

Promoting self-direction in I/DD service delivery



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 service providers can consider regarding implementing self-directed plans for the individuals that they serve.

Developmental disabilities are severe chronic conditions that can be cognitive or physical or both and last indefinitely. Intellectual disability and other disabilities such as autism or fetal alcohol syndrome are first diagnosed 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 age 3–17 years 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 age 6–21 with I/DD received special education services.²

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.

Optum Integrated Solutions for Individuals with I/DD partners with providers and systems of care. Their purpose is to facilitate person-centered services that focus on community inclusion, self-determination, life satisfaction and improved health outcomes. Through provider collaborations and personal supports, 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.

Partnering with providers, Optum recognizes that self-direction is now an established best-practice-based approach in service delivery. This element of I/DD services has grown from small pilot programs in a handful of states to current programs in every state. Additionally, these evidence-based practices support self-direction. These services present unique opportunities for individuals to engage in self-determined behavior and shape and control the care and services upon which they rely. As the cost of home and community-based services (HCBS) continues to rise and more individuals seek services, states and providers have turned to Optum to provide thought leadership and solutions. Optum works to enhance the delivery of services while maximizing their resources. This is achieved in part through effective partnerships and collaborations with I/DD providers and systems of care.

Key concepts for providers and service delivery systems

Defining 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. For providers and service delivery systems, the key concepts in self-direction are the development of person-centered partnerships that promote an individual's role in their care plan design, the selection of services and their utilization. Self-directed strategies shift control over resources and staffing to the individual, allowing each person to determine the role that the provider will play in his or her life. From the individual's point of view, it means determining personal goals, having control over available resources and supports necessary to achieve these goals and assuming responsibility for these decisions and actions.

The three core tenets of self-direction include:

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

Guiding principles of self-direction

The guiding principles³ 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** — The freedom to decide how one wants to live his or her life.
- **Authority** — You have authority over a targeted amount of dollars.
- **Responsibility** — Being responsible for the careful use of state funding.

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.

- **Choice and control** — Self-determination means that people have the power to make decisions and truly control their lives. This includes controlling their budget for supports services and the authority to hire the people who will provide those chosen supports.
- **Relationships** — It is important that each person have a circle of friends and family chosen by him or herself to provide strength and assistance.
- **Dreaming** — All people have hopes and dreams which 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 us establish a sense of belonging and identity. This includes having a job, a place to live, and friends, to be truly involved in our community and to make a difference in the lives of others.

Supported decision making in self-direction

The underlying premise of supported decision making is that everyone has the right to self-determination and the right to exercise legal capacity to self-direct their choices for supports and services provided in the context of trusting relationships. The roles of providers, service systems and 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 by a representative or guardian. Supported decision making, understood in this way, is a legal framework that recognizes decision making as a process and gives formal standing to supporters.

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

Self-directed services are an alternative to traditionally managed services. According to the Centers for Medicare and Medicaid Services (CMS), self-directed Medicaid services means 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 and providers.

CMS common characteristics of self-directed services:

- **Person-centered planning:** CMS requires that a person-centered planning process and assessment be used to develop a person-centered service plan. The process is directed by the individual, with assistance as needed or desired from a representative of the individual's choosing including providers and other supports. It is intended to identify the strengths, capacities, preferences, needs and desired measurable outcomes of the individual.
- **Service plan:** A service 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. The goal of the service plan is to assist the individual to direct those services and supports so that he or she may remain in the community.



An estimated **1.8 million** children age 6–21 with I/DD received special education services in 2009.⁴

- **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 service plan.
- **Information and assistance in support of self-direction:** States are required to provide or arrange a system of supports to assist individuals with developing the person-centered service plan and budget plan, managing the individual's services and workers, and performing the responsibilities of an employer. These supports should be responsive to the individual's specific needs and desires.

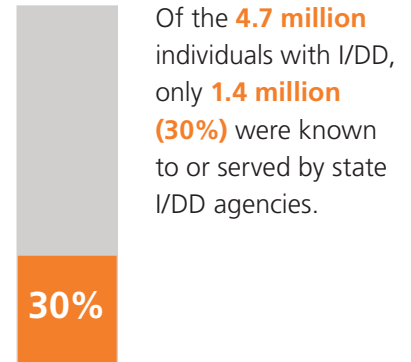
Self-direction best practice examples

The Human Services Research Institute (HSRI) identified six state 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 self-direction. Some of the lessons for providers and service systems that can be drawn from the experiences in these states include:⁵

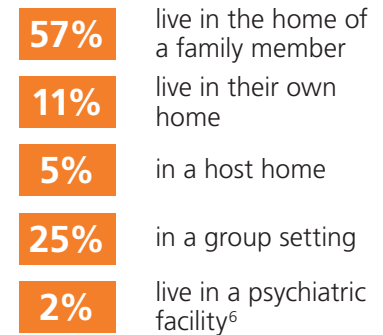
- Programs must be clear and simple with a modest number of self-direction options;
- Clear and organized policies and procedures make the self-direction option more accessible;
- States with self-direction specialists who became proficient in helping individuals decide on self-direction and then operationalize their plans were more successful;
- Support from peer mentors and experienced family members is an important ingredient;
- Special supports are needed for participants who do not have a large involved network of family and friends.

Conclusion

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



Of the 1.4 million:



Sources:

1. 2014 RISP Report — Institute on Community Integration, University of Minnesota.
2. Lakin KC, Larson SA, Salmi P, Webster A. (2010). Residential services for persons with developmental disabilities. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
3. A Guide to Self Direction, published in May 2016 by the Massachusetts Department of Developmental Disabilities.
4. Lakin KC, Larson SA, Salmi P, Webster A. (2010). Residential services for persons with developmental disabilities. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
5. HSRI. hsri.org/project/evaluation-of-self-directed-supports.
6. 2014 RISP Report — Institute on Community Integration, University of Minnesota.



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