Human Services Research Institute

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Memorandum

To: State RWJ Self Determination Projects

From: Valerie Bradley & John Agosta

Date: April 20, 2000

Re: Enclosed copy of the RWJ Year One Impact Assessment Report

We are pleased to provide you with a copy of the report entitled: *The Robert Wood Johnson Self-Determination Initiative: Year One Impact Assessment Report.*

The purpose of our first year assessment was to explore the policy impacts and implications pertaining to efforts across the country to establish self-determination practices for people with developmental disabilities. This report offers documentation and observations related to efforts undertaken during the demonstrations' first year.

In preparing this report, our staff gratefully acknowledge the contributions made to our effort by so many across the country. Project directors in each state, people with disabilities, their family members and friends, advocates, agency staff and administrators all took the time to talk to us about the initiative or send us information. Additionally, we benefited from the advice and editorial comment offered us by staff at the Self-Determination National Program Office and our Advisory Team.

We hope that you will find the enclosed report useful. If you have any comments about our findings or observations, please feel free to contact us.

We are presently undertaking a follow-up impact assessment to complement this first year report. We hope to complete our field activities by early Summer, 2000 and have findings to share with you again soon after. We look forward to working with you again in this next round of inquiry.

The Robert Wood Johnson Foundation

Self-Determination Initiative:

Year *One* Impact Assessment Report

December, 1999

Human
Services
Research
Institute

The Robert Wood Johnson Foundation Self-Determination initiative:

Year One Impact Assessment Report

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All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Robert Wood Johnson Foundation or any government authority.

What follows are findings stemming from a recent impact assessment of RWJ's Self-Determination Demonstration for people with developmental disabilities.

Acknowledgments

The preparation of this report was undertaken by the staff of the Human Services Research Institute with contributions from many other sources. These contributions are gratefully acknowledged.

We wish especially to thank the many people with disabilities, their family members and friends, advocates, agency staff and administrators who took the time to talk to us about the RWJ Self-Determination Demonstration initiative.

We are particularly grateful to the self determination project directors in each state for their patience and assistance in answering our questions, identifying key informants to interview, and sharing their enthusiasm and commitment to this project.

Further, we have sincerely benefited from the advice and active participation in the project by the Self-Determination National Program Office and our Advisory Team. Team members each brought much experience and expertise to the project, offering periodic and significant support.

Preface

The Robert Wood Johnson Foundation Self-Determination Demonstrations afford states an extraordinary opportunity to explore new ways of supporting people with developmental disabilities. The 19 participating states seized this opportunity and moved forward enthusiastically. Our task was to assess the actions taken by these states and the resulting outcomes. The task was a challenging one.

While the underlying values and the goals set by states were similar, the amount of time for the Demonstrations, the budgets allotted and the actions taken were not. Inevitably, each Demonstration encountered its own unique obstacles to overcome and made its own path. It was not surprising to observe that the "working models" that were developed for self-determination and the progress actually made toward implementation differed from state to state and even within states.

Because of all these important differences, we could not easily narrow our focus or develop a "one-size-fits-all" assessment protocol. In this first-year impact assessment, we sought to describe the full range of experiences and activities undertaken by the states. Our findings, however, do not offer any definitive conclusions pertaining to any particular Demonstration or to the overall effort. We expect that our second year assessment will come closer to addressing issues like these.

We were also taxed by the quick evolution of the Demonstrations and our own logistics. Our actions to collect information and complete on-site visits spanned several months ~ from September 1998 until February 1999. We observed the projects evolve as we were still compiling information and forming opinions. As a result, we realize that our understanding of the Demonstrations simply reflects their status at a particular point in time. Most likely, by now these Demonstrations differ from what we observed just a few months ago. Readers should take this into account.

Finally, we understand the enormous interest in these Demonstrations and the need to make these findings accessible. Toward this end, a plainly written executive summary of this report will be made available.

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Appendices

1 Introduction and Study Background

The changes that are emerging in systems of support for people with developmental disabilities are part of a trajectory of reform that began decades ago. These reforms have encompassed the exposure of the inhumane conditions associated with institutions, the creation of alternative residential and day supports in the community, the passage of significant federal and state legislation supporting legal and civil rights of people with disabilities, and the provision of supports to families in the interests of maintaining children with disabilities in their communities. As each component of reform has taken root, the power of ideas like *normalization, inclusion,* and *participation* to criticize practice and to inform further change has increased. It is as if the closer we think we are to the realization of these ideals, the more they demand of our skills and creativity.

In the most recent manifestation of change, these ideals have lead many in the field to question the almost total control that public funders and providers have over the life choices of individuals with developmental disabilities and their families. In this system, funds are allocated to providers and people with disabilities and their families have little or no say as to which providers are to supply services or what the configuration of those services should be. Changing this imbalance of power and control is at the heart of the ideal of *self-determination.* A recent definition of this transformative notion is as follows:

> Self-determination is a national movement to redesign long-term care for individuals with developmental disabilities that eschews traditional program models and facility placement approaches... Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as help create them where they do not now exist (Nerney, 1998).

Efforts surrounding self-determination are guided by these four principles (Nerney & Shumway, 1996):

1. Individuals have the **freedom** to plan their own lives and make life choices.
2. Individuals have **authority** or control over one's own life, including control over resources so that needed and preferred supports can be acquired.
3. Individuals have access to the **support** they need and opportunity for increased community integration.
4. Individuals take on the **responsibility** of living in interdependent communities, participating in and contributing to their community. This also includes the need to act with fiscal responsibility.

The RWJ Self-Determination Demonstrations

To bring about a system consistent with the principles of self-determination, various social or legal barriers must be overcome. Inevitably, changes are required in both bureaucratic structures (e.g., funding, quality assurance) and in the attitudes and capabilities of providers, service coordinators or case managers, monitors, families and people with disabilities. The amount of change required, however, varies from state to state, given the state's present vision and practices for delivering developmental disability services. To facilitate these comprehensive changes, the Robert Wood Johnson Foundation established the Self-determination Demonstrations.

The Robert Wood Johnson Foundation is supporting a range of demonstration activities around the country to explore ways where people with developmental disabilities can *self-determine* the supports they receive. The Foundation has allocated $4,976,341 million to support projects in 19 states. Allocations for each project range from $400,000 for a 3-year period, to $200,000 for a 2-year period and $100,000 for a 1 -year period. Additionally, the Foundation granted $740,000 to New Hampshire for a four year, statewide self-determination effort.

The goal of the self-determination demonstrations is to make the choices, preferences, and individual gifts of people with developmental disabilities the most powerful influences on the system. This requires a transfer of control over resources to the person receiving services. To achieve this overall aim, the 19 self-determination projects are - in one form or another - attempting to put into place the following components:

Individually controlled budgets that can be allocated and dispersed given an agreed upon person-centered supports plan,

Means to ensure that people with disabilities receive the assistance necessary to identify and obtain necessary supports, and

Mechanisms to provide needed administrative support to assure that the systems work efficiently and effectively (e.g., to complete associated paperwork, maintain a satisfactory audit trail, disperse funding, or provide ample oversight).

Because the changes anticipated in the Foundation's initiative represent major alterations in the existing approach to providing services, the ability to document the process of implementation as well as the outcomes for individuals is crucial for others to

gain a practical understanding of the self-determination approach. **The purpose of this study -- an impact assessment of the demonstrations - is to document important process, cost and policy variables associated with the demonstrations.**

Five Recent Trends And Implications For the Demonstrations

As suggested earlier, regardless of the Foundation's initiative, the service system continues to evolve in face of a variety of irreducible pressures. While the nature and magnitude of these pressures are not easily quantified, we understood that each could either have a positive or hindering effect on the RWJ Demonstrations, or no effect at all. Agosta (1997) describes five such pressures:

Five Recent Trends

1. Continued changes in service systems to encourage community integration and self-determination (e.g., person-centered planning).
2. Growing service demand.
3. Continued pressure to contain Medicaid spending.
4. Potential application of managed care strategies to social service systems.
5. The emerging re-structuring of the developmental disabilities provider industry.

