

Self-Determination

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Introduction

Origins of self-determination

Self-determination is a name that has been given to a set of policy initiatives that have focused on giving people with disabilities control over individualized, flexible funding for long-term support services. Other terms that have been used to describe this concept include “self-directed services” and “consumer-directed supports”. A basic idea behind the self-determination initiatives is that people’s control over their lives and status as community members could be enhanced by giving them more control over human service funding. This idea grew out of some important observations about the way long-term support has been planned and delivered in the past:

- planning long-term support for people often focuses on the person’s disability and on assuring health and safety, without consciously addressing whether the plan fits the person’s aspirations and preferences or promotes the person’s basic right to control over his/her own life. (In Wisconsin, it is typical for a person with significant support needs to control an annual income of less than \$8,500 per year, while \$30,000 per year or more is being spent on his/her behalf by the service system.);
- people with disabilities who need support services often live in poverty and have little economic power or ability to make an economic contribution to their communities. At the same time, relatively large amounts of money are being spent by government agencies, professionals and human service providers on their behalf;
- money is power. Where service funds are contracted out by the government directly to providers, service plans will usually say that people “need” the services the government has already decided to buy. From the provider’s point of view, the government is the customer, not the person who receives the services; and
- while often meeting essential needs, formal human services tend to interfere with natural connections to a person’s community.

Broader meaning of self-determination

The words “self-determination” existed before the initiatives, and their full meaning is not confined to control of funding for services. In its broadest sense, *self-determination* is the idea that decisions about what people want their lives to be like, and about how they want to try to make their goals into reality, should be made by each person for

him/herself. If the person wants or needs help to decide, the help should come from the people who are closest to the person and know and care about the person the most. In other words, in some circumstances “self-determination” can actually mean “consumer/family/friend shared determination”.

Fundamental rights of community members

Unfortunately, society has often focused on what people with disabilities may be unable to do, or on what kind of help they may need, rather than on their status as full and equal members of the American community. For much of our history, people with disabilities were seen as unworthy of even second-class membership in the larger community. **Self-determination asks us to take seriously, and to keep constantly in mind, the idea that the fundamental principles Americans hold sacred apply to all community members, regardless of disability.** These fundamental rights and ideals include:

- constitutional rights to be free of government interference about our choices concerning: who our friends are, what we say, and to whom we say it, what our religion is, whether to have children, and how we raise our children;
- the ideal that all people are born equally free and independent and have rights to life, liberty and the pursuit of happiness; and
- freedom from interference by other private citizens in our rights to move around freely, to make decisions affecting our lives, and to control our own property, unless there is some clear legal basis for the interference.

Is self-determination “new”?

The principles and ideas behind self-determination are as old as our nation itself. In the human service world, many of the ideas and methods adopted by self-determination have been promoted and applied by the Independent Living movement since the 1960s. The importance of relationships, person-centered planning and personal autonomy and control are all part of the principles that have governed progressive services for people with developmental disabilities during the same period. What is different about self-determination is its emphasis on the rights of people with disabilities as full community members as primary considerations in service planning and implementation, and its emphasis on shifting practical power over human service funding as a means to give people more control over their lives.

Self-Determination Initiatives for People with Developmental Disabilities

Robert Wood Johnson Foundation program

Building on earlier work in Canada and the U.S., a self-determination initiative was developed and evaluated for people with developmental disabilities in the U.S. in the Monadnock service region of New Hampshire with funding from the Robert Wood Johnson Foundation

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(RWJ). From 1997 to 2000, RWJ, working through the National Program Office on Self-Determination for People with Developmental Disabilities at the University of New Hampshire, funded self-determination initiatives for people with developmental disabilities in over 100 local jurisdictions in 25 states. RWJ continues to fund the National Program Office. Information on national and local projects is available on their internet website, and in their newsletter, *Common Sense*.

RWJ program in Wisconsin

Wisconsin was one of the states that received funding under the RWJ program, with primary implementation sites in Dane, La Crosse and Winnebago counties. Marinette, Rock, and Sauk counties have also implemented large-scale self-determination initiatives for people with developmental disabilities. In addition, several other counties have begun developing initiatives, and/or have tried to provide individualized, flexible funding accounts to people in particular cases. These have included Clark, Door, Fond du Lac, Lincoln, Portage and Richland counties.

Consumer directed support waiver service category

One result of the self-determination initiative in Wisconsin was the development of the consumer-directed supports category in the three state home and community-based waiver programs that serve people with developmental disabilities (*See Medicaid Waiver Home & Community-Based Services chapter, pg. 197.*) This service category allows people in participating counties, within general restrictions on waiver funding, to control individualized budgets, to design their own support services and set their own criteria for qualified providers. Counties must apply to participate.

Self-Management of Service Funding in Family Care

HFS 10.44(6), Wis. Admin. Code

All Care Management Organizations (CMO) pilots providing long-term care under the Family Care Program are required to provide Family Care participants with the opportunity to manage their own support services funding within individualized, flexible budgets. (*See Family Care chapter, pg. 203.*) Whether or not consumers choose to manage their own service funding, Family Care rules provide for a high degree of choice and control, both over setting priorities among long-term care outcomes, and over service planning and choice of provider. The self-directed service option should provide a way for the person to be more independent in planning and managing services, and to use providers who are not under contract with the CMO.

