Promoting self-direction in state and local I/DD programs

Presented by Optum and the Spark Initiative

The Spark Initiative, developed by Optum, *brings together experts from government, nonprofit and private sectors to spark new thinking on major health and human service issues. This report focuses on individuals with intellectual and/or developmental disabilities (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.*

Optum® Integrated Solutions for Individuals with Intellectual and/or Developmental Disabilities (I/DD) provides person-centered services that focus on community inclusion, self-determination, life satisfaction and improved health outcomes. Through support and assistance, Optum helps individuals achieve their life goals and fulfill their aspirations. This approach promotes and supports self-determination, offering individuals the ability to design, implement and self-direct their own individual support plans (ISPs). Along the way, Optum also strengthens vital programs and systems that serve individuals with I/DD.

Developmental disabilities are severe chronic disabilities that can be cognitive or physical, or both, and will last indefinitely. Intellectual disability and other disabilities such as autism or fetal alcohol syndrome are apparent during childhood. Today, many individuals with I/DD live, work and play in the community, with self-determination and self-directed supports needed to live full lives.

The Centers for Disease Control and Prevention (CDC) estimate that in the U.S., about one in six (roughly 15%) children ages 3–17 has one or more developmental disabilities. Across the nation, at least 4.7 million individuals have an intellectual or other developmental disability. Of the 4.7 million with I/DD, only 1.4 million (30%) were known to or served by state I/DD agencies. Of that 1.4 million: 57% live in the home of a family member, 11% live in their own home, 5% in a host home, 25% in a group setting, and 2% live in a psychiatric facility.[1] In 2009, an estimated 1.8 million children ages 6–21 with I/DD received special education services.[2]

Key definitions

An **intellectual disability** is characterized by significant limitations in intellectual functioning and adaptive behavior (conceptual, social and practical skills used in everyday life) and is first apparent before adulthood.

Developmental disabilities are a group of conditions, first apparent in childhood, that are lifelong and may impact day-to-day functioning in the physical, behavioral, communicative or learning arenas. Well known types of developmental disabilities include intellectual disability, autism spectrum disorder, cerebral palsy, and Down syndrome.

Self-determination is the idea that people should set their own goals and be involved in decision making about all aspects of their lives.

Self-direction is the idea that individuals with I/DD (and those who support them) decide on the types and levels of supports that will work best for their needs.

Self-advocacy is the ability to speak up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want, and are able to tell people about your thoughts and feelings.

Self-direction is now a well-established strategy in service delivery. This element of I/DD services has grown from small pilot programs in a handful of states to at least one program in every state. For individuals with I/DD, self-direction presents unique opportunities to engage in self-determined behavior to shape and control the services upon which they rely. As the cost of home and community-based services (HCBS) continues to rise and more individuals seek services, Optum has joined states and providers to develop solutions to address their increasing challenges to enhance the delivery of services while maximizing their resources.

States have several options under the Medicaid State Plan and Medicaid waivers for providing enrollees with the option to self-direct Medicaid services. These include:

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

Self-direction in systems of care and services for individuals with I/DD

According to the Centers for Medicare and Medicaid Services (CMS), self-directed Medicaid services mean participants, or their representatives (if applicable), have decision-making authority over most, if not all services, and take direct responsibility to manage them with the assistance of a system of available supports (e.g., financial management agencies and support brokers). Self-directed services are an alternative to traditionally managed services, such as those delivered by an agency.

Today, many individuals with I/DD live, work and play in their community, with self-determination and supports needed to live full lives.

CMS notes that each Medicaid funding authority has different guidelines. However, all authorities share some common characteristics, including:

- **Person-centered planning:** CMS requires that a person-centered planning process and assessment be used to develop an individual support plan. The process is directed by the individual, with assistance as needed or desired from a representative of the individual's choosing. It is intended to identify the strengths, capacities, preferences, needs and desired measurable outcomes of the individual.
- **Individual support plan:** An individual support plan is the written document that specifies the services and supports (including natural supports and non-paid services) that are to be furnished to meet the preferences, choices, abilities and needs of the individual, and that assist the individual to direct those services and supports and remain in the community.