1. **The push for continued changes in the service system to promote community integration and self-determination.**

   The RWJ Demonstrations may be viewed as part of an ongoing change process beginning with the exposure of the dehumanizing conditions in institutions. Over the past 30 years, the field has shifted away from a reliance on facility-based or congregate service approaches. In their place, approaches to promote community integration and person-centered supports are have gained favor.

   However, until recently, professional judgment was still more influential in decisions about the character of services and supports than were the choices and preferences of service recipients. In addition, the choices available to people with disabilities were restricted to the residential and vocational slots available. Emerging practice, however, suggests that people with developmental disabilities must play leading roles in determining the substance of their lives, and that relevant and preferred supports should be provided as needed. Moving past traditional professional or industry-dominated approaches, the field is struggling to become more responsive to the demands of service recipients ~ to promote and honor <u>self-determined</u> lives.

   At the core of this concept is the belief that individuals must have the authority and resources to plan their own futures, negotiate for funds, and direct the use of an allocated amount of money (Nerney, Crowley, Kappel et al., 1996; Nerney &

Shumway, 1996; Agosta & Kimmich, 1997). Such reforms will inevitably change the structure of the service system.

2. The growing demand for developmental disabilities services and the presence of service "wait lists."

America is graying. Due to advances *in* medical care, people are living longer and that includes people with disabilities. In addition, the parents of many adults with disabilities are growing too old to continue to provide care at home. Middle aged baby boomers that had children with disabilities are finding that their children are now aging into the adult system. Consequently, the pressures placed on the long-term supports system for adults with disabilities can only grow over the next several years.

Prouty and Lakin (1999) estimate that in June 1998 there were 61,373 individuals who were on wait lists for residential services. They conclude that: States "would need to expand their current residential services capacity by 17.6% to create residential services for all the people presently on waiting lists for them. This does not include growth in specific types of services needed to serve persons wishing to move from one type of residential setting to another (e.g., a large facility to a community residence)" (p. 78). In addition, these estimates do not address the thousands others who may be waiting for daytime vocational services (e.g., supported employment).

Echoing such research, a National Arc study concludes that the nationwide shortfall of community support services has reached crisis proportions for people with mental retardation and their families. The Arc's report examines state-by-state data regarding the status of requests for critical residential, day/vocational and other community support services. According to the report, more than 218,000 requests for support remain unanswered for people with mental retardation and their families (Arc, 1997).

Despite encouraging events where "new money" is allocated to state developmental disability authorities to accommodate portions of the wait list (e.g., as in MA, MT, NC, LA, OR and NJ), the field must face up to the sobering challenge it faces. These numbers - and accompanying personal stories ~ reflect a growing problem for policy makers.

3. Continued pressure to contain the growth of Medicaid spending.

Medicaid was created in 1965 to help states pay the medical bills of low-income individuals. Today, Medicaid has three service domains: a health insurance program for low income individuals, a long-term care program for seniors and people with disabilities, and a specialized service program for people with developmental

disabilities or mental illness (Congressional Research Services, 1993). The costs of Medicaid services nationally are split between the federal government and the states. The percentage of costs borne by the federal government varies from state to state, but the national average is 57% federal and 43% state.

Medicaid financing is especially important to the developmental disabilities field. Today, about 76% of what states spend on *long-term* services and supports (excluding acute health care) for people with developmental disabilities is paid by state and federal Medicaid dollars, at a cost of over $22 billion annually (Braddock et During 1977-1988, total federal-state Medicaid spending for individuals with developmental disabilities grew by 15% annually in real economic terms, declining to about 9% annually from 1988-1992 and holding steady at an estimated growth rate of 9.5% for 1996 (Braddock and Hemp 1996).

During the 1990s, there was enormous pressure building within the federal government to contain Medicaid costs (which coincided with the spike in waiting lists noted above). Medicaid spending increased by 22.4% from 1988-1992 and 9.5% from 1992-1995 (Holahan & Liska, 1996). At the time, increases like these stirred interest for significant Medicaid reform. Since then, however, growth rates have dropped (3.2% in 1995-96). The lower rates coupled with a strong national economy imply lower annual costs and reduced pressure for Medicaid reform, at least at the federal level.

Stateside politics, however, are not so clear. Strong state economies have eased some concern over spending. Indeed, several states are operating with budget surpluses. Yet, competition for resources remains great within state budgets. From a state perspective, in 1970 Medicaid spending amounted to about 4% of state budgets, but by 1995 the proportion had nearly quintupled to 19% (NASBO, 1996). And this trend is predicted to continue on through the year 2002 (Wharton Economic Forecasting Associates, 1995). This poses enormous problems for state policy makers who must juggle competing demands, such as education, corrections and transportation. When Medicaid takes up more of the budget, then less is left for other important functions. As a result, with or without federal action, governors and legislatures have made holding down Medicaid spending a top priority.

4. The potential use of "managed care strategies" to administer social service systems.

The term "managed care" refers to strategies that reduce costs and maximize the value of services by controlling spending and service use. Typically, managed care arrangements involve the enrollment of individuals in a managed care organization (MCO), where the MCO has contractual agreements with a payer and providers to assure delivery of services to the enrollees. In essence, the MCO is a risk-bearing

entity which receives a fixed payment to assure that a set of people get the services they need as specified in the managed care plan.

During the mid 1990's there was growing interest nationally over the use of managed care strategies to contain spending for health care and other social services, including developmental disabilities. Indeed, managed care strategies are now routinely used to administer Medicaid health and behavioral health care systems, and have entered the child welfare field.

Developmental disability systems, however, have typically not been asked to participate in managed care arrangements. And, as the decade concludes, the "managed care scare" of the mid-1990s has subsided. Yet in some states (e.g., MD, MI, WI, PA) the prospect of systems reform based in managed care was quite real and continues to play a role in state decision-making.

More than that, the underlying appeal and potential utility of certain managed care strategies have not evaporated. Indeed, as states work to integrate the concept of self-determination into their systems, selected managed care strategies are being put to work. These include concepts such as capitation, risk management and service substitution (Agosta & Kelsch, 1999).

5. The emerging re-structuring of the developmental disabilities provider industry.

While there is no ground swell for provider restructuring yet apparent in the developmental disabilities field, there are clear signs of change:

With increasing frequency, multi-state service providers are accelerating their entry into developmental disabilities service markets. These types of organizations have existed for many years and have contributed to the development of the present service system. Over the past few years, however, some have gained the capital (e.g., through association with much larger health oriented organizations) to aggressively expand their base, either through outright purchase of provider businesses or by contract with a state or local payer.

Providers in several states are pursuing efforts to organize as formal service networks. Such networking could result in: (a) increased administrative efficiencies, (b) enhanced and consolidated capacity to deliver direct services, and (c) a formal organization for future payers (e.g., government or people with disabilities) to negotiate and contract with. In addition, because small or niche (e.g., supported employment only) providers may have difficulty competing with larger organizations in a more competitive market, networking may be desirable for such providers because of the added size and safety a coordinated network can bring.

Are trends like these good or bad for the developmental disabilities field? It's hard to say, yet the trends are easily observed from state to state and are working to reshape the industry.

These five trends have and will have an influence on the conduct of the self-determination initiatives. Specifically, in those states where there has been substantial momentum toward inclusion and person-centered practices, the projects have a distinct foundation on which to build and the presence of a mind-set and language from which to draw The pressures of the mounting wait list present another somewhat more unpredictable element in the calculus surrounding the self-determination initiative. In Maryland and Oregon, for instance, the tide of self-determination has risen significantly because of the large infusion of resources as part of a related wait list reform. While this collateral initiative has helped accelerate the diffusion of self-determination practices around the state, it is still not clear whether the pressure to distribute the windfall of wait list funds will take precedence over the need to create self-determined futures one person at a time.

The pressure to contain Medicaid costs and the subsequent exploration of managed care alternatives to fee for service and "grant in aid" funding presents planners and advocates in some states (e.g., Vermont, Wisconsin and Michigan) with the opportunity to turn adversity into possibility. That is to offer policy makers an alternative to the models that dominate behavioral health care through the marriage of self-determination with selected managed care constructs such as capitation, risk management and service substitution.

