

Developing and Implementing Self-Direction Programs and Policies: A Handbook

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Dedication

During development of this Handbook, Gary Smith—one of its principal authors—died.

Gary was a valued colleague and a wonderful friend; a towering figure in the developmental disabilities field and the preeminent expert on Medicaid policy.

He was a resource to hundreds of people around the country and was always generous with his time—never letting a request for help go unanswered.

Although millions of people with disabilities have never heard his name, his work in public policy has made an ongoing positive difference in their lives. We dedicate this Handbook to his memory.

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Reviewers

The Handbook benefited from the comments of multiple reviewers of earlier drafts, including several staff at the Centers for Medicare & Medicaid who were asked to give particular attention to references to federal laws, regulations, and policy guidance in order to ensure factual accuracy.

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Purpose, Audience, and Organization of This Handbook

Increasingly, states are implementing home and community service delivery models that provide options for individuals and their families to direct and manage their own services and supports. These models are called self-direction and are also referred to as “consumer direction” and “participant direction” when referring to specific programs. This Handbook uses the terms self-direction and participant direction unless referring to programs that use other terms.

Over the last decade the amount of information about self-direction has increased enormously. For states that want to start or expand a self-direction program, finding the exact information they need can be a time-consuming, challenging, and not always successful process.

This Handbook was developed to provide state staff, policymakers, service providers, program participants, and other stakeholders with a single comprehensive source of information about self-direction programs and policies. Its primary purpose is to explain how States can increase program participants’ choice of and control over their services and supports. The Handbook will be a useful tool for all those working to expand self-direction options in programs already providing home and community services and supports, and to develop new self-direction programs.

Chapter One—Self-Direction: An Overview—provides an overview of the key features of self-direction as a service delivery model in the provision of long-term services and supports to public program participants living at home. It describes the two major features of self-direction—employer authority and budget authority—and the key program design choices within these two features that account for state program variations.

Chapter Two—Legal Authority—describes several statutory authorities under which self-direction may be incorporated into the delivery of Medicaid-funded home and community-based services (HCBS). While the authorities differ, they share common features, including empowering Medicaid program participants and their representatives to hire their workers, to direct how and when services are provided, and to exercise authority over an individual budget. The chapter also examines options for self-direction in other federal and state long-term services programs.

Chapter Three—Involving Participants in Program Design, Implementation, and Evaluation—describes several approaches for involving program participants in two areas: program design, implementation, and evaluation; and peer support and mentoring. Program participants are the primary stakeholders and to ensure their buy-in, they need to be involved at every stage of program development—from its initial design to activities for continuously improving services.

Chapter Four—Enrollment—presents enrollment strategies, policies, and procedures and discusses different approaches to designing these elements, including their advantages and disadvantages. The chapter also provides information about how to identify and address issues that may slow enrollment, especially in the early stages of program implementation.

The next three chapters discuss the basic elements of a self-direction program: individual budgets, counseling, and financial management services.

Chapter Five—Individual Budgeting—discusses the essential elements of individual budgets: person-centered planning, budget methodologies, determining needs, and service planning. It also discusses methods for calculating the budget amount; the process for authorizing spending plans; and approaches for monitoring, managing, and modifying individual budgets.

Chapter Six—Counseling—discusses the key components of counseling: providing information and assistance to individuals electing to direct their services—a key supportive service in self-direction programs. It also discusses the differences between counseling and traditional case management and describes various counseling models states use, and how programs can ensure quality counseling services. States use a variety of terms to describe the counseling role, including support broker, service coordinator, flexible case manager, consultant, advisor, and community guide. This Handbook uses the terms *counseling* and *counselors*.

Chapter Seven—Fiscal/Employer Agent Services—describes the key features of five financial management services (FMS) models and focuses on the issues and challenges related to two in particular: the Government and Vendor Fiscal/Employer Agent models. These two FMS models are highlighted because they provide participants with a high degree of choice and control over their services—allowing them to be the common law employer of their workers while providing needed payroll and other fiscal supports.

Chapter Eight—Quality Management in Self-Direction Programs—provides information about quality management elements that are relevant for *all* service delivery models as well as those that are unique to self-direction programs. It also describes the key components and principles of quality management for self-direction programs.

Chapter Nine—Self-Direction and Health Care—discusses ways in which self-direction programs, especially those that provide individual budgets, can facilitate participants' access to health care and maintain and improve their health and functioning. The chapter also discusses how Nurse Practice Acts can hinder or facilitate self-direction, how states can address safety risks when participants have extensive health care needs, and how a few states have incorporated self-direction options into managed care plans.

Chapter Ten—Looking Ahead—discusses emerging issues, including unionization of participant-directed workers and how they might affect self-direction programs as well as new opportunities to offer self-directed services.

Three Appendices discuss specialized topics.

Appendix I discusses the use of strategic communications to ensure the success of a self-direction program.

Appendix II describes an information technology designed to meet certain unique requirements of self-direction programs. This technology—called the Consumer Direction Module (CDM)—is a secure web-based software application specifically designed to support self-direction programs that allow individual budgets.

Appendix III describes the origins, development, and expansion of self-direction programs.

Designed to serve as a reference guide, the Handbook is written in easily understood language, but with sufficient annotation of source material to fulfill its technical support role. The endnotes in each chapter provide not only citations of source material, but also web-links for obtaining the material, when available. The endnotes also provide additional background or technical information about issues discussed in the chapter as well as web-links to other information sources. Each chapter also includes a resource section with relevant publications and web-accessible resources. All publications include links for obtaining them online.

Obtaining the Handbook and Updates

The Handbook was designed as an online document that will be updated to reflect current policy and to provide new resources. The Handbook is available at www.participantdirection.org.

Each Handbook chapter has been designed to be downloaded easily and to fit into a three-hole punch binder. Individuals who download the Handbook will be given the option of being notified of updates. Once available, updates can be downloaded and inserted in the binder, as a substitution or an addition.