



Self-Determination for Persons with Developmental Disabilities

An RWJF National Program

SUMMARY

The *Self-Determination for Persons with Developmental Disabilities Program* was a national program that began in 1996 to help 18 states implement a more cost-effective system for serving persons with developmental disabilities while simultaneously giving those persons and their families more choice in determining the services they receive.

In the mid-1990s, state programs serving individuals with developmental disabilities faced three serious problems, according to the [Institute on Disability at the University of New Hampshire](#), Durham, N.H.:

- Rapidly rising costs for services.
- Insufficient resources to serve everyone who needed help.
- Fixed sets of services that gave individuals and their families little control over what services were provided, when or how.

Key Results

RWJF retained the [Center for Outcome Analysis](#), Havertown, Pa., to evaluate the effect of the program on individuals, and the Human Services Research Institute, Cambridge, Mass., to examine institutional changes in the project states.

- The Center for Outcome Analysis reported a shift in decision-making from professionals to individuals with disabilities, and improvement in some but not all quality-of-life indicators.
- The Human Services Research Institute found that flexibility, a systemwide approach and the availability of direct support workers were critical factors in the success of self-determination initiatives.

See [Project List](#) for reports on projects.

Administration

The national program office at the University of New Hampshire Institute on Disability managed the project selection process and provided technical assistance to the federal and state policy-makers.

A national advisory committee reviewed proposals, participated in site visits, made funding recommendations and monitored the ongoing operation of the program.

Funding

The Robert Wood Johnson Foundation (RWJF) Board of Trustees authorized the program in November 1995 for up to \$5 million.

THE PROBLEM

The federal Administration on Developmental Disabilities estimated that at the time of this program there were nearly 4 million Americans with developmental disabilities—severe, chronic disabilities attributable to mental or physical impairments that occur before age 22 and are likely to continue indefinitely. The vast majority of developmentally disabled people live with their families, who provide financial and other support.

Others, whose families are financially or otherwise unable to support them, may become eligible for benefits under Medicaid, a program jointly funded by federal and state governments, or other state-funded programs.

Although people with developmental disabilities made up less than 1 percent of those eligible for Medicaid, the cost of long-term care was approximately 10 percent of 1994's total Medicaid expenditures, or about \$15 billion. In addition, states spent an estimated \$5 billion on other programs to serve this population.

From Institutions to Group Homes

Recent decades have seen a major evolution in the way states serve this population. In 1967, 190,000 persons with mental retardation lived in large, usually state-sponsored institutions, according to the Institute on Disability at the University of New Hampshire. By 1995, fewer than 65,000 people with developmental disabilities remained in institutions.

Many of the people who left large institutions were placed in group homes and similar facilities, which Medicaid also covers. States also provide a variety of services and supports to people with developmental disabilities who live in the community—including

case management, personal care services, homemaker/home health aide services, adult day care, transportation and home and vehicle modifications.

States can receive federal Medicaid reimbursement for part of the cost of these services by applying for a Home and Community-Based Services Waiver specifying the types of services they wish to offer and the populations that will receive them. The cost of services received under such waivers cannot exceed the cost of institutionalization.

Each state organizes its system for providing such services differently, but a common approach is to delegate administration and case management to local or regional agencies, which may be public or private. These agencies contract with organizations that provide the actual services. (Some agencies also provide some services themselves.)

Services are generally offered in preconfigured bundles, often designed for various levels of disability. When a person with a disability applies for assistance, the agency first determines his or her eligibility for public support, then tries to assign the individual to a residential or community-based support program that offers a bundle of services that meet at least some of the individual's needs.

Major Challenges Facing Developmental Disability Programs

While the shift away from large institutions, and the wider use of Medicaid waivers, has led to greater flexibility in living arrangements and service delivery, three serious problems plagued developmental disability programs in the mid-1990s:

- The rapidly rising cost of both medical care and other funded services was putting a severe strain on state Medicaid budgets, prompting governors and legislatures to look for cost savings. Because recipients with developmental disabilities accounted for a disproportionate share of Medicaid spending, their programs became a natural target of budget-cutters.
- While de-institutionalization and Medicaid waivers allowed states to serve more people, many states did not have the resources to meet the long-term care needs of everyone who sought public help. These states maintained lengthy waiting lists of people eligible for but not yet receiving services.
- Individuals with developmental disabilities (and their families) often had little control over where the disabled persons lived, which services they received and who provided them.

States began to realize—with the help of families and persons with developmental disabilities—that they had established community-based service delivery infrastructures that were costly, ineffective in providing support that helps people be as independent as possible and lacking in accountability to beneficiaries and their families.