Between the years 2000-2002, the initial CMO pilots may operate a phase-in plan under which the CMO develops needed policies and structures and offers the self-directed supports option to an increasing number of participants each year. After January 1, 2003, required policies and structures should be in place and self-management of service funding must be available as a choice for all participants.

Components of Self-Determination Initiatives in Long-Term Support

Self-determination initiatives are efforts to increase people's control over their lives by giving them more control over the money that pays for support services. While each initiative is locally planned, they have common characteristics. Initiatives typically:

- Test policies and practices against a **statement of principles** that puts rights to personal dignity and control at the core.
- Seek to put **choice and control as close to the person as possible**, so that decisions are made by people who know the person best and are committed to learning about and trying to implement the person's goals and preferences. Not all consumers are able or want to have total control over decision-making. For a person who needs support in decision-making, the issue is not whether the person can participate in self-determination, but what kind of support is needed for the person to do so and whether that support is available or can be made available.
- Provide or encourage **support for greater self-advocacy** by individuals and independent organizations of people with disabilities, both in people's individual lives and in systems issues that affect them.
- Use **individualized, flexible, transferable funding accounts** for support service funding. The person knows up front how much money is available to him/her for support services. The amount may be based on historical costs or on a rate-setting process that reflects the costs of people with similar support needs. A review and appeal process is available to assure that budgets reflect actual and changing needs. The person has the power to determine the goals of support services, to select the form of services, to select providers, to move funds to a new provider, and/or to use funds to pay for another way of meeting support needs that may or may not rely on a formal human service provider.
- Recognize that **flexibility has limits**. All systems have nonnegotiables: legal limits on use of public funds, rules for particular funding programs, basic guarantees of health, safety and personal freedom, etc.
- Use **person-centered planning and service coordination** to ensure that service outcomes and the form of services match the person's goals and preferences. The role of the case manager becomes one of helping the person as needed; building relationships with a circle of people who can help with planning;

identifying strategies and formal and informal supports that might help achieve chosen goals; and negotiating arrangements for service payment and delivery. In some cases, this new role is reflected by a new job title: “support broker” or “support coordinator.” Some counties have established systems to provide a full range of support coordination independent of both the county and service providers.

- Provide **practical support with money management**. Consumer control does not necessarily mean responsibility for all aspects of managing funds. Support coordinators assist with budgeting to meet support needs. In most counties, some form of voucher system puts the person in the role of authorizing payments for services provided, emphasizing their role as the primary customer. Fiscal intermediaries make payments authorized by the person, track funds, and, where the person employs individuals directly, handle payroll, taxes and benefits. Co-employment agencies employ and pay individuals who are chosen by the person to work for the person, while also providing access to group rates for benefits such as unemployment and worker’s compensation and health and disability insurance.
- Place an **emphasis on building relationships and use of informal supports**. Attention is paid to taking advantage of naturally occurring supports, providing supports in ways that build rather than interfere with natural connections, and giving people ways to give something back to friends, family and the community.

Potential Risks of Self-Determination Initiatives

Self-determination initiatives may produce unintended risks or side-effects. These are not reasons for failing to give people control of their lives, but it is important that they be considered as initiatives are developed and implemented. Concerns raised have included the possibility that:

- counties will use preset individual budgets as a way to set unrealistically low budgets and to shift the problem of dealing with inadequate human service funding to consumers.

Note: Under both Consumer-Directed Supports and Family Care, consumers have a right to appeal budget amounts on the grounds that they do not reflect what the county would have spent to provide appropriate services under “traditional” service planning approaches;

- people will make choices that present unacceptable health and safety risks, or that result in isolation or increased dependence;

- people or their families and friends will be forced to take on complicated planning, budgeting and management responsibilities that they do not want, and that this will take away energy from paying attention to the person's hopes and dreams, and from the importance of simply being there as a relative or friend;
- the service system will fail to take responsibility for planning to ensure that services are developed to meet changing needs and preferences, and that there is back-up where support arrangements break down; and/or
- transfer of power from the service system to the person and those close to him/her may increase the risk of control or exploitation by others in the person's life who are not committed to his/her well-being.

Substituted Decision-Making and Guardianship

For a person with mental disabilities who may be in need of supported or substituted decision-making, respect for the principles of self-determination requires that planning for decision-making support (including guardianship) assist the person to retain as much choice and control as possible, and that decision-making support be provided in ways that develop the person's skills and knowledge so that s/he can retain or regain the maximum level of self-determination. Examples of approaches to this difficult problem include:

- conscious planning about how to meet the person's needs for support in decision-making, by the person and those who know the person best, in ways that least limit the person's legal and human rights;
- Limited guardianship**
- use of limited guardianship to tailor guardianships to individual needs and retain control for the person over decisions where s/he has decision-making capacity;
 - education of guardians in their obligation to protect and promote the person's exercise of constitutional, legal and human rights. Many guardians do not understand that, because their power comes from the state, they may only interfere with the person's constitutional rights where there is a compelling need, such as preventing a significant risk to health and safety;
 - providing resources for recruitment of committed, competent peer mentors, citizen advocates and guardians, and for training and ongoing support for people who take on these important responsibilities; and/or
 - continued involvement of people in all decisions, to develop decision-making skills and to reduce learned dependence.