

Chapter 1

Self-direction

What It Is and How It Works

The emergence of self-directed supports as a mode of service delivery in human services constitutes a major if somewhat overlooked national shift. Simply put, self-direction is changing the way services are planned, managed, and delivered. Specifically, it is changing the way that individuals who need long-term care in the public sector—usually Medicaid recipients with disabilities or who are elderly—interact with public-service systems by encouraging them to exercise choice among providers and, in turn, to exercise more control in the marketplace. Unlike system participants served by traditional providers, individuals who self-direct can use their individual budget to secure services from a wider market to meet their needs. This approach goes against the typical ways in which public authority managers, program administrators, and case managers have functioned. Typically, public authorities have circumscribed choices and offered limited service menus. In self-direction, professional roles are changed, and the balance of power is altered in favor of the participant. The outcomes of self-direction that have been documented so far are very positive. This change, which until recently has flown under the radar, will potentially revolutionize assumptions about public sector services and is likely to have a permanent impact across the country.

Self-direction is the newest and fastest-growing platform for the delivery of community based services and supports to individuals needing long-term care in the public sector. It creates a direct connection between the public entity and the individual rather than channeling resources to providers who

in turn offer services. In other words, self-direction eliminates the middleman and places the purchasing of resources at the disposal of the individual. With self-direction, public funders enter into agreements directly with participants through an individual budget. The participant then develops a plan with their supporters and within the guidelines and approval of the funding agency. Purchasing decisions and resource management are now the responsibility of the person receiving services. Public agencies allocate resources, approve service plans, and oversee the management and quality of self-directed services. Participants decide who to hire as well as what to purchase and from whom. In some self-directed programs, individuals can select services and supports provided not only from health care or social service agencies but also from local businesses and community agencies of their choosing.

Self-direction creates two options for people directing their own services: *employment authority* and *budget authority*. With employment authority, participants are allowed to recruit, hire, manage, promote, and dismiss their personal support workers. They are recognized to have full employer responsibilities and authority. When participants have budget authority, they can purchase a wide range of services and supports from traditional providers and nontraditional providers; these may include improvements and equipment for residential services that enable them to remain in their homes. In both models, all payroll and purchases must be made within an allocated budget based on an individual service plan.

Figure 1.1 also shows the management supports required by the participant: financial management, support broker, and authorized representative. The financial manager is usually an agency that holds the funds and makes the purchases, runs the payroll, and deducts and pays the taxes and benefits as required. The support broker, often a case manager, helps the participant develop the plan and understand the spending, hiring, and firing decisions. Some participants require personal assistance in making final decisions. The authorized representative is chosen by the participant to speak or act on his/her behalf without pay. This creates an entirely new structure and process for the management of Medicaid and other public funding sources for services and supports.

This approach started informally about 70 years ago in California, first for people with polio and then for people with disabilities living on college campuses. It became a state program service model in California, Massachusetts, and Wisconsin in the 1980s. In the 1990s, the Robert Wood Johnson Foundation gave the self-direction movement significant momentum. First, the foundation was one of the sponsors of the Cash and Counseling pilot