A New Approach

In 1993, under its national program *Building Health Systems for People with Chronic Illnesses*, the Robert Wood Johnson Foundation (RWJF) provided a grant (ID# 023006) to Monadnock Developmental Services to test a new approach to the delivery of services to persons with developmental disabilities. The approach gave individuals, along with their families and advocates, greater control over the services they received.

Monadnock, based in Keene, N.H., has a contract with the state to provide services to eligible persons living in southwestern New Hampshire through subcontracts with actual service providers. The three-year project, Self-Determination for Persons with Severe Mental Disabilities, sought to test whether giving more control to those with developmental disabilities could improve their quality of life while reducing the cost of meeting their needs.

Under the grant, Monadnock changed the way it provided assistance to a group of 45 developmentally disabled individuals:

- Individuals controlled planning for their own support needs, with the assistance of family and friends they designated (often referred to as a circle of support).
- Individuals each controlled a sum of public money that they had the authority to spend on residential, vocational and personal needs.
- Individuals could contract directly for any and all services through individual contracts.
- Individuals could purchase supports from whomever they chose, rather than being limited to providers with whom Monadnock had contracted.

Independent evaluators at Conroy Outcome Analysts reported an improved quality of life for the participants, and a cost savings of 12 to 15 percent, even for the most severely disabled participants (ID# PC379).

Monadnock expanded the program to cover all of the approximately 500 people it served. It was also able to pare down its waiting list for services, because some individuals were able to find the help they needed from generic services within the community rather than waiting for a program slot to open up.

To build on these results, in 1995 RWJF awarded a four-year \$744,965 grant (ID# 027576) to the State of New Hampshire to replicate the principles and structure of the Monadnock self-determination project statewide. This grant was made outside of the *Building Health Systems* national program.

CONTEXT

Based in part on the achievements of the Monadnock project, in October 1995, RWJF's Board of Trustees authorized funding of up to \$5 million to *Self-Determination for Persons with Developmental Disabilities*, to help states implement a more cost-effective system for serving persons with developmental disabilities while simultaneously giving those persons and their families more choice in determining the services they receive.

The program sought to build on the principles of the Monadnock self-determination project by providing grants for similar self-determination efforts to state agencies that oversee the delivery of services to people with developmental disabilities. The \$5 million was for grants to implement the program; the grants to manage the program were outside of the authorization.

PROGRAM DESIGN

While the *Self-Determination Program* would be implemented differently in the various states, both because of varied understandings of the concept and because the structure of each state's developmental disabilities system was unique, four elements present in the Monadnock demonstration were central to this national program:

- **Person-centered planning.** Under the traditional system, many states required caseworkers to develop an individual service plan for each person, but the individual often had little say in the process; the caseworker controlled the choice of services, which were limited to those services offered by contracted providers. Under the projects in the *Self-Determination Program*, each individual:
 - Defined his or her needs.
 - Learned about the services, providers, and options available.
 - Received assistance in planning the services and supports that answer those needs. The individual could designate family and friends (a so-called "circle of support") to help in decision-making.
- **Independent support brokerage.** Rather than rely on case workers—employed by the state, local agencies or service providers—to assess the needs of persons with developmental disabilities, self-determination projects used independent professionals (brokers) who helped individuals and their families identify their needs and find services and providers who can meet those needs.
- **Individual budgets.** State self-determination projects allocated a pool of money that the individual could use to pay for the services and supports he or she chose. This freed the individual from having to rely on the services for which, and providers with which, the agency has contracted.

The size of the individual budget is usually based either on what the individual has needed in the past or on what people with similar disabilities or needs generally receive. Some portion of each individual budget goes into a risk pool (state-created, nonprofit associations that are temporary stopping points for individuals who are denied health insurance for medical reasons; they often help individuals fill a gap in insurance coverage), which is available to cover unanticipated expenses such as emergency medical care. Only a few projects in the *Self-Determination Program* developed risk pools.

- **Fiscal intermediaries.** State self-determination projects need a more flexible mechanism for paying for individualized services. An individual or family could designate a fiscal intermediary to act as business agent, purchasing services and managing wages, taxes, fringe benefits, accounting and compliance with labor and tax regulations. (Fiscal intermediaries usually received payment out of the individual budget, but some states paid for them out of administrative budgets.)

The *Self-Determination Program* established two main objectives for participating states:

- **State policy reform,** to include:
 - Changing quality assurance and financial monitoring requirements to be consistent with self-determination principles.
 - Enlisting legislative and executive branch support.
 - Redirecting the use of non-Medicaid funding to further program goals.
 - Helping to identify necessary federal policy changes.
- **Implementation of pilot programs** in at least two geographic areas in the state that would give developmentally disabled persons greater control over the services they receive.

THE PROGRAM

National Program Office

The national program office for the *Self-Determination Program*, located at the [Institute on Disability at the University of New Hampshire](#), Durham, N.H., operated from April 1996 through July 2001. Donald Shumway, who had directed the New Hampshire Division of Mental Health and Developmental Services and Thomas Nerney, who had directed the Monadnock Self-Determination Project, co-directed the national program office from its inception through 1998.