Finally, the pressures generated by changes in the "provider marketplace" are by no means uniformly distributed nationally, and do not immediately impede or facilitate the implementation of self-determination. It does seem inevitable, however, that an initiative premised significantly on choice will at some point butt up against the increasing consolidation of corporate provider auspices.

Underlying Impact Assessment Strategy

An assessment of the impact of self-determination activities should address three distinct goals:

To assess whether particular projects reach the goals outlined in their proposals;

To document the changes that take place at the state and local level, as well as the constraints and obstacles encountered (e.g., provider performance, staffing, regulatory and statutory issues, etc.), and the relevant national policy issues;

To assess whether self-determination approaches result in increased choice and control among project participants, and the creation of individual supports.

This impact assessment report focuses on the first two goals noted above. Actions and outcomes related to the third goal on project participants are being examined by the Center on Outcome Analysis (COA). In addition, project costs and their relation to impacts on individuals is being investigated collaboratively by COA and HSRI.

To assess the progress made by the demonstration projects to achieve these goals, information was collected to address five fundamental questions:

1. What were the goals, implementation strategy and/or planned outcomes of each project?

2. What actions did the projects actually take to achieve their goals?

3. What actions went smoothly and well?

4. What obstacles or constraints were encountered?

5. What were the results of the actions taken?

An important key to the impact analysis has been to ensure that the impacts that are emerging are in fact a reflection of the key components of self-determination rather than some other intervention or construct. Comparing outcomes to process and theory provides a means of validating the consistency between the program "theory" and the actual intervention that was implemented.

The first step in the impact analysis process was to articulate the underlying assumptions that give an activity its momentum and credibility. In the case of the self-determination projects, it is assumed that a system in which individuals with developmental disabilities and their families are given control over resources and the ability to make choices about the nature of their supports, is more cost effective and responsive than conventional service systems. It is further assumed that such a model should lead to proximal outcomes that include more individually tailored supports, and the use of a broader array of natural and generic as well as specialized supports. The ultimate outcomes should include the realization of individual choices and aspirations, more cost effective services, higher individual satisfaction, and improved consumer participation and inclusion in communities. The initiative also anticipates changes in state systems (quality assurance, resource allocation, Medicaid policy, etc.) designed to allow consumer choice.

The next step was to enumerate the structural elements that will make the theory take shape in practice. Such ingredients may include - depending on the state or local area

- an agent or service broker, person-centered planning approaches, flexible funding, self advocacy training and organizing, and so forth. With respect to the success of each individual project, project staff sought to document the particular implementation details. For instance, did funding mechanisms change, were fiscal intermediaries put into place, were participants given access to independent support brokers?

Further, those elements that were hypothesized to be associated with successful outcomes (e.g., training, technical assistance, leadership, and client characteristics) were also documented in order to understand the context within which the implementation of self-determination efforts is going forward. Given that the Foundation anticipates changes at the state level, it was also important to document key variables in the state context including extent of institutionalization, historical use of Medicaid waiver, level of support among key policy makers, and provider configuration.

Finally, the methodology provides a means to link the results of the client outcome information generated in the separate evaluation -- as well as the quantitative cost data - with the qualitative information catalogued at the site and state level.

The Organization of This Report

This report documents all activities associated with the Year One Impact Assessment and the resulting findings. The remainder of the report is organized as follows:

Chapter 2 - Study Methods - This chapter provides an overview of the assessment methods that were applied to complete this phase of the television.

Chapter 3 - State Summaries - This chapter includes brief descriptions of the initial objectives and implementation strategies of each state project.

Chapter 4 - Findings: Mediating Factors - The demonstrations did not unfold in isolation, but within an already active systems context. This chapter describes several of the mediating factors at work in state systems.

Chapter 5 - Findings: What Was Done - This chapter describes the "independent variables" or discrete actions taken by states to promote in success.

Chapter 6 ~ Findings: First Year Progress - This chapter presents findings related to the site demonstrations' "dependent variables" or the outcomes, overall analysis of the goals set by the sites and the progress made toward these goals.

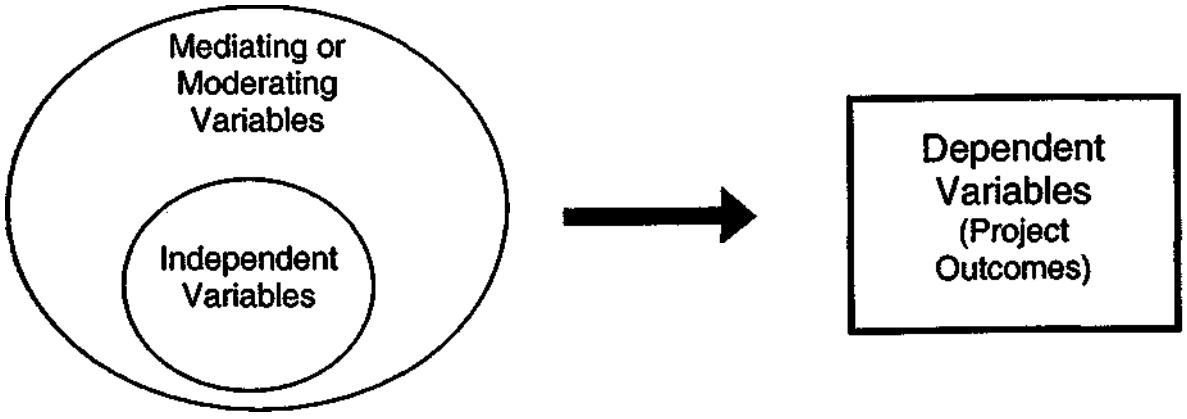
Chapter 7 - Observations and Concluding Remarks This chapter describes the facilitating factors and obstacles that were encountered by the projects. Additionally, it offers final summary observations and conclusions regarding project findings.

2 Study Methods

This impact assessment focuses on the development and implementation of strategies to promote self-determination for people with developmental disabilities. Although all of the 19 state projects proposed to achieve similar self-determination-related outcomes, the strategies each state applied were somewhat different. These strategies range from broad-based reform initiatives to programs targeted to a discrete group of individuals and families. Some projects span statewide systems, while others encompass specific regional, metropolitan, and even neighborhood areas. As a result, a single means for data collection could not be rigidly applied across all the sites. Instead, multiple data collection strategies were employed within a uniform structure that was used in all first year sites. In this chapter, the information domains that were targeted and the strategies used to collect information are described. In subsequent chapters, these methods are documented in greater detail as warranted.

The Information Domains Targeted

It is understood that the projects differ from one another, and that each is unfolding within its own unique context. As a result, the study team collected information to describe: (a) a variety of contextual factors (i.e., *mediating or moderating variables),* as well as, (b) the precise actions that were taken by the project to evoke the desired results (i.e., *independent variables).* To complete the picture, the team is also collecting data related to the outcomes of the project (i.e., *dependent variables).*



Each of these variable types is shown below, along with the primary topics of interest that fall under each. **Appendix A** lists these topics and breaks them down further to show many of the particular variables that were tracked. (Note that several important variables were not examined within the scope of this impact assessment, but were tracked by other research partners. Examples include: (a) the characteristics of and impacts on individuals served by the projects (tracked separately by COA), and (b) cost implications (tracked separately by COA and HSRI).

1. **Mediating Variables**
   - *Contextual factors:* the existing developmental disabilities services system.
   - *Local program design and underlying program theory:* the values or principles that underlie the project and the project's structure.
2. **Independent Variables**
   - *Participant planning & individualized budgeting:* practices used to develop a plan for providing the individual with services and supports and the procedures used to decide what amount of money each participant receives.
   - *Service brokers:* agency structure and staff activities associated with "brokering" functions.
   - *Fiscal intermediaries and other allocation mechanisms:* the structure and functions of organizations that are used to manage the budgets that are allotted to participants.
   - *Advisory Councils:* the presence and responsibilities of advisory committees, including the participation of self-advocates in council deliberations.
   - *Training and education:* efforts to provide participants and family members with information about the project and how to participate effectively.
   - *Regulatory relief:* efforts to eliminate, waive or alter rules or regulations.
   - *Identification of non-traditional resources:* efforts to access additional money or other sources of support for participants.
3. **Dependent Variables**
   - *Participant Outcomes:* impact on people with developmental disabilities.
   - *System Outcomes:* impact on the overall developmental disabilities system.
   - *Service Outcomes:* impact on the traditional service provider system.
   - *Project Specific Outcomes:* unique impacts anticipated by particular Projects.

