often forces agencies to be in a position of power and control versus shifting control to the person choosing services.

Models that deter adoption: Several states continue to pay higher rates to congregate service models, such as intermediate care facilities and group homes, than to individualized services, such as self-directed supports, supported living and shared living. This deters agencies from transitioning to self-directed services because many do not believe that they are able to fund the same level of supports in an individualized, community setting.

Additionally, cumbersome processes and complex layers of administration often make the execution of self-directed models difficult for agencies. This complexity often trickles down to the individual and caregivers who want to access self-directed supports but aren't successful in navigating an onerous system.



There is a need to educate the public — especially individuals with I/DD, family members, teachers, school administrations, service and health care providers, lawyers and judges — on the principles and effectiveness of supported decision making.



Shortages of direct support workers: Natural supports, such as family and friends, are not always available for participants, so they must rely on direct support professionals. However, such professionals can be in short supply, even when the means for individuals to hire and manage them are in place.

A shortage of nearly 450,000 direct support workers is projected by 2024, and according to the Bureau of Labor Statistics, median annual pay for such workers is just \$24,060 — lower than the national average.^{14,15} With low wages, it's difficult to attract new workers into the field and build a pipeline to meet market demands for the future. Likewise, it's equally challenging for agencies to recruit and retain today's existing workforce.

Limited care coordination: Because services in self-directed models vary widely — as they should due to their individualized nature — coordination can be complex. In many cases, individuals receive an interdisciplinary combination of natural and paid supports that vary in duration. Supports often originate from various sources that have no formal connection in order to foster coordinated efforts.

Lack of research: There is a need for more research on self-direction in practice, as well as on the reasons why individuals choose or do not choose the service model. With Medicaid programs under ongoing budgetary pressure, quantifying outcomes for services provided to individuals with I/DD have never been more important. However, stakeholders often lack empirical evidence and feedback from participants.⁸

Strategies to consider

The opportunity for greater adoption of the self-directed model is clear. Individuals with I/DD and their families, friends and caregivers would benefit from understanding the principles and advantages of self-direction. Meanwhile, policymakers would benefit from understanding how self-direction fits into broader health care and social services strategies.



Examples of paid services

- Support coordinators or brokers
- Service consultants
- Personal consultants
- Personal care assistants
- Job coaches
- Educational counselors
- Transportation services
- Communication services, including access to assistive technology and devices
- Housing services
- Personal financial assistance
- Financial management

The list below describes opportunities for advocates and advocacy groups to discuss and influence the path toward greater adoption.

- Advocate for changes in federal and state policies, regulations and processes that are restrictive when it comes to supports that promote the use of self-direction.
- Advocate for states and the federal government to incentivize self-directed services and supports. Strategies include outcomes-based funding; enhanced rates paid for individualized, self-directed services; funding for agency transition costs; and short-term rate increases for transitions from congregate to individualized services.
- Reduce the risk-averse approach among providers of services and state regulators. Policies should not be counterintuitive to allowing individuals to take risks and self-direct their supports and services.
- Educate policymakers to ensure assumptions are not made about the I/DD population. Aim to reduce the disconnect between policy and implementation by providing narratives from individuals who are impacted by specific policy decisions.
- Increase community awareness and reduce the stigma associated with individuals with I/DD. Aim to open more doors of opportunity and interaction within the community (housing, employment, transportation, etc.) to reduce barriers overall.
- Align community systems, opportunities and attitudes toward accepting and advocating for self-direction as a prevailing framework rather than an exception.
- Encourage coordination and partnerships among stakeholders. A true continuum of care must be developed among a wide range of professionals to foster comprehensive, uninterrupted self-directed services.
- Encourage providers, states and managed care organizations to conduct an in-depth investigation into internal agency factors (structures, values and practices) that may be associated with their capacity to deliver self-directed services and supports. Advocate for having self-direction principles and language clearly included in written materials, policies, handbooks and service plans.
- Encourage revisions to regulations to allow providers to hire the best and most competent staff. Promote funding that allows for more competitive wages, educational opportunities, professional credentialing and career paths to bolster the direct support workforce.
- Advocate for training and support for individuals so they might gain insight on how to be truly in control of their services.
- Advocate for training and support for individuals so they might gain insight on how to manage their own service budget, spending money, education, health and leisure activities.
- Aim to uncover methods to streamline an otherwise slow and complicated delivery system that may discourage self-direction.
- Advocate that states should ease administrative burdens (provide easy-to-use electronic billing platforms, streamline documentation requirements, etc.) and make self-direction specialists available to provider agencies to answer questions, address concerns and offer strategic support.



Individuals with I/DD are “entitled to the freedom, authority, and supports to exercise control over their lives.”¹⁶

- Provide technical assistance and support to agencies that are interested in transitioning to self-directed services.
- Advocate for alignment of managed care organizations to support the shift to self-directed services and supports, giving consideration to rate structures, policies and processes.
- Promote information sharing among states, agencies and managed care organizations. Advocate for hands-on, practical peer learning to help agencies adopt strategies, policies and practices that have demonstrated successful transformation. Promote partnerships with managed care organizations and state agencies to offer more widespread technical assistance, support and insight.



Individuals with I/DD who are empowered to make decisions have greater happiness, satisfaction and confidence.



Conclusion

Because of their pivotal role as change agents, advocates and advocacy groups are uniquely positioned to move systems toward greater adoption of self-directed service-delivery models in the United States. Knowing the benefits of the model, advocates can encourage individuals and their representatives to seek these person-centered programs. They also have a clear opportunity to educate policymakers and work with them to reduce the barriers to adoption. Finally, they can champion research on self-directed service delivery to further refine its value.

Advocate's checklist

- Educate individuals with I/DD and their families, friends and caregivers on the concepts of self-directed service-delivery models.
- Support individuals with I/DD and their families, friends and caregivers in developing leadership and decision-making skills applicable to self-directed services.
- Provide information to communities, health care providers, educators and legal professionals about self-direction and its person-centered approach.
- Provide tools and resources to facilitate an individual's employer authority and budget authority, especially for those who lack natural supports.
- Explore your state's Medicaid provisions for self-directed services.
- Connect with federal and state policymakers to influence broader adoption of the self-directed model and to include self-direction principles and language in regulatory documentation.
- Ask for clear and organized policies and procedures to make the self-direction option more accessible.
- Ask communities and policymakers to allocate additional funding and other measures to expand self-directed service capacity.
- Support greater adoption of assisted technology and communication devices to ensure more individuals with I/DD have an opportunity to make their preferences and decisions known to others.
- Engage in thought leadership that promotes the benefits of the self-direction.
- Recommend further research on the practical application of the self-direction.
- Support measures that encourage the use of less-restrictive alternatives to guardianship for adults with I/DD.
- Gather narratives from individuals who want to tell their success stories in self-direction and share those stories with communities and policymakers.
- Consult with the Optum Spark Initiative network for information on the interface between self-directed service delivery and managed care. Visit <https://www.optum.com/resources/library/spark/contact.html> to request a callback.

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To find out more about the ways Optum and Spark Initiative members are helping individuals with I/DD lead a self-directed life, visit <https://www.optum.com/resources/library/spark/contact.html>.



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