Charles Moseley, Ed.D., replaced Shumway in January 1999. Nerney left the program in August 2000.

The national program office's primary responsibilities were to:

- Plan and implement a process for selecting state agencies to receive project grants.
- Assist states in changing the policies and processes of service delivery systems to ones that support consumer direction.
- Provide technical assistance to grantees while planning and implementing their pilot projects, and to non-grantee state and federal agencies through national meetings and upon request.
- Provide technical assistance to federal, state and local policy-makers, including assistance in understanding how self-determination can work with Medicaid waivers.
- Support program communications by:
 - Preparing and distributing technical assistance materials.
 - Developing a website and newsletters to link all project sites, the national program office, the program's national advisory committee members, all interested academic sites, government agencies and individuals.
 - Developing and distributing video materials.
 - Conducting annual and regional meetings.
- Define research and evaluation agendas on providing self-directed services.

National Advisory Committee

The national advisory committee, chaired by C. Everett Koop, MD, former Surgeon General of the United States, assisted in proposal review, participated in site visits during the review process, recommended grants to RWJF staff and assisted in monitoring the ongoing operation of the program (see [Appendix 1](#) for a list of members).

Following selection of the state grantees, the committee developed criteria for awarding additional funding in small technical assistance grants, evaluated the proposals and recommended awards. Over the course of the program, the committee offered advice on such topics as strategy, technical assistance and communications; attended annual program meetings; and monitored the ongoing operation of the program.

Site Selection and Awards

Two levels of award were originally planned for the *Self-Determination Program*:

- Development grants of up to \$500,000 for a three-year period to 10 states to support the transition to a system that gave greater control to individuals with developmental disabilities.

- One-year planning grants of up to \$70,000 to two states to initiate public dialogue on, and to plan the reshaping process involved in, moving to such a system.

The national program office issued a call for proposals in June 1996, and 38 states and the District of Columbia sent responses, which staff evaluated according to the following criteria:

- The likelihood that projects would be used to jump-start statewide changes.
- The size of the population targeted in community initiatives and the potential for applying the principles of self-determination.
- Demonstrated support of key partners, including legislative and executive agencies, individuals with developmental disabilities and their families.
- The extent to which states would redirect existing service dollars to allow for greater individual control over services.
- The degree to which the state's plan would support decision making by individuals and families and increase their engagement in community life.

National program office staff and national advisory committee members made site visits to 18 states. In order to broaden the reach of the program, RWJF accepted the national advisory committee's recommendation that some funding be extended to all of the states that received site visits. Therefore, grants were awarded at three levels (projects underlined in blue are described in this report; click on the title to be linked to the project report):

- **Full Award:** Nine states received \$400,000 over a three-year period to support both state reform efforts and implementation of pilot programs:
 - [State of Hawaii Department of Health](#)
 - State of Kansas Department of Social and Rehabilitation Services
 - [State of Maryland Department of Health and Mental Hygiene](#)
 - State of Michigan Department of Community Health
 - State of Minnesota Department of Human Services
 - State of Ohio Department of Mental Retardation and Developmental Disabilities
 - State of Texas, Texas Department of Mental Health and Mental Retardation
 - State of Vermont Agency of Human Services
 - State of Wisconsin Department of Health and Family Services

- **Pilot Award:** Five states received \$200,000 over a two-year period to move their plans for change forward and support the first steps of reform:
 - Arizona Department of Economic Security
 - [State of Connecticut Department of Mental Retardation](#)
 - State of Iowa Department of Human Services
 - Oregon Technical Assistance Corporation
 - State of Utah Department of Human Services
- **Planning Award:** Four states received \$100,000 over a two-year period to build public engagement, develop detailed plans, train staff in self-determination or engage discrete populations in model self-determination efforts:
 - State of Florida Department of Children and Family Services
 - Commonwealth of Massachusetts Department of Mental Retardation
 - [Commonwealth of Pennsylvania Department of Public Welfare](#)
 - State of Washington Department of Social and Health Services

In addition to these 18 sites, the national program office treated the existing New Hampshire Project for Long-Term Supportive Services for Developmentally Disabled Residents of New Hampshire (see the [Program Results Report](#) on ID# 027576) as a project site, providing assistance, inviting its staff to annual meetings and including it in the program evaluations (see [Evaluation](#)).

To further expand the reach of the *Self-Determination Program*, in 1997 the national program office offered small technical assistance grants to states that had not received a larger grant but were moving toward adopting self-determination principles.