The Spark Initiative

Optum has launched a thought leadership forum, the "Spark Initiative," which brings together leaders in government, nonprofit and private sectors, as well as self-advocates, to discuss solutions to better support individuals with I/DD. The goal of this initiative is to define and drive a national effort to better serve individuals with disabilities, mainly through changes in the service delivery system.

One key focus of the Spark Initiative focuses on defining a "Shared Framework" that explores what self-determination should look like for individuals with disabilities. This includes addressing key issues of informed decision-making, and how individuals can access information about their options in order to make their best decisions.

Drawing on the expertise of those participating in Spark, Optum champions the goals of supporting a comprehensive and consistent definition of "self-determination" and how systems can be improved to better serve and support individuals with disabilities.

- **Individualized budget:** An individualized budget is a spending plan that is unique to the individual's needs, developed within a self-directed framework, and aligned with their individual support plan.
- **Information and assistance in support of self-direction:** States are required to provide or arrange for the provision of a system of supports that are responsive to an individual's needs and desires for assistance in developing the individual support plan and budget plan, managing the individual's services and workers and performing the responsibilities of an employer.

The prevalence of individuals participating in self-directed services is currently low, and presents an opportunity for expanding state programs. In 2013, there were approximately 838,503 individuals participating in self-directed services. This represents approximately 1.2% of the more than 68 million individuals enrolled in Medicaid and 8.2% of the more than 10 million individuals who qualified on the basis of disability.

Of the individuals who self-direct services, there were 808,847 individuals who used Medicaid waiver- and state-plan-funded services, while 77,816 used managed long-term services and support (MLTSS) programs, with some overlap between the two numbers.[3]

According to the National Core Indicators (NCI) data, the percentage of individuals using self-directed service options was only 4% in 2008/2009, as compared to 10% in 2014/2015.

Of the individuals using self-directed service options in 2013/2014 by residence, 8% resided in their own apartment, compared to 17% in their parent's home.[4]

Of the **4.7 million** individuals with I/DD, only **1.4 million (30%)** were known to or served by state I/DD agencies.

The goal of self-direction

The central goal of self-direction is to maximize an individual's opportunities to live independently in the most integrated community-based setting of his or her choice. Self-directed strategies shift control over resources and staffing to the individual, allowing each person to determine the role that service providers will play in his or her life. From the individual's point of view, it means determining your goals, having control over resources and supports necessary to do so, and assuming responsibility for your decisions and actions.

Central to the definition of self-direction are three core tenets:

- High-integrity person-centered planning
- Individual served has authority over budget
- Ability of individuals to employ providers

Of the 1.4 million:

57%	live in the home of a family member
11%	live in their own home
5%	live in a host home
25%	live in a group setting
2%	live in a psychiatric facility[6]

Guiding principles of self-direction

The guiding principles[5] of self-direction include:

- **Dignity and respect.** All people have the right to be treated with dignity and to be respected as a person.
- **Freedom.** Freedom to decide how one wants to live his or her life.
- **Authority.** The individual has authority over a targeted amount of dollars.
- **Responsibility.** The person is responsible for the careful use of state funding.

- **Choice and control.** Self-determination means that people have the power to make decisions and truly control their lives, including self-directing their services and selecting (and firing) service providers.
- **Relationships.** Relationships are the sense of connectedness, and people are free to choose their circle of family members and friends who would provide support.
- **Dreaming/Vision.** All people have hopes, dreams and visions of the future that guide the actions that are most meaningful to them. It is important that people listen to and respect those dreams and help make them come true.
- **Contribution and community.** Community membership helps establish a sense of belonging and identity. This includes having a job, a place to live, friends, to be truly involved in our community and to make a difference in the lives of others.