Data Collection Strategies

To amass the information necessary to describe all of the above variables, project staff pursued the following activities:

Records and literature review involving analysis of secondary data available nationally and in each participating state. During the project, project staff collected a range of materials that were available to depict funding and service utilization nationally and in each state (e.g., Braddock, Hemp, Parish & Westrich, 1998; Prouty & Lakin, 1999). Materials related to each of the targeted sites were also collected and reviewed.

Telephone interviews to acquire first hand information regarding the perceptions of people most familiar with RWJ demonstrations. These were often completed as an informal discussion between project staff and individuals on-site.

On site visits and interviews of project participants, advocates, providers, RWJ project staff, government staff and others were conducted in sites across the country. To collect information during the site visits, interviews were guided by the *RWJ Project Evaluation Coding Form* (See **Appendix B).** The form could not be rigidly applied across all sites due to the variations in what states were attempting to do; however, it did offer guidance to the interviewers. In addition, project staff referred to an interview guide, which listed broader, open-ended questions.

This was the primary method of collecting both quantitative and qualitative information. Site visits were conducted in 16 of the 19 states by project staff beginning in the Fall of 1998 and concluding in March 1999. Follow-up phone interviews were also conducted after many of the in person state visits to collect additional information.

It is important to understand that the sites did not begin operations at the same time, and that our interviews spanned several months. As a result, our assessment ~ though labeled as a "one year" impact assessment - did not inspect each site precisely 12 months after it began operations. The timing of our inquiry was not referenced to each site's start date. Rather, the assessment was conducted roughly one year into the overall RWJ initiative and provides a snapshot of where states were at that time. As a result, during our inquiry some states may have already pushed into their second year, while others may have still been working within their first year.

In the three states (Florida, Iowa and Pennsylvania) where site visits did not take place, we felt that for a variety of reasons (e.g., progress to date, independent information on the state, etc.) that phone interviews would suffice. In the fourth state (Hawaii) the state was visited and there was telephone contact but no formal inquiry was undertaken in this project year. Hawaii, however, is targeted for a thorough inquiry in the coming year.

The Figure below illustrates the times of our site visits and interviews by state.

Times of the Site Visits By State

The following Year One report presents initial findings based on these multiple data collection strategies. Quantitative findings are discussed in a descriptive fashion and are augmented by qualitative insights. In the final report of the impact assessment, the quantitative data will be linked with the individual outcome data collected by COA to determine whether particular demonstration characteristics can be linked to aggregate individual experiences.

3 State Summaries

Nineteen states were selected to participate in RWJ's Self Determination demonstration. New Hampshire may be counted as a 19th state given that it was awarded an inaugural RWJ grant on self determination in advance if the larger multi-state initiative. This chapter provides a list of the participating states along with important descriptive information. In addition, a summary of initial project goals set by each state is offered.

Nineteen RWJ Demonstration Sites

The following is descriptive information pertaining to the grants offered to the states.

RWJ State Self-Determination Sites

State	Original No. of Grant Years	Amount of Grant	Target No. of Planned Sites	Target Number of People to be Served by Grant's End
Arizona	2	$150,000	2	72
Connecticut	2	$200,000	all regions	125
Florida	1	$100,000	plan only	planning only
Hawaii	3	$400,000	Statewide	exact # not specified
Iowa	2	$200,000	5	250
Kansas	3	$400,000	2	85
Maryland	3	$390,000	2	exact # not specified
Massachusetts	2	$100,000	1	400
Michigan	3	$397,000	5	525
Minnesota	3	$400,000	3	150-200
New Hampshire	4	$750,000	Statewide	300
Ohio	3	$400,000	4	223
Oregon	2	$200,000	1	60
Pennsylvania	1.5	$100,000	3	200
Texas	3	$396,000	3	180
Utah	2	$200,000	5 to start	1,100
Vermont	3	$400,000	Statewide	exact # not specified
Washington	1	$100,000	2	30-45
Wisconsin	3	$400,000	3	exact # not specified

Summaries of State Project Goals

What follows is a summary of the project goals articulated by each state in their initial RWJ proposals. Changes may have since been made by individual states to alter goals and/or planned actions.

Arizona (two years - $150,000)

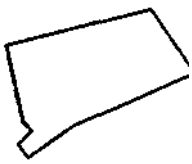
Arizona's Self-Determination Project created, for the first time, a working partnership between the state's Division of Developmental Disabilities and Centers for Independent Living (CIL). The Division, undergoing an effort to make major reforms in the agency's daily practice, initiated the project, *This is My Life: Arizona's Response to Consumer Control, Choice and Responsibility."* This initiative provides a springboard for the agency's actions to develop long-term supports that emphasize self-determination for people with developmental disabilities. It also emphasizes the Division's efforts to change their operations, indoctrinating consumer choice and control into their daily business activities. Arizona's Self-Determination initiative seeks to empower people with developmental disabilities and their families by providing them with the information they need to control their own service budgets, choose their own supports and support providers, utilize existing community supports - while reducing their reliance on traditional case management.

To bring about this change, the Division is collaborating with Centers for Independent Living in the Phoenix and Tucson areas to develop Peer Mentoring opportunities. Over a two-year period, the project hopes to achieve three main goals:

1) Match 50 trained volunteer peer mentors with 72 individuals with developmental disabilities,

2) Decrease costs by shifting some tasks (traditionally provided by case managers) to peer mentors, and

3) Add a management-level Systems Change Ombudsperson who has the authority to remove systems barriers and ensure that consumer choices infiltrate the Division at every level. Peer mentors act as buddies and/or advocates to individuals with developmental disabilities and their families, and offer support as they identify and work toward achieving personal goals. Case managers will be given the opportunity to become personal agents, providing information about service options and facilitating system cooperation with consumer budget management.



Connecticut (two years - $200,000)

The Self-Determination Systems Change Initiative in Connecticut was intended to stimulate a restructuring of the service system to better

meet the needs of both the people currently served and those who are on waiting lists. Recent pilot programs in support brokerage, person-centered planning, and related activities provided early progress toward self-determination on a small scale and surfaced the many system barriers to implementing meaningful reforms. To facilitate self-determination arrangements throughout the state, the Connecticut project has contracted with fiscal intermediary providers to assist project participants in the management and allocation of individual budgets, and is currently revising fiscal and accounting structures within the DMR to better accommodate individual budgets.

Through the Initiative, it was expected that the Department of Mental Retardation would greatly increase the numbers of individuals who have opportunities for self-determination. Connecticut's commitment to facilitate self-determined supports for people with the highest priority needs has meant a longer development period for support arrangements than anticipated.

The Connecticut Self-Determination Systems Change Initiative had several objectives and one main goal. The overall goal was to assist 50 people in the first year (about 27 were assisted), and an additional 75 in the second year, to arrange supports and services to meet their individual needs in cost effective ways that result in a higher quality of life. Objectives in order to reach this goal included:

Regional demonstration projects to advance systems changes toward self-determination;

Development of the support broker system;

Development of data processes and fiscal mechanisms that promote consumer-directed supports;

Enhancement of the personal outcome planning system;

Review of relevant state policies, procedures, and regulations;

Survey of support option needs;

Training for consumers, families, and staff on person-centered planning, individualized budgets, support brokerage, and quality outcome measures;

Information dissemination; and

Advancement of outcome based quality assurance efforts.