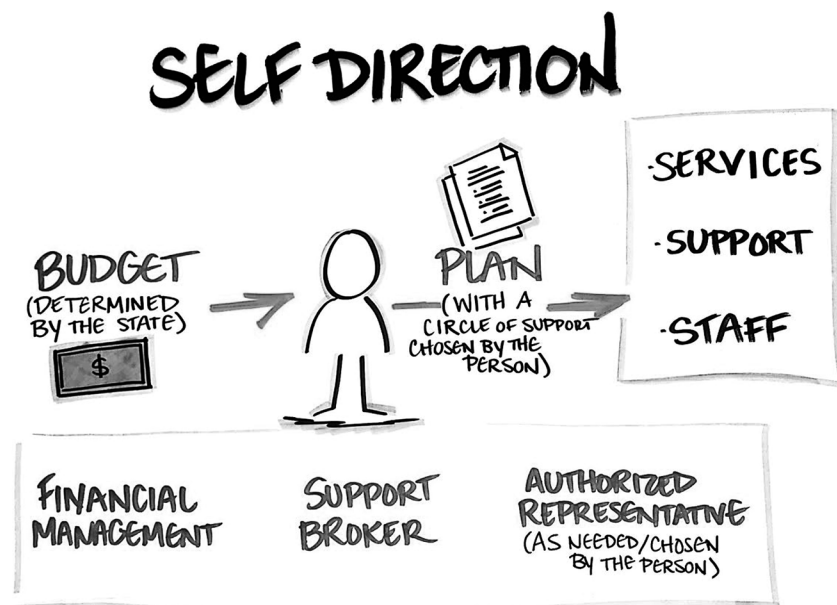


Figure 1.1. Elements of Self-Direction. Illustration by InkyBrittany commissioned by the authors.

program, which was a randomized control experiment that explored a new way of serving individuals with physical, developmental, and intellectual disabilities and problems of aging in Florida, Arkansas, and New Jersey. After several successful and well documented years, the program was expanded to 12 more states. The Robert Wood Johnson Foundation then funded 19 state self-direction pilot programs focused on individuals with intellectual and developmental disabilities.

Since 2003, self-direction has been a service option for all states under federal home and community based services (HCBS) Medicaid waivers¹ that serve the elderly, people with intellectual and developmental disabilities, people with physical disabilities, autistic individuals, individuals with serious mental illness, individuals living with HIV/AIDS, and individuals with acquired brain injury. Over the past decade and a half, the number of individuals using waiver funds to self-direct their services has grown consistently across the country. Today more than one million people, living in every state and the District of Columbia, have chosen to purchase and direct their own services.

The rapid expansion of self-direction is in part due to the rapid growth in the nation's older population and their desire to stay in their homes as they age. The Veterans Health Administration—working with the aging and disability networks—created the Veteran-Directed Home and Community Based Services program (VD-HCBS); and self-direction has recently expanded to persons with mental illness. (Both groups are detailed in chapter 9.) We expect that self-direction will expand to an even broader range of groups as the outcomes of self-direction—in terms of both individual outcomes and the cost efficiency of service systems—become more widely understood and as states develop the infrastructure to manage self-direction on a larger scale.

Most individuals who require long-term public supports are now given a choice: “You can have your community based services and supports provided by local agencies, or you can receive a budget that will allow you to schedule your services, hire people to come into your home to provide them, and, in many cases, purchase certain goods and services from individuals, agencies, and businesses in your community.” Initially, many participants were wary of taking on this responsibility, and many state human service agencies did not have the infrastructure to support self-direction; however, the program is now growing and expanding. It is reaching a broad range of participants with diverse support needs and has spawned a new industry focused entirely on supporting individuals who are making their own choices and managing their services.

Satisfaction with self-direction, as indicated by the review of research in chapter 6, is high among participants and family members, and they uniformly said they would recommend self-direction to a friend who needed services. Respondents went on to say that they valued the choice and control that self-direction gives them. Further, total costs are managed within the projections established by the Medicaid waivers and the rate structures of Medicaid state plan services as reviewed in chapter 7. Rather than creating budgets without limits or budgets that are continually renegotiated, self-direction creates a discipline. The spending budget is agreed upon by the individual and managed throughout the process. Most states set aside a small amount of savings that can be used for unplanned emergencies or changes. This enables state agencies to accurately project costs and manage changes in the program.

Another reason self-direction has become so popular is that it meets the needs and values of different stakeholder groups: public agency managers, elected officials, clinicians, consumers, families, and advocates. It can meet conservative goals by using the marketplace to manage costs and expand

choice. It can meet progressive service goals for individual consumers who seek more independence and inclusion in their communities. There is no other program model that so effectively straddles these different goals.

For self-direction to work well and continue to grow, several new policies and processes have been required; these are described later in this book. States have implemented new technology and business approaches to track expenditures, meet reporting requirements, and manage payrolls. Further, to support individuals who cannot communicate their needs during the planning process, states have created a role called an “authorized representative” to provide participants with assistance to direct their services and communicate their desires. The authorized representative is usually a family member or close friend who agrees to play this role without compensation.