Supported decision-making and self-direction

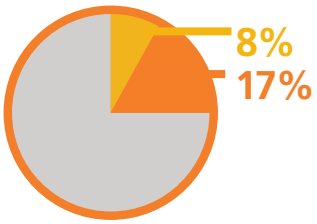
The underlying premise of supported decision-making is that individuals should make important decisions about their lives with the support of others, rather than having such choices made for them. The roles of supporters are to explain issues, explore options, and support the expression of preferences. For individuals with more severe intellectual disability this support may extend to interpreting signs and preferences, ascribing agency to a person's actions, or co-constructing preferences with the individual based on understood wants and needs. Supported decision-making, understood in this way should have a legal framework that recognizes decision-making as a shared process and gives formal standing to supporters.

Benefits of self-direction

A range of benefits have been noted when individuals participate in self-directed services. For individuals and families, these include:

- Improves satisfaction with support services, quality of life, and reduces costs compared to provider-directed services, as well as decreases institutional stays.[7]
- Empowers individuals participating in public programs and their families by expanding their degree of choice and control over their long-term services and supports.
- Provides attractive alternatives to individuals who find the traditional services system inflexible, as well as those who have been unable to receive all the services they need.
- Offers strategies and solutions to overcome shortages of traditional providers by unlocking a wider labor pool, such as neighbors, friends and family.
- Elements of the person-centered philosophy can also be applied to both agency-directed and self-directed models to accommodate the individual's goals, strengths and preferences.
- Enables quality-management strategies that empower individuals and/or their representatives to be the primary judges of the quality of the services they direct.[8]

Residence and self-direction 2013/2014



Of those using self-directed services, 8% lived in their own apartment, compared to 17% who lived in their parent's home.[9]

Cost-effectiveness of self-direction

The fundamental aim of most self-direction programs is not to save money, but to give individuals with disabilities greater control over the services and supports they receive and when, by whom, and how they are delivered. In virtually all instances, however, the increase in personal control is accompanied by requirements that total service costs are not to exceed the costs that a community provider would incur in delivering the same array of services and supports.

In some instances, the upper limit on self-directed support plans is set at 100% of the cost of provider-directed services and supports. In other programs, a discount factor is applied to self-directed support plan allocations (e.g., 90% of provider costs) to be held as a "risk pool" of funds that can be used by the state agency or provider to meet unanticipated cost increases over the course of the year. As a result of such policies and the variability among self-directed programs across and within states, it can be difficult to draw valid comparisons between the costs of self-directed versus provider-directed services.[10]

In Michigan, one study reported a median reduction of 8% in the cost of serving 70 individuals with I/DD in a self-directed demonstration program. Comparisons of expenditures on behalf of these individuals were made before they entered self-directed programs and again three years following their enrollment in the program. The study did not analyze control or comparison group data, and therefore the authors warn against generalizing from the findings of this small, single-state study.[11]

The same study found that program savings increased to 14% when expenditures were adjusted for inflation over the three-year period, with the median public cost per participant declining from $67,322 to $56,778 in inflation-adjusted dollars. The study also found that participants reported they had more and better choices, less professional domination and a higher overall quality of life.

Another study evaluated the cost impact of the Cash and Counseling demonstration program, a joint venture between the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services, which was implemented in 15 states to expand self-directed services for Medicaid beneficiaries with chronic disabilities. When personal care cost data of participants in the Cash and Counseling demonstration program were compared with those of a control group receiving provider-directed personal care services, researchers reported that:

- Participants incurred higher costs, primarily because program enrollees received more of the types of care they were authorized to receive than the control group members.
- The increased personal care costs were partially offset by lower institutional and other long-term care outlays on behalf of Cash and Counseling participants.
- The evaluation team concluded that, if a state carefully designs and monitors its Cash and Counseling program, self-directed services should not cost any more than traditional, provider-directed services.[12]
- The Arkansas Cash and Counseling program saved $5.6 million after nine years of operation, not including the additional savings associated with reduced nursing home utilization.[13]