Florida (one year -$100,000)

With a focus on building the capacity and commitment to transform the state system to one animated by the principles of self-determination, the designers of the Florida initiative chose to concentrate on educational and planning activities. As part of this

strategy, the Florida project has made significant contributions to the state's multi-year plan for Developmental Services. A number of key self-determination elements are included in the plan that is shaping the allocation of additional resources as well as the current revision of Chapter 393, Florida's enabling statute for disability services. These changes include: launching a pilot in two districts for the use of vouchers by families and individuals; expanding the scale of a "cash and counseling" pilot (partially funded by a separate RWJ initiative); the creation of Family Councils in each district to increase consumer and family input into disability policy; and the creation of a system of service performance "report cards" to assist individuals and families in making informed choices about support providers. The objectives of this project were:

To put people with developmental disabilities and their families in control of decisions affecting desired outcomes in their life;

To put people with developmental disabilities and their families in control of the supports, services and financial resources used to accomplish those outcomes;

Develop interdependence with community members and generic community resources as personal and family supports for participation in everyday life;

Empowerment of consumers and families in the development, monitoring and improvement of supports for participation in everyday life; and

Develop personal assertiveness and self-advocacy on the part of individuals with developmental disabilities and their families.

Hawaii (three years -- $400,000)

The main goal of Hawaii's Self-Determination Initiative was to develop a cost-effective system consistent with self determination principles, offering a higher quality of life for individuals with developmental disabilities. Objectives to meet this goal included:

Enabling and supporting people with developmental disabilities to make decisions on:

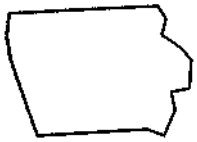
1. What supports and services they need, and
2. How to allocate funds to obtain these supports and services.

Facilitation and enhancement of quality of life for people with developmental disabilities;

Demonstration of significant cost efficiencies;

Re-examining the quality assurance system for consistency with individual and family values; and

Establishing a community controlled managed support organization to house fiscal intermediary and broker functions.



Iowa (two years - $200,000)

By the end of Iowa's project, it was expected that an organized system would be developed to identify, provide and assess individualized services for people with developmental disabilities, based on the ideals of choice, empowerment and community integration. The model was to focus on local involvement and control, with a system responsive to local needs. The objective was to serve a minimum of 25 people the first year and more in the second year as the process became ingrained. The project's objectives included:

Involvement of consumers and their families in all levels of planning;

The formation of representative local project teams (including self-advocates and family members), relying on local decision making and building knowledge and expertise at the local level;

Training local project teams and case managers in person centered planning;

Assistance in modifying/developing the infrastructure needed to implement the consumers' plans. This infrastructure includes developing alternative providers and utilizing natural supports and generic services. It also includes how to contract and pay for these needed services;

Assistance in assessing the outcomes of the services through a quality assurance system; and

A set of standards for accreditation and licensing of services that supports consumer choice.

Kansas (three years at $400,000)

The purpose of the Self-Determination project in Kansas was to examine the elements related to creating an infrastructure that implements an option for self-determination for persons with developmental disabilities in Kansas. The cornerstone of the project was to be the development of a method to place people with developmental disabilities or their families in charge of their lives through direct expenditures or authorized payments through a signed authorization.

The Kansas Self-Determination Project set out to achieve the following goals:

Develop implementation strategies by project participants and training materials through the University Affiliated Program at the University of Kansas;

Develop a method to make direct expenditures, or authorize payments through a signed authorization;

Create a flexible funding stream that allows for the creation of individualized budgets, within appropriate parameters, and with sufficient accountability for protection of the consumer;

Develop a mechanism at the point of entry to the developmental disabilities system to implement self-determination as defined for this project;

Refine person-centered-planning to assist persons who have no support network to ascertain their preferred lifestyle;

Create a system culture that supports self-determination; and

Implement a quality assurance system, which can oversee a wide array of lifestyle options in generic as well as traditional developmental disabilities service settings.

Maryland (three years - $390,000)

Maryland's Self-Determination Initiative is a collaborative effort of the Maryland Developmental Disabilities Administration (DDA) and the Arc of Frederick County, with active support of the Governor's Council on Developmental Disabilities. The initiative began as a pilot in two DDA regions, encompassing four counties: in Central Region, suburban Howard County; and in Western Region, rural Allegheny County, suburban Washington County, and rural Garrett County. Three groups of people were originally targeted: people currently receiving services but wanting a change; people on the waiting list; and youth transitioning from school to DDA services.

The Self-Determination Initiative seeks to create systems change in Maryland. The primary goals of the initiative are:

to give people with developmental disabilities and their families greater choice and control over the services and supports their receive;

to increase the efficiency and cost effectiveness of DDA-funded services; and

to promote the principles of self-determination throughout the DDA system.

In its proposal, Maryland also envisioned that the project would create fundamental change within the structure of its service system for people with developmental disabilities. This goal is being substantially implemented, given the adoption of self-determination principles as part of the statewide waiting list initiative.

Massachusetts (twoyears- $100,000)

The original goal for the two-year Massachusetts project was to use the funds "to serve as a catalyst ...toward the achievement of individual outcomes and statewide systems change." Specifically, the effort is aimed at changing a "predominantly professionally driven 'one-size-fits-all' model" to one that is

focused on the preferences and choices of individuals and families and that places the control of financial resources for those supports in their hands.

Specifically, the outcomes included in the Massachusetts proposal include:

Increased community capacity to provide informal or alternatives supports to people with disabilities;

Increased choice and control by individuals in designing supports;

Wider use of person-centered methods of support planning;

Flexible approaches to the allocation of resources on an individual basis;

An accountable system of community safeguards for individuals who control their own resources; and

Decreased cost.

To achieve these goals, Massachusetts project staff have implemented three major strategies:

1. Creation of family governing boards in Metro Boston that are representative of major ethnic groups in the area including Haitian, Asian, and Latin Americans. These boards are given control over financial resources and work together to determine how funds should be allocated;

2. Selection of service coordinators in the Metro Boston region to demonstrate the feasibility of a service brokerage approach, the "deconstruction of provider budgets to accommodate individual plans, and the identification of consumers and families interested in self-directed supports; and

3. Work with selected providers interested in organizational changes consistent with a more "consumer-directed" approach.

Michigan (three years - $397,000)

Michigan's Initiative to promote Self-Determination was meant to promote the evolution of a system of long term support for people with developmental disabilities that is cost-effective, socially and culturally responsive, and beneficial to all. Michigan designed its project to integrate with the planned transformation of the public service delivery system to a managed care arrangement.

An involvement of over 600 persons with developmental disabilities in self-determination, across three local project sites was the goal of the project. The initiative also sought to:

Demonstrate that the level of satisfaction and quality of life can increase when individuals with disabilities are primarily responsible for the supports they chose as necessary to achieve their goals and dreams; and for controlling the disbursement of resources allotted for their supports;

Demonstrate that individuals with developmental disabilities will make cost and benefit-effective decisions about the resources and supports they require;

Demonstrate that costs of services and supports can be contained, if not decreased, when individuals with disabilities are able to exercise greater personal choice over the activities in which they engage, and control over the resources available to conduct these activities;

Identify and remove or resolve barriers inherent in current policy and practice that interfere with or reduce the potential of individuals with disabilities to define and achieve their goals; and

Apply the principles and practices of self-determination to the evolving managed care planning for Michigan's system of services and supports for persons with developmental disabilities.

Minnesota (three years- $400,000)

Minnesota, in its three year project, is committed an overall goal "to further the opportunity of people with developmental disabilities to enjoy the pride, power, and satisfaction that comes from self-determined lifestyles." The project has focused its efforts in three different counties - Dakota, Olmsted, and Blue Earth. Each locality is given a significant amount of autonomy in the design of the local program, but each is anticipated to include "person-centered planning, individually-controlled budgets, consumer-controlled housing, outcome-based quality assurance and quality improvement assistance, consumer education and support, and consumer and family choice of providers, support staff, and type and amount of support."

Specific goals included in the original proposal include:

Within each demonstration site, to set goals and expectations that are consistent with the self-determination initiative;

Improve management and administrative services;

improve services financing and design;

Improve access to services;

Improve quality assurance and monitoring; and

Redesign roles to assure that a viable, accountable, and effective infrastructure is created to support and sustain the services and supports created.

New Hampshire (four years - $750,000)

The intent of the New Hampshire Self-Determination project was to expand, over a four year period, the pioneering demonstration in the Manadnock Region of the state. That demonstration, also funded by the Robert Wood Johnson Foundation, showed that positive outcomes were associated with the exercise of individual choices and preferences made possible through individual budgets, person-centered planning and support from personal brokers. The current project supports unique, regionally specific strategies, organizational structures and financing approaches that will assist over 300 individuals with developmental disabilities and their families to arrange and gain access to responsive, personalized, and cost-effective supports.