State developmental disabilities agencies could apply for the one-year grants of up to \$15,000 or designate another entity (such as the state's developmental disabilities council or an advocacy group) to apply. The process allowed only one application from a state, and agencies that provided direct services to people with disabilities were not eligible. Activities funded by the grants could include:

- Establishing statewide planning processes involving stakeholders in reforming systems.
- Organizing multi-state meetings to explore implementation issues in self-determination.
- Developing leadership by individuals and families to contribute to state policy.

- Retraining and restructuring traditional case-management agencies to become independent service brokerage agencies.

Ten states or their designees (listed in [Appendix 2](#)) received grants.

Technical Assistance and Direction

The national program office provided technical assistance on a variety of topics, including:

- Self-determination principles.
- Medicaid waivers.
- Individual budgeting.
- Fiscal intermediaries.
- Risk pools (state-created, nonprofit associations that are temporary stopping points for individuals who are denied health insurance for medical reasons; they often help individuals fill a gap in insurance coverage).
- Organizing advocacy operations.
- Engaging multicultural groups in self-determination.
- Promoting reforms leading to self-determination.

The methods the national program office employed to deliver technical assistance and direction included:

- Site visits to all of the grantee states.
- Presentations on request to federal and state officials.
- Participation in federal workgroups on self-determination issues.
- Training for policy-makers, professional organizations and advocacy groups.
- National and regional meetings attended by state grantees, program participants and their families, self-advocate organizations and others interested in self-determination.
- Articles, newsletters, videos and a program website. (See [Communications](#) and the [National Program Office Bibliography](#) for a more complete description of these activities.)

Special Program Elements

In addition to providing direct support to state agencies adopting self-determination, RWJF sought to enhance the ability of individuals with developmental disabilities and their families to promote self-determination through advocacy organizations.

The 10 Self-Determination Technical Assistance mini-grants (see [Site Selection and Awards](#), above) provided assistance to a variety of such groups (see [Appendix 2](#) for list of sites that received these awards). RWJF also awarded two grants separate from the *Self-Determination Program* with the same goal.

In March 1997, RWJF awarded a \$74,393 grant (ID# 030917) to Self-Advocates Becoming Empowered, a Nashville, Tenn., organization whose mission is to promote greater self-determination for its members, who have developmental disabilities. The organization used the funds to foster collaboration among its regional representatives, allowing them to share lessons learned in promoting self-determination and using self-determination as a principle to reform state policy.

The two-year project produced a set of training materials (a Self-Advocacy Toolkit and a video), a [website](#), and a toll-free phone number providing updates on efforts to reform state policies. Group members developed leadership skills that helped them to work with policy-makers in *Self-Determination Program* states.

In November 1999, RWJF awarded \$206,597 to the national program office (ID# 036492) to support efforts by national and state organizations to expand awareness of self-determination and promote leadership among people with disabilities, parents, families and professional groups. The national program office provided \$200,000 in grants to organizations that accomplished the following:

- The National Association of State Directors of Developmental Disabilities Services (\$20,000) produced two papers, one describing the implications of adopting self-determination on mainstream service provision, the other highlighting key issues facing states as they adopt self-determination principles. Dissemination of the papers is unknown.
- The Self-Advocacy Association of New York (\$25,000) made presentations around the state, established regional and statewide task forces, sponsored three regional and one statewide conference, produced a newsletter and established a clearinghouse of information related to self-determination.
- People First of Tennessee (\$25,000) held two regional meetings to provide training and education on self-determination to individuals with disabilities, their families and professionals. It also participated in state-level and multi-state planning sessions.
- The National Parent Network on Disabilities (\$130,000) established a Parent Collaborative, which disseminates information on self-determination to more than 200,000 parents and parent organizations, and held a National Parent Leadership Forum in Washington in October 2000. It also provided funding to five national parent advocacy organizations (ARC of the United States, Brain Injury Association, National Down Syndrome Society, Autism National Committee and National Down Syndrome Congress) to support their own efforts to promote self-determination.

Communications

A primary function of the national program office was to provide information on the philosophy and practice of self-determination. Its communication efforts aimed both to promote the principles of self-determination among public agencies and stakeholders and to provide practical advice and assistance to organizations working to implement those principles.

The national program office used multiple channels of communication to disseminate technical assistance materials and program news, including reports, articles, a newsletter, audio and videotapes, conferences, hundreds of presentations and the Internet. Ryerson Communications, a firm based in Hilliard, Ohio, served as the primary communications consultant.

With the help of Ryerson, the national program office produced nine issues of a national newsletter, *Common Sense*, which was mailed to 11,000 subscribers and distributed at meetings. The original *Self-Determination Program* website, which is no longer maintained, featured newsletters and other publications, links to other projects and organizations interested in self-determination, a members-only section, project directors' updates for each program site and access to an international listserv on self-determination efforts.