Michigan program study:

Median reduction of **8%** in the cost of serving 70 participants in a self-directed demonstration program for individuals with I/DD.[14]

Examining the experiences of states operating self-directed support systems for individuals with I/DD, one study found that cost savings expectations are usually built in to a state's funding assumptions. Typically, a state either pays a set fraction (e.g., 90%) of the total amount allowed for traditional provider-directed services, or establishes a lower allowance for self-directed administrative/overhead costs than for provider-directed administrative/overhead costs.[15]

Additionally, some states have created self-directed support programs with tight spending caps that are aimed at stabilizing families and preventing emergency out-of-home placements of individuals on a waiting list for full-time residential supports. By dampening demand for emergency residential placements, this comparatively low-cost option allows a state to extend services to additional, wait-listed individuals, thus reducing the gap between supply and demand. One I/DD program administrator estimated that his state was saving more than $1 million a year by offering low-cost self-directed support options to families caring for loved ones with an I/DD in their homes.[16]

According to the **National Core Indicators (NCI) data**, the percentage of people using self-directed service options was only **4%** in 2008/2009, as compared to **10%** in 2014/2015.[21]

Barriers to self-direction

There are a number of barriers to fully implementing self-direction in service delivery. Results of the 2018 I/DD Provider Survey on Self-Directed Supports and Services, developed by the National Leadership Consortium on Developmental Disabilities of the University of Delaware, and sponsored by Optum's Spark! Initiative, found that the top three barriers to providing self-directed services and supports are:

- State policies, regulations, funding and service definitions
- Federal policies, regulations, funding and service definitions
- Family attitudes, knowledge and involvement

Another way to conceptualize these challenges is to break them down into the areas of: providers and service systems; individuals and families; legal, policy and regulations; and financing and risk. Some of these examples include:

Provider and service system challenges:

- Administrative concerns. Concerns about the volume and complexity of paperwork, levels of responsibility and difficulties in recruiting good-quality support workers.
- Practitioner reluctance to promote self-directed services. Professionals fear that self-directed budgets could potentially place vulnerable people at risk of abuse or exploitation.
- Traditional service provider concerns. Direct support agencies feel threatened about losing clients to self-directed options and fear a loss of business from independent workers or family members.[17]
- Intra-organizational issues. Implementation of a new service delivery model is a difficult process, and confusion or difficulties in administration can lead to delays, resistance to self-directed options, or deviations from state policy.[18] States have identified a lack of clear policies, leadership and training opportunities as important factors in confusion about, or opposition to, self-direction.[19]
- Existing service programs. Although knowledge gained in previous programs is valuable, the existing service programs may also act as a barrier to program implementation. State HCBS programs often present a fragmented approach with multiple programs and disparities in access, funding and services.[20]

- Shortage of direct support workers. While participants are able to hire family, friends or neighbors to provide personal support work, that mechanism relies on natural supports that are not always present.
- Unionization of workers. Direct support workers are unionized in some states (e.g., California, Michigan, Oregon and Washington). Generally, unionization has led to higher wages and improved benefits (including health insurance coverage for workers in some states), as well as better retention rates and an enhanced sense of professionalism among direct care workers. Some workers (including family members of participants), however, object to joining a union because of all the obligations such membership entails (e.g., payment of union dues, mandatory training and criminal background checks).

Individual and family challenges:

- Individuals with I/DD are not adequately informed, supported or empowered to self-direct.
- Conflicts may arise over who within the individual's life actually directs supports (i.e., the person him/herself, family members, staff, others).
- Locus of power is not always clear. The reality is that individuals who need support and the people that support them struggle with the "self" in self-direction. This leads to tension between and within the individual, family, paid staff and providers. Individuals may not be trained to speak for themselves.