The central premise of this project is to increase the level of control that individuals have over their own lives and over the supports they need. According to the original proposal, the demonstrations will result in:

More effective organizational model for funding and providing supports;

Increased flexibility to customize supports according to need;

More flexible processes for planning, arranging, and providing assistance;

More effective collaboration between formal and informal supports systems;

Improved cost-effectiveness resulting from combining resources and allocating them according to consumer determined needs;

An increased level of satisfaction with the supports received;

An increased systems capacity to respond to people on waiting lists; and

Improved transitional planning for school aged children and adolescents aging into the adult service system.

To manage the project, a central state coordinator has been hired who assists the area agencies in the state to evaluate their projects, to train key constituencies and to secure technical assistance. Regular meetings of the area self-determination coordinators are conducted to enhance the sharing of information, strategies, solutions, and experiences.

Ohio (three years - $400,000)

The Ohio Self-Determination Initiative was to provide leadership to effect changes that result in an environment where people with developmental disabilities have authority and control over their lives. Together, with

people with disabilities, their families and friends, and guided by vision-driven principles, this project was to restructure the current system. The intent of this project was to provide a focus and structure that brings together the policy, funding, processes and politics to restructure the mental retardation and developmental disabilities system and form the basis for Medicaid reform in Ohio. At the end of Ohio's Self-Determination project, expected accomplishments included:

Self-determined support of 223 individuals across 4 selected sites;

Self-determined support of an additional 420 individuals from other county boards; and

Removal of regulatory barriers over which the Ohio Department of Mental Retardation and Developmental Disabilities have direct control over.

Oregon (two years -- $200,000)

The mission of the Oregon Self-Determination Project was to create practical and affordable systems of support using a consumer-driven model; make use of innovative, flexible funding structures; and connect individuals and families to generic and natural supports in local communities.

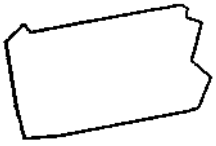
Under Oregon's Self-Determination Project, it was expected that 60 individuals in Multnomah County would choose and direct their supports through a service brokerage. During year two of the project, other brokerage sites were to be chosen through a competitive process. Other goals included:

Training in self-determination values and techniques such as person-centered planning, consumer management of supports and service brokerage to consumer consultants, providers and other key players;

A Statewide education campaign to inform consumers about system changes and choice;

Policy Task Force to research and redesign program policy and funding structures to facilitate consumer choice and control of resources; and

Evaluation to identify effective self-determination practices and system changes, analysis of outcomes for consumers, providers and funding agencies.



Pennsylvania (1.5 years - $100,000)

The state of Pennsylvania originally intended to participate in the Robert Wood Johnson Self-Determination Project for a period of three years, with the involvement of nine counties. Pennsylvania subsequently submitted an addendum to change the time frame of

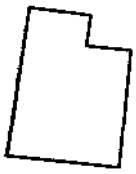
the grant period to eighteen months, with a reduction in funding from $400,000 to $100,000. The original nine counties that intended to be piloted in the project were reduced to three; Allegheny, Lehigh and Blair. The Funding was divided evenly among the three counties.

The initial application for the project identified three broad categories of outcomes which they hoped to address in the self-determination demonstration: 1) the creation of a reformed service system, 2) resources controlled by consumers, and 3) the development and support of natural supports. Control over the projects was to be held at a local, not state, level.

Texas (three years - $396,000)

Texas has been moving towards a system of increased person-centered planning for the past three years. The RWJ pilot itself is actually a part of a larger, Managed Care pilot. The three Texas counties involved in the RWJ project are concurrently participating in an MRLA evaluation being conducted by Human Services Research Institute. This pilot has presented the opportunity for the state authority functions to be shifted to the local level. In recent history, the emphasis of funding has shifted from residential services, where it was attributed after the closing of institutions, to more community-based services. The funding is primarily General Revenue monies, which are flexible in the ways in which they can be spent.

The goals for this piloting program were as follows: 1) The implementation of self-determined, individual budgets and support plans with individual control (by the consumer), 2) the creation of an administrative structure which would reflect the priorities of person-directed supports and 3) the development and presentation of a model for training and technical assistance, to be disseminated throughout the state.



Utah (two years - $200,000)

In Utah, the Division of Services for People with Disabilities (DSPD) plans to transform the design and delivery of their services, to a system of self-determination, for people developmental disabilities receiving services. By the end of the three-year project, DSPD expects one-third of consumers to be exercising self-determination - having choice and control over their supports, support budgets, and choice of providers. The transition begins with five provider-based implementation sites during the project's first year, and expands by 20 sites each additional year.

The implementation goals for the project include:

training teams of consumers, staff, and others in the principles and tools of self-determination;

implementing self-determination by consumers at the project sites (giving people control over their service budgets and choice of provider);

redesigning DSPD's and provider organizations' management structures;

extending services to individuals on the waitlist through a more cost-effective system;

implementing a statewide electronic technical assistance and payment information system accessible to consumers, parents, providers, and support coordinators; and

changing policies as needed.

Vermont (three years - $400,000)

Vermont's Self-Determination Initiative was statewide in scope and designed to be fully implemented over the course of three years. It hinged on a system of service delivery for people with developmental disabilities in Vermont that assured consumer choice and control while utilizing managed care principles to control the escalating cost of service.

The "Just Do It" project targeted resources and activities of the restructuring plan that were the most critical to the success of the overall effort, the achievement of real consumer choice and control. Goals of the project included:

Creation of an "environment of support" for people with disabilities to determine the nature, duration and extent of services;

Promote self-determination initiatives within the system restructure activities;

Establishment of a statewide support network of stakeholders that will meet on a regular basis to share information among themselves and others, and develop local resources to enhance consumer and family directed services;

Development of alternative support options for consumers that facilitate consumer and family choice and control. Develop the capacity of service providers to support self-directed services;

Identification and resolution of technical issues related to implementing a system to promote self-determination;

Build a statewide capacity for training and technical assistance. Develop and implement flexible training and technical assistance to educate consumers, families, guardians, agencies, service providers, contracted workers, state staff and community members on a variety of aspects of consumer directed and controlled services; and

Perform a project evaluation. Develop a project evaluation methodology incorporating qualitative and quantitative measures and an independent review of the project.

Washington (one year -- $100,000)

Washington's Self-Determination Project was initiated in two distinct counties, each with it's own goals. In Spokane County, the project sought to work with people in a particular neighborhood to increase self-determination for adults with developmental disabilities, and for the families of children with disabilities. Additionally, the project hoped to increase the community/neighborhood's capacity for supporting its citizens in general. Funding for three years was requested, yet only one year of funding was approved. The self-determination project anticipated 15-25 indivuduals/families would participate during the first year.

Island County was also identified as a site for the self-determination project. Here, the focus was on providing self-determined or family-directed supports to families with small children (ages birth to seven). This project was designed to assist families in learning how to obtain information and access all of the supports available in their community. The goal was to have educated families who see their children as active participants in any community that they may live in, and families who know how to seek, locate and use community resources outside the developmental disabilities system.

Wisconsin (three years - $400,000)

Wisconsin's Self-Determination Project was also broken into three county sites. Winnebago County intended to change its county provider driven system into consumer driven system for people with developmental disabilities by putting support service dollars into the hands of 60 selected consumers by the end of 1997. County objectives include: (a) reduction of waiting lists, (b) cost containment, and (c) enable people with disabilities to lead regular lives.

Lacrosse County meant to develop and implement a self-determination model for 25-30 people. Objectives were to provide people with a larger choice of supports verses services, greater flexibility and a sense of control.

Dane County had already been doing self-directed services with selected participants and their families and wanted to involve additional consumers as a result of the Self-Determination Project. Participants in the project were to choose a broker, sanctioned by the county. A voucher system was to be used and consumers were to negotiate a rate with the county with help from their brokers. Objectives were to increase consumer choice and to reduce costs by removing excess staff and supports.