To determine the allocation of resources to an individual, the service plan must be monetized to determine what it costs and how it can fit within the budget of the public agency that is managing the services. The monetized plan or individual budget is sometimes simple, covering just a few services, and sometimes complex, involving a large number of services and supports. Budgets range from several hundred dollars a month to more than \$10,000 per month depending on the goals and needs of the participants. People who self-direct their services may need just intermittent support to remain in their home or they may need round-the-clock care every day; both work well in self-direction. The different approaches and processes for setting individual budgets are discussed in chapter 5.

The individuality and complexity of these budgets are unprecedented in public administration. Literally every budget could be different in terms of the kind and quantity of services and supports that are delivered. This creates an enormous database on services provided, their costs, and their providers. It also required several new public management service inventions: the financial management services agency (FMSA) and support brokers.

Financial management service agencies, usually hired by state Medicaid or service agencies, support participants in a number of ways: (a) they help participants manage their budgets; (b) they support the employee recruiting, hiring, and payroll processes; (c) they ensure compliance with state labor laws; (d) they file federal, state, and local taxes and pay fringe benefits; (e) they assist the participant to purchase goods and services; (f) they provide “live” reports to participants on their budgets and expenditures; (g) they identify expenses that are not authorized by the individual’s budget; (h) they provide customer service and assistance to participants and workers; and (i) they provide a Medicaid billing process for the state agencies. The Internal

Revenue Service qualifies most FMSAs as “fiscal employer agents,” which means they serve as the hiring agent on behalf of participants, accountable for all employer responsibilities while participants make decisions on the hiring, supervision, and termination of their workers. FMSAs have developed in every state. Some are small local agencies focused on a particular community; others are national organizations able to enroll and support tens of thousands of participants per program.

The other new entity created for self-direction is usually called a support brokerage. Support brokers work directly with participants and their families to (a) help them to develop a person-centered service plan and individualized budget; (b) provide assistance in hiring, managing, and terminating personal support workers; (c) provide assistance in making purchases of services and supports; (d) help participants coordinate and back up their services, particularly for people who require services and supports daily; and (e) perform other employer-related and budget management tasks requested by participants that enable them to meet their goals and changing needs. These services are provided in-person, on the phone, and sometimes online. Some states have created a separate Medicaid reimbursable service—referred to as support brokerage, individual counseling, or personal guide—to perform these functions and act as a liaison between the individual and the program. Support brokers can be local individuals usually qualified by the state agency, specially trained state workers, or private agencies hired to provide this service to all participants in the waiver.

Participation rates, satisfaction, and outcomes continue to improve every year. Costs are managed within state budgets. And yet self-directed services remain poorly understood by eligible individuals, helping professionals, and the general public. We hope this book will change that for individuals eligible for long-term care, for professionals providing services, for public officials creating legislation and public programs, for administrators managing services, and for taxpayers paying for services.

We will follow the social history of the self-direction movement as well as the judicial and legislative history at the federal and state levels. We will examine the current research on the impact on participants and direct care workers as well as studies on the costs and outcomes of self-direction. As a national case study, we will look at the implementation and growth of programs for similar participants in different states and try to understand why the utilization rates vary widely and how utilization can be increased. We will look at how service plans are developed and how their costs are determined, or “monetized.” Since this is an international movement, we will

look briefly at the Netherlands, Germany, England, and Australia—countries that have made a national commitment to self-direction.

At the end of many of the chapters, we will use interviews with participants and family members to illustrate the lessons that have been learned and the changes that have been experienced across the country. We believe these interviews will clearly explain how self-direction works, why participants in self-direction embrace the freedom to make choices about their supports, and how it can be improved. In the final chapter, we will summarize what we have learned from policy leaders and evaluators across the country on the future of self-direction and how it can be expanded and improved.

We hope to inform current and future policy makers about what self-direction has accomplished and how it could be used for current and new populations. We believe we are at the beginning of a new chapter in the delivery of human services for people with disabilities and those who are aging. This is a population that is very large and becoming larger, that is more outspoken about their needs, and that is aware of what works and what doesn't work for them. And we are at a time when the demand and cost of long-term care is becoming part of a national conversation for a rapidly growing population.