All of the communications (listserv, state-by-state info and newsletter) have been moved to the [website](#) of the Center for Self-Determination in Ann Arbor, Mich. (see [Afterward](#)).

The evaluators disseminated their findings through published articles, reports and presentations. [Bibliographies](#) of materials generated by the national program office and the evaluators appear at the end of this report.

EVALUATION

In 1998, RWJF commissioned an evaluation of the *Self-Determination Program* to:

- Assess whether self-determination improved the quality of life for participants.
- Assess whether program goals were met in a cost-effective fashion.
- Document the resulting changes in service delivery at the state and local levels, as well as the constraints and obstacles facing implementing agencies.

RWJF retained two firms to conduct the evaluation: the [Center for Outcome Analysis](#), Havertown, Pa. and the Human Services Research Institute in Cambridge, Mass.

Evaluators from the Center for Outcome Analysis, which had conducted the evaluation of the precursor project run by Monadnock Developmental Services in New Hampshire under ID# PC379 (see [A New Approach](#)), focused on how the program affected

individuals, including changes in their quality of life and the cost of providing services to them.

Human Services Research Institute evaluators examined institutional changes in the state, local and private agencies that manage programs for and provide services to people with developmental disabilities. An advisory committee of people with developmental disabilities and researchers in the field reviewed the evaluation design and process (see [Appendix 3](#)).

Under the initial evaluation design, the evaluators were to measure individual and organizational change, respectively, in all 18 of the program states, as well as New Hampshire, which was running its separate project concurrently (see [Program Results Report](#) on ID# 027576).

Human Services Research Institute evaluators planned to create a comprehensive database to examine the program as a whole, to analyze and compare the state self-determination initiatives and to interpret individual outcomes and cost data within the context of each self-determination initiative.

The evaluators encountered several difficulties in carrying out their intended evaluations. The state projects got underway at different times, and some spent considerable time in planning before actually implementing changes.

Many states enrolled clients in self-determination projects much more slowly than had been anticipated. The two-year length of most projects limited the impact that could be expected. States also differed in their approaches and aims, making comparisons across states difficult.

To cope with these challenges, evaluators at both organizations scaled back their research to examine the program's impact in only a subset of the states, and delayed some data collection in order to capture effects after the initiatives were well underway.

The evaluators also largely abandoned the effort to analyze the change in the cost of providing services to people with developmental disabilities before and after the introduction of the self-determination projects, because most states did not track such costs on an individual basis. Rather than evaluate the program's impact on organizations, evaluators focused on analyzing program implementation.

Changes in Individuals' Quality of Life

Center for Outcome Analysis evaluators collected data on changes in the quality of life of individuals who participated in the self-determination projects in two ways:

- They conducted two rounds of in-person interviews with program participants, both early in the program and then one to three years later. When participants could not

complete questions on their own, they or an ally could choose a surrogate who knew them very well to help complete the survey.

Interviewers collected two rounds of responses from 360 participants in five program states: Hawaii, Maryland, Michigan, Ohio and Wisconsin. (The final report to RWJF also included data from a sixth state, California, which was not part of the *Self-Determination Program*.)

The interview included questions about both the level of control participants had over decisions affecting them and various aspects of their quality of life, including their independence, productivity, integration with the community and satisfaction.

- Evaluators conducted a mail survey of family members of participants in state self-determination initiatives. There were 248 responses (out of 760 questionnaires sent, for a 33 percent response rate) from people in 13 states, including four states not in the program.

Limitations of the Center for Outcome Analysis' Evaluation

Because evaluators interviewed only a limited number of participants and did not select them randomly, their findings may not reflect outcomes for all individuals served by self-determination initiatives.

The number of participants interviewed varied greatly from state to state, ranging from 15 in Maryland to 135 in Michigan. In addition, there was no uniformity in the administration of the in-person interviews.

In order to enhance cooperation, evaluators granted substantial leeway to those in each state who were administering the surveys. These included both people hired by the evaluator and personnel working in the self-determination projects. Interviewers did not conduct the second round of interviews at a uniform time. The time period between the first and second interviews ranged from one to three years.

Human Services Research Institute's Implementation Analysis

This analysis included three components:

- A policy analysis of the initiative's impact on programs and agencies serving individuals with developmental disabilities.
- A financial management analysis of how states designed and implemented new procurement methods in accordance with federal Medicaid requirements.
- A study of the role that individuals with developmental disabilities and organizations representing them played in reform efforts.

Evaluators conducted each of these assessments in a subset of the states. For a list of the states studied, see [Appendix 4](#). For its analyses, site visits, interviews and meetings with program principals and reviews of written records provided data. For its examination of the role of self-advocates in reform efforts, it also convened a two-day meeting in the fall of 2000 to:

- Discuss the role self-advocates have played in their state's self-determination effort.
- Make recommendations for promoting increased participation in those efforts by individuals with developmental disabilities.