4 Findings: Mediating Factors

The RWJ Demonstrations are set within dynamic state contexts where a variety of factors influence how the projects have unfolded. For instance, the demonstrations were influenced by prevailing local values, service system history and spending patterns, level of commitment, system capacity and financing, politics and other factors. This chapter provides information on a range of mediating factors that may have influenced events within each state. This chapter describes the self-determination projects in terms of factors related to state (variables 1-12) and local (variables 13-14) demonstration characteristics.

State Level Mediating Factors

The following variables describe the state system context in the demonstration sites. Frequency counts are displayed as the number of states by the total number of states or localities reporting. A total number of respondents ("N") of less than 19 indicates that information for that particular variable was unavailable in some states.

Variable 1: System Configuration. The Self-determination initiative states reflect a range of organizational structures, the operational characteristics of which may influence the way that implementation goes forward. Demonstrations managed by single purpose departments, such as those in Connecticut and Massachusetts, may benefit from the targeted focus of the agency and the ability to change policies in a unilateral fashion without consulting other state agencies. On the other hand, state mental retardation/developmental disabilities agencies within an umbrella agency, such as Michigan, may benefit from the enhanced collaboration with critical collaborators, such as the Medicaid agency.

Variable 1: Configuration of the MR/DD State System

	Number of States/Valid N (%)	
MR/DD Authority is part of umbrella Human Services agency	8/18	(44.4%)
MR/DD Authority is combined with Mental Health and/or Substance Abuse	5/18	(27.8%)
MR/DD Authority is a separate state department	5/18	(27.8%)

Variable 2: Tenure of the MR/DD state director. The tenure of the state director of developmental disability services may influence the conduct of the initiative by enhancing the continuity of the project with other evolving policies. In the first year, qualitative observations would suggest that in states such as Vermont, this was certainly the case. However, other state observations suggest that longevity may also inhibit progress because of perceived threats to established leadership approaches.

Variable 2
Tenure of MR/DD State Agency Director (N = 16)

Average length of service	4.9 years
Range	1 month – 13 years

Variable 3: Configuration of Substate Systems. As the distribution of responses indicates, the demonstration states represent a range of configurations from centralized state-managed systems (e.g., Connecticut and Massachusetts), to state and local government partnerships. Observations to date suggest that each end of the centralization-decentralization spectrum has strengths and limitations. Centralized systems, such as Connecticut and Massachusetts, have the advantage of being able to make changes in an expeditious and comprehensive fashion, but lose the diversity of approaches that come with a system composed of local, idiosyncratic entities. Decentralized systems, such as Wisconsin, can point to a diversity of approaches, but appear to be less adept at ensuring system change across multiple jurisdictions.

There are also some states in transition. For instance, In the past few years, the role of the state agency in Iowa has been changing as the system has moved toward managed care. The state has assumed more costs in order to relieve property taxes, and in doing so has demanded more oversight of the county operations. County managed care mandates, more state control over service delivery, and more state control over county financial growth are the result.

Variable 3. Configuration of Sub-state System

	Number of States / Valid N	(%)
County-based public agencies	8/17	(47.1%)
State regions	6/17	(35.3%)
Local private non-profit agencies	2/17	(11.8%)
Other	1/17	(5.9%)

Variable 4: Service Population: The great majority of states define their eligible population as serving people with "developmental disabilities." These distinctions, however, are not perfect since states that ostensibly serve those with 'mental retardation" may support children with a range of disabilities in early intervention programs.

Variable 4. Definition of Service Population

	Number of States/ Valid N	(%)
Developmental disabilities	14/18	(77.8%)
Mental retardation	4/18	(22.2%)

Additionally, states that tied exclusively to developmental disabilities may adhere to a very narrow definition of the term. At this point, it is not clear that this variable has any impact on implementation of self-determination.

Variables 5-7: Characteristics of the Medicaid Waivers in use. The 1915 (c) Home and Community Based Waiver (HCBS) is a staple in the funding arsenal for long-term community support services. The Self Determination states, with the exception of Arizona, which functions on a statewide 1115 waiver, all have HCBS waivers [initiated from 7 to 19 years ago **(Variable 7)].** States may also utilize other types of Medicaid waivers, including "model 200" or "targeted case management" waivers. The role that Medicaid waivers play in the implementation of self-determination and the extent to which the structure of such waivers facilitates or hampers the initiative is a key system impact issue.

While the extent and coverage of HCBS waivers is similar across states, some of the states in the project had explored new applications and innovative changes in the basic formula. In Michigan, through a redesigned waiver, the state is pioneering the implementation of a managed care system of services and supports for persons with developmental disabilities. Michigan's waiver is a combination of the 1915(b) and 1915(c) options with a "pre-paid health plan" amendment. Captitated funding to County Community Mental Health Services Programs began in October 1998 and as these local programs became prepaid health plans or MCOs. At the same time, all ICFs/MR were decertified.

In Texas, the self-determination project is being carried out within the context of a managed care pilot supported by a significantly altered HCBS waiver. This pilot has shifted state authority functions to local authorities and created a single access point (with the exception of ICFs/MR at the local level. Ironically, however, the self-determination initiative, for the moment, is funded primarily by General Revenue monies, which allows for more flexibility. To this point, each of the three sites has avoided addressing people with disabilities who are receiving waiver services because of the administrative and financial constraints. In Minnesota, the HCBS waiver was amended to include "consumer-centered" language and the expansion of reimbursement for such activities as self-advocacy training and education. These

changes have facilitated self-determination by making the definitions of services and supports more flexible and by signaling a more holistic vision of individual needs.

Other states, such as Florida, Connecticut and Hawaii, have waivers that cover an array of services but the structure of these waivers is compartmentalized and presents roadblocks to individualized responses.

Variable 5: Waivers Implemented			Variable 6: Number of People Served Under the Main HCBS Waiver		Variable 7: Barriers Related to Flexibility of Waiver
Number of States / Valid N (%)			(N = 15)		
1915(c) HCB waiver	17/18	(94.4%)			✓ 6/17 (35.3%) of states reported barriers to "use of non-traditional providers."
1915(b) HCB waiver	1/18	(5.5%)	Average	5,539	
Pre paid Health Plan	1/16	(6.0%)	Range	2,100 – 13,000	
1915(g) Targeted Case Management	10/16	(62.5%)			✓ 4/17 (23.5%) of states reported barriers to implementation of "participant-authorized payment
1115 Waiver	1/18	(5.5%)			

Variable 8: HCB Constraints/Benefits. The structure of the waiver and the way it is administered in a state is assumed to have substantial impact on the ability of people with disabilities and the brokers who support them to secure "non-traditional," individually determined services. Almost a third of states responding reported that the waiver did provide a barrier to securing such services. However, states such as Connecticut, Arizona, Oregon and Washington suggested that their waivers facilitated access to idiosyncratic supports. For instance, Michigan informants reported that they had been able to fund the recording of a CD by an individual who wanted to be a Christian rock musician.

About a quarter of the states reported that the waiver interfered with their ability to foster "participant authorized" payment schemes. Conversely, the states of Wisconsin, Maryland, Oregon and Connecticut reported that the waiver supported such efforts.

Variable 9: CSLA Participation. Four of the self-determination states participated in the Community Supported Living Arrangements demonstration - a HCFA demonstration and early (1991) precursor of self determination. The four CSLA states were Florida, Maryland, Michigan, and Wisconsin and represented 50% of the original group of eight states. As noted earlier, CSLA was part of the "trajectory" of

reform noted earlier and it is not surprising that these same states would be interested in self determination as the next step along the spectrum of reform.

Variable 10: Managed Care. A potentially important contextual issue in self-determination is the role played by managed care. The approaches implied by managed care (e.g., capitation, local flexibility) can theoretically facilitate self-determination. On the other hand, constraints on service offerings, rates, and eligible populations can also impede self-determination. Thus in states like Michigan, the implementation of the principles of managed care are seen as beneficial to the cause of self-determination. Likewise, The primary aim of the self-determination project in Iowa is to blend the concept of "customer designed" services with the emerging, state-regulated, county managed care structure.