Legal, policy and regulatory challenges:

- Legal constraints. There are unique legal issues within each state that affect the implementation of self-direction. Throughout the history of self-direction, there have been legal concerns about who is considered the employer of record and how withholding, workers' compensation and labor laws would impact service.[22]
- Federal rules and regulations. Despite the structure and flexibility offered by Medicaid, many program administrators report that federal rules and regulations are seen as barriers to implementation and expansion of self-direction.[23]
- Public policy constraints. It is the responsibility of policymakers to direct the public treasury to achieve policy goals, and so there are limits or restrictions on the type and amount of services individuals may choose.
- Training and credentialing requirements. The central premise of self-direction — that participants set the required qualifications of personal support workers and use the resulting criteria to screen and select job candidates — may be abridged by state or local training and credentialing requirements for direct support workers, which may limit the number and types of job candidates available to individuals wishing to self-direct their services.

Financing and risk challenges:

- Funding difficulties. Coordination and integration of supports may be more difficult when multiple funding streams are used to pay for services.
- Systemic limits imposed on individuals. As is the case with all state HCBS waivers around the country, systemwide limits are common and can be imposed on individuals, regardless of who directs their services.

In 2013, there were approximately **838,503** individuals participating in self-directed services. This represents approximately **1.2%** of the more than **68 million** individuals enrolled in Medicaid, and **8.2%** of the more than **10 million** individuals who qualified on the basis of disability.[24]

- Systems are risk-averse. There is a relationship between the perceived risk and the amount of "license" service systems are willing to give to individuals.
- Risk management. In self-directed services, risk management is a critical ingredient in striking a balance between individual safety and personal choice and control.
- Managed care. Unless a state establishes policies that allow self-direction to flourish within a managed care environment, the opportunities of individuals with disabilities to self-direct their own supports could be significantly curtailed once they are enrolled in any managed services or support programs. Therefore, it is important to ensure managed care organizations understand the value, benefits and importance of self-direction.

Best practices in self-direction

The Human Services Research Institute (HSRI) identified six state I/DD agencies that had significant experience with developing self-direction options and conducted interviews with key experts from these states. Each interviewee expressed a belief that self-direction is an important option, and each state has specific plans to continue to grow their self-directed options. Some of the lessons that can be drawn from the experiences in these states include:[25]

- Programs must be clear and simple with a modest number of self-direction options.
- Clear and organized policies and procedures make the self-direction option more accessible.
- States with self-direction specialists who became proficient in helping individuals utilize self-direction options and then operationalized their plans were more successful.
- Individuals with support from peer mentors and family members have better outcomes with self-direction options.
- Special supports are needed for participants who do not have a large, involved network of family and friends.

Of the **838,503** individuals who self-directed their services, the majority, **808,847**, used Medicaid waiver- and state-plan-funded services, while **77,816** used managed long-term services and support (MLTSS) programs (with some beneficiaries using both services).[26]

Strategies to promote self-directed services in provider practices

States and provider systems have unique opportunities to promote and implement self-directed services within the resources available for individuals with I/DD. Results of the 2018 I/DD Provider Survey on Self-Directed Supports and Services, developed by the National Leadership Consortium on Developmental Disabilities of the University of Delaware, and sponsored by Optum's Spark! Initiative, recommended strategies associated with provider capacity for the development of self-directed services. These include:

- Including clear self-direction principles and language in provider policies and handbooks, and written individual support plans and goals
- Providing tools and support to individuals with I/DD about how to manage their own service dollars and spending money
- Providing tools and support to individuals with I/DD about how to choose their leisure activities
- Providing staff formal training about how to facilitate self-directed services
- Providing staff tools and support about how to assist individuals with I/DD to manage their own service dollars and spending money, and how to assist individuals with I/DD to be truly in control of their services

Conclusion

It is time for all key partners — individuals with I/DD and their families, state agencies, and service providers — to join in a concerted effort to scale up self-directed options. By replacing barriers with best-practice approaches, states and service providers can expand self-direction and achieve the outcomes for and expectations of individuals with I/DD.

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

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