Two individuals with developmental disabilities and one support person attended from each of the seven states that were the focus of the self-advocacy component of the evaluation.

OVERALL PROGRAM RESULTS

Findings from Center for Outcome Analysis' Evaluation

Based on its two rounds of in-person interviews, the Center for Outcome Analysis reported the following findings to RWJF:

1. **Respondents in all five states (Hawaii, Maryland, Michigan, Ohio and Wisconsin) reported a shift in decision-making away from professional workers and toward individuals with developmental disabilities and family members and friends helping them.** Questions covered such major and minor life decisions as where to live, with whom to live, what to eat, whether to have a pet, what to do with personal funds and who to hire to provide needed services.
2. **Perceived changes in quality of life showed consistent improvement in all six states.** Questions in this part of the survey called for each respondent to rate the quality of his or her health, relationships, safety, activities, comfort and other aspects of their lives before and after participating in the self-determination initiative. Surrogates provided the majority of the responses to these questions.
3. **Other quality-of-life indicators showed inconsistent results from state to state.** These indicators included changes in the respondent's productive behavior, reported progress toward the respondent's goals, respondent access to transportation and the number of outings. While researchers found some statistically significant positive and negative results in these areas in one or more states, results in other states were not significant.

Findings from Human Services Research Institute's Evaluation

- **Critical factors for or barriers to success:**
 - **Flexibility is key to the ability of funding systems to accommodate individual budgets and to expand the pool of contracted providers.** Where systematic approaches to budget development (e.g., based on costs, and/or individual characteristics) were already in place, the task of making these individual resource allocations was facilitated.
 - **The self-determination effort in certain program states succeeded because the leaders there embedded the approach throughout the system rather treating self-determination as a "project."**
 - **Across the country, the ability to lead a self-determined life was significantly influenced by the availability of people to work as direct support staff.**
- **Self-determination's impact:**
 - **The juxtaposition of the self-determination demonstration projects with the emerging aspirations of people with developmental disabilities combined to spur the growth of organized self-advocacy.**
 - **The combination of person-centered planning and self-determination has sharpened the practice of person-centered planning in many states because it added person-centered "doing" to person-centered "thinking."**
- **Future policy considerations:**
 - **Administrative aspects of budget and employee management systems can be extremely complex and may inadvertently give more power to families and brokers (independent professionals who help individuals and their families identify their needs and find services and providers who can meet those needs) rather than to individuals.** Many states/sites were able to find workable solutions to these challenges.
 - **Supporting an individual in a person-centered process is a highly labor-intensive process, according to brokers interviewed.** Given the turnover in case managers nationwide, attention must be paid to finding ways to separate administrative from other brokerage functions in order to ensure that adequate attention can be paid to both.
- **Human Services Research Institute's recommendations included:**
 - **Design self-determination structures and implementation strategies to "fit" within the context and culture of where services are being delivered.** There is no one way to "do" self-determination. There are many different models and individual components that work, depending on the local service system.

- **Self-determination can be implemented gradually, but it should be the long-term vision for the "way of doing business" in the system, not just another program option.**
- **Expand leadership opportunities for self-advocates:**
 - Ensure self-advocate representation at all meetings where decisions about self-determination are being made.
 - Support statewide self-advocacy councils that can make recommendations on an ongoing basis.
 - Hold meetings in accessible places.
 - Support meaningful self-advocate participation by providing training and technical assistance.
 - Provide transportation support so that self-advocates can attend meetings.
- **Continue to study the effects of self-determination on direct support workers.** Conduct training on the principles of self-determination and promote "person-centered doing" as well as person-centered planning. Look at job design, salary, benefits and retention issues and how they differ when services are delivered within a framework of self-determination.
- **Continue to develop fair and accurate methods of establishing individual spending amounts.**
- **Bring management information systems up to speed by developing individual cost tracking and service utilization capabilities.**
- **Continue to examine how self-determination is being defined.** If the power is shifting, is it moving toward self-advocates or to another player in the mix?
- **Continue to study how risk will be managed and distributed among different players, and develop new solutions and strategies to handle the shifting risks.**

LESSONS LEARNED

1. **System change is messy; conflict is not necessarily the sign of an initiative falling apart.** Despite well-constructed implementation plans and well-orchestrated activities, the process of change is not linear; it happens simultaneously on many fronts, and it involves many more individuals and diverse interests than can be predicted. (National program director)
2. **Opportunity comes when least expected and program management needs to retain the conceptual and operational flexibility to seize it.** Each state structured the delivery of services differently. Having a flexible, individual budget may be business as usual for people in one state, while in another it is a rare privilege.