In Wisconsin, informants noted that the threat of the managed care "tide" to engulf services and supports to people with developmental disabilities was a stimulus for reform as well as a facilitative factor for self-determination.

Variable 10. Managed Care

12/18 (66.7%) of states reported plans for managed care strategies for long-term services for people with developmental disabilities in the year prior to the start of the Demonstration project.

8/13 (61.5%) of states reported that managed care is having an impact on self-determination activities.

Variable 11: Related Initiatives. There clearly are a number of precursors or foundations for the implementation of self-determined approaches. One significant reference point is family-directed family support. States such as New Hampshire, Michigan, and Wisconsin pioneered flexible family support programs, providing exemplars and analogues for current self-determination approaches.

More than one half of the states were mounting some effort to attack the wait list for services and supports. As was the case with impending managed care initiatives, the specter of the waiting proved to be a powerful catalyst for change in the organization of services and the ways in which resources are allocated.

Fewer than one half of the states had a statewide self-advocacy organization. Even where such organizations do exist, there is little indication that formal self-advocacy

groups have played a significant role is the design and conduct of the self-determination initiatives. This may change in subsequent years of the projects.

Further, one third of the states reported a mandate for person-centered planning - a crucial foundation for self-determination. Finally, some of the states were involved in community-oriented lawsuits and a roughly comparable number have Department of Justice investigations taking place in their institutions. The import of these state characteristics may not become apparent until project outcomes are linked with these aspects in the final analysis of the project database.

Variable 11.
Current System Demands and Elements Related to Self-Determination

18/18 (100.0%) of states presently offer some kind of family-directed family support options.

15/18 (83.3%) of states reported pre-existing self-determination activities (broadly defined).

9/17 (52.9%) of states have a specific initiative to address waiting lists.

7/18 (38.9%) of states reported the presence of a statewide self-advocacy movement.

6/18 (33.3%) of states have a relevant legislative mandate, e.g. for person-centered planning.

7/18 (38.9%) of states have a major community-oriented law suit.

5/17 (29.4%) of states have a Department of Justice inquiry.

Variable 12: Administrative Constraints. There was somewhat surprising agreement regarding the nature of the constraints that put limits on implementation of the self-determination initiative. The constraint cited most often was the lack of accounting systems capable of tracking individual budgets. There were some notable exceptions including Dakota County in Minnesota (which had developed a "checking account" system and Austin-Travers local authority in Texas that had developed a budget tracking and voucher system). It is anticipated that progress in overcoming this constraint will be made by the time the next round of site visit takes place - particularly in places like Oakland County (an affiliate Michigan site) and Metro Boston which are in the process of hiring fiscal intermediaries who will have the express responsibility of creating such accounting systems.

Variable 12.
Administrative Constraints and Challenges

	Number of Sites/ Valid N	(%)
Accounting systems do not accommodate individual budgeting	6/17	(94.1%)
Case management caseloads too high	14/17	(82.4%)
Lack of availability of support providers	14/17	(82.4%)
Inadequate Management Information Systems	13/15	(86.7%)

Case management caseloads were also seen as a constraint in several states (e.g., LaCrosse County in Wisconsin). Because many service brokers were current case managers, many - such as those in Massachusetts - noted that facilitating self-determination came on top of the responsibilities they already had. Thus with no reduction in responsibilities or caseload, self-determination efforts (though valued highly by informants) were seen as additional work.

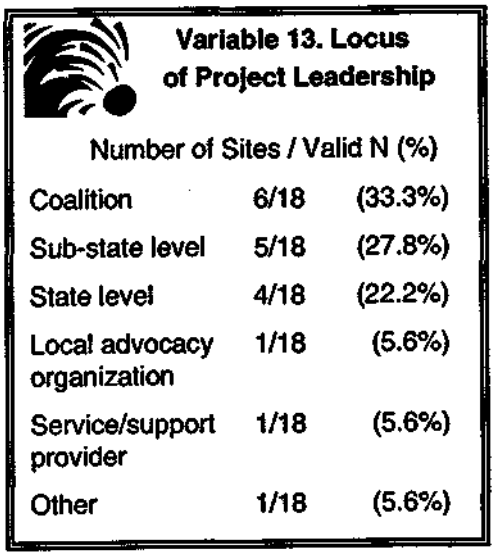
One of the hopes of the self-determination effort over time is to increase competition and availability or providers. Though this was beginning to happen in some areas, the biggest difficulty in diversifying supports was occurred in rural areas such as Blue Earth County in Minnesota and northern rural communities in New Hampshire. In the former, project staff are attempting to work with the few existing providers in order to bring about change. In New Hampshire, local area agencies are sometimes the only provider of case management and direct services and supports.

Finally, the adequacy of management information systems is also seen as a significant barrier. Winnebago County in Wisconsin designed and implemented its own system in great part to account for information within a new self-determination service structure. In tandem with subsequent results regarding the ability to develop individualized costs, this constraint will continue to pose problems.

Site Specific Characteristics

There were 40 local site demonstrations. This section summarizes the locus for project leadership and staffing constraints related to the local site. Counts are expressed as number of sites by the total number of sites reporting (percent).

Variable 13: Project Leadership. The predominant location for project leadership was within a coalition or at the local level.



Variable 13. Locus of Project Leadership

Number of Sites / Valid N (%)		
Coalition	6/18	(33.3%)
Sub-state level	5/18	(27.8%)
State level	4/18	(22.2%)
Local advocacy organization	1/18	(5.6%)
Service/support provider	1/18	(5.6%)
Other	1/18	(5.6%)

- 5/18 (27.7%) are statewide and 13/18 (72.2%) are local in scope. All of the local projects report that they are either partially or completely autonomous; none are managed centrally.
- 16/18 (88.9%) of projects report that the original authors of the project are involved with implementation. This was a particularly important variable in the success of the CSLA demonstrations several years ago.
- 4/17 (23.5%) have a contract with a self-advocacy organization to provide training or some other form of assistance.
- 11/17 (64.7%) of projects extended their timelines.
- 11/18 (61.1%) of projects report at least some expansion of self-determination to other sites around the state. Some positive and negative comments regarding the potential for expansion include:

Positive Comments	Negative Comments
lots of interest, some development	lots of talk about self-determination, but little impact so far
some participants are hopeful	structures have not penetrated the larger system
there is more talk about creating meaningful roles for self-advocates and families	skeptical that it will take off
positive willingness to change among providers	general confusion around concept; definition is evolving
self-determination principles included in multi-year plan	not much enthusiasm overall - it's up to the counties
gradually pervading state; tough for agency middle managers	

Variable 14: Staffing Constraints. In addition to issues regarding the availability of providers, it was also assumed that the availability of direct support staff influences implementation. Recruitment proved to be a particularly important issue followed by the training and values of staff. Clearly, in a system that is increasingly becoming more and more decentralized and person-centered, the quality, availability and responsiveness of direct support workers is critical.

Variable 14.
Staffing Constraints at Local Level

	Number of Sites / Valid N	(%)
Staff recruitment	28/35	(80.0%)
Training/values	26/32	(81.3%)
Staff retention	23/33	(69.7%)
Staff salaries	22/31	(71.0%)

Some of the other constraints reported included:

- lack of creativity among administrators and other;
- state fiscal regulations (which prevented non-traditional purchases);
- inflexible state funding (e.g. vocational rehabilitation funding);
- unions resistance to expanded role of case managers;
- waiting list initiative created flood of people into project sites; and
- lack of training and orientation of supervisors.

5 Findings: What Was Done

This chapter addresses "independent variables," or the actions that were taken to implement self-determination in the various sites. Through our inquiries and visits to the sites, we collected information that captures a "snapshot" of the evolving projects. As described earlier, we used a standard form and interview guide to structure the data collection. Where possible, we will summarize the different project approaches and implementation factors in quantitative terms.

A Few Assumptions and Qualifications

What follows are descriptive results. Once individual participant data has been collected by the Center on Outcome Analysis, these variables will be analyzed to determine their relationship, if any to individual outcomes.

Some sites define self-determination approaches in terms of the "tools" that are being developed including individual budgets, person-centered planning, support brokerage independent