To adapt to this variability, the national program office, rather than insisting on a particular strategy or method, took a supportive approach to helping the project states find solutions to their problems. (National program director)

- 3. Collaboration with Independent Living Centers, federally funded centers across the United States that provide information and other resources to people with disabilities, can bring useful experience to the policy table, support self-determination in the community and offer persons with developmental disabilities a connection in the community.**

In Arizona, collaboration between the state developmental disabilities system and local Independent Living Centers led to:

- Shared knowledge between the organizations.
- The Independent Living Center's involvement in advisory councils.
- The education of both the organization and persons with physical disabilities living in the community about issues pertinent to persons with developmental disabilities.

Personal friendships between consumers with developmental disabilities and their mentors with physical disabilities. (Project Director/Arizona)

At the same time, one of the national program directors felt these collaborations offered no real advantages. (Program Director/Nerney)

- 4. People with developmental disabilities may need encouragement and practice in self-advocacy because they may not have had the freedom to act on their own behalf in the past.** Many consumers with developmental disabilities for years have had to trust the system to determine what they needed.

They may not have the experience or the ability to say what they want. Mental retardation/developmental disabilities systems, directly or through self-advocacy organizations, need to help these consumers realize that they have a voice and that it can be heard. (Evaluator)

- 5. Case managers may need additional training and adjusted roles so that they do not become barriers to self-determination.** Some case managers refer consumers to the same set of providers for years, and develop working relationships with them. Referral nonetheless must use the individual's plan as the guiding principle.

Case managers may also need training to adapt to their new financial responsibility in relation to individual budgets. Traditionally, only finance personnel looked at how money was used. (Project Directors/Hawaii, Michigan)

- 6. Providers fear the risks that system change creates for them, and need education and training to adapt to the changed business environment created by consumer-directed care.** They fear that self-determination will result in "a situation

like [vouchers in] the schools, where [consumers] get their money and exit the system," according to one project director.

Providers and local agencies with authority over health care delivery need to understand that consumer choice will require their flexibility, inventiveness and regard for customer satisfaction, as is required in most other successful businesses. (Project Director/Michigan)

7. **Systems don't change from within; change needs an outside force to act as catalyst.** Self-determination will need to be pushed along from outside the system or it may stall due to inertia. Without an ongoing advocate or force for the concept, crises or other more urgent organizational issues such as emergency cases, end-of-year closing, contracting or politics, will push aside the long-term efforts to institutionalize self-determination. (Evaluator)
8. **Availability of transportation affects the degree to which individuals can become independent.** Many projects reported that lack of or inconvenient transportation limited what their consumers were able to do. Some states include no allowance for transportation support; one project evaluation found that transportation strongly influenced consumers' feeling of independence. (Project Directors/Maryland, Kansas, Hawaii; National program director)
9. **Small changes in a person's life may be exceptionally important to their quality of life—it depends on the context.** Typically, human service environments, which are very artificial, exert a tremendous amount of control over a whole range of decisions, from what might seem insignificant (such as when to eat or what to wear) to important decisions (such as where and with whom to live).

More research needs to be done to understand which changes in health care service delivery and which decisions make the most difference in the quality of life of people with developmental disabilities and other groups that depend on long-term health care. (National program director)
10. **Annual conferences provide a great opportunity for networking among staff at the projects.** Staff from the project states networked during annual conferences and regional meetings and cross-pollinated ideas about how to implement self-determination. (Evaluator, Project Director/Pennsylvania)
11. **Communicating with computers aids people with disabilities.** Computers enable communication between advocates and advocacy groups working for people with disabilities, and the Internet offers information about services, like-minded people and new technologies that may be available. Another benefit is that online, people do not have disabilities. (Communication Subcontractor)
12. **Use the general population as a comparison group if you want to understand and highlight the needs of a sub-population.** One way to define program goals is to start with a model of basic human needs and then compare that to what people in a given

program experience. Human rights have costs associated with them and typical human services don't budget for these costs.

Relationships, for example, require financial resources and transportation, yet programs designed for people with developmental disabilities traditionally don't budget for this expense. And while consumer-directed services may represent a huge improvement over the status quo, that freedom means nothing if something like transportation is absent.

Comparing one method of service delivery with another method of delivery to the same sub-population may not reveal where it inhibits individuals' quality of life. Including a comparison group from the general population may illuminate deficiencies in a model. (National Program Director/Nerney, Project Director/Hawaii)

- 13. Availability of transportation affects the degree to which individuals can become independent.** Many projects reported that lack of or inconvenient transportation limited what their consumers were able to do. Some states include no allowance for transportation support.

One project evaluation found that transportation strongly influenced consumers' feeling of independence. (National program office/Nerney, Project Director/Md., Project Director/Ariz., Project Director/Kan.)

- 14. Consumer involvement in changing systems of health care delivery may need to be mandatory for change to take place.** Although the program encouraged state agencies to include people with developmental disabilities and their families in the design and implementation of state projects, most states included only few consumers until evaluators brought attention to their absence.

In retrospect, a program director thought consumer participation would have been more widespread had it been mandatory. (E/Bradley, E/Agosta, National program office/Nerney)

AFTERWARD

While the *Self-Determination Program*, and RWJF's involvement in self-determination for persons with developmental disabilities, ended in July 2001, efforts to increase the control that people with developmental disabilities exercise over the services they receive continued at both state and federal levels, and among interested private organizations.

The Path of the Co-Directors

One of the original national program office co-directors (Nerney), helped to found and is now president of the Center for Self-Determination in Ann Arbor, Mich., a collaborative of individuals and organizations that both supports advocacy by people with

developmental disabilities and provides educational and technical assistance in adapting programs to incorporate the principles of self-determination.

The center developed a communications strategy that includes a quarterly newsletter, a monthly online newsletter, a listserv and a state-by-state update on self-determination through a map on the [website](#).

Nerney has written two papers, "System of the Future," which presents the case for fundamentally restructuring human services for individuals with developmental disabilities, and "Promise of Self-Determination for Persons with Psychiatric Disabilities," which presents an agenda around the implications for self-determination for those with psychiatric disabilities. The University of Illinois at Chicago released this paper on November 14, 2003.

When the *Self-Determination Program* ended, its director (Moseley) took a position at the National Association of State Directors of Developmental Disability Services, in Alexandria, Va. This organization is the equivalent of a trade association for state directors.

His position offers a huge dissemination opportunity because he can use all its existing communications channels to spread information about the program's innovations.

Developments in the Field

Separately, in 2001, a group of people with developmental disabilities, parents and family members founded the National Coalition on Self Determination to serve as an advocacy organization on behalf of self-determination.

The federal Centers for Medicare & Medicaid Services continues to assist states in developing Medicaid waivers that permit the more flexible use of federal funds to support *Self-Determination Programs*.

In October 2003, Florida's Department of Children & Families announced that it will use a \$500,000 grant from the U.S. Department of Health and Human Services (HHS) to launch a pilot program aimed at promoting self-sufficiency and financial independence among people with developmental disabilities served by the department.

The grant is part of the Real Choice Systems Change Grants for Community Living administered by HHS. The program, called Florida Freedom Initiative, is a cooperative effort between the Department of Children & Families, the Florida Developmental Disabilities Council, the Center for Self-Determination, the Southern Movement for Independence, the Agency for Health Care Administration, the Department of Elder Affairs and the Department of Health.

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APPENDIX 1

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(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

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APPENDIX 2

Technical Assistance Awards (mini-grants from the national program office)

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

- Alabama: People First of Alabama (self-advocates)
- Colorado: Developmental Disabilities Services (multi-group committee)
- Georgia: People First of Georgia (self-advocates)

- Idaho: Developmental Disabilities Council (multi-group committee)
- Louisiana: Louisiana State Office for Citizens with Developmental Disabilities
- New Jersey: University Affiliated Program of New Jersey
- New Mexico: Arc of New Mexico (parents)
- New York: State of New York Office of Mental Retardation and Developmental Disabilities
- North Carolina: North Carolina Council on Developmental Disabilities (multi-group committee)
- Tennessee: People First of Tennessee (self-advocates)

APPENDIX 3

Evaluation Advisory Committee

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

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APPENDIX 4

States Examined in HSRI's Evaluation

(Current as of the time of the grant; provided by the grantee organization; not verified by RWJF.)

State	Policy Analysis	Financial Management	Roles of Self-Advocates
Kansas	X	X	
Maryland	X	X	X
Massachusetts	X	X	
Michigan	X	X	X
Minnesota		X	
New Hampshire	X		
Ohio	X		
Oregon		X	X
Utah	X	X	X
Vermont	X	X	X
Wisconsin	X	X	X

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PROJECT LIST

Reports on the projects managed under this National Program are listed below. Click on a project's title to see the complete report, which typically includes a summary, description of the project's objectives, its results or findings, post grant activities and a list of key products.

- [Connecticut *Self-Determination for Persons with Developmental Disabilities* Pilot Takes off With "Support Broker" for Mentally Retarded](#) (Grant ID# 31169, January 2004)
- [Hawaiian *Self-Determination for Persons with Developmental Disabilities* Pilot Project Helps People in Remote Areas](#) (Grant ID# 31171, January 2004)
- [Maryland *Self-Determination for Persons with Developmental Disabilities* Project Extends Outreach, Customizes Services](#) (Grant ID# 31174, January 2004)
- [Pennsylvania *Self-Determination for Persons with Developmental Disabilities* Promotes Flexibility in Living Arrangements and Services](#) (Grant ID# 31180, January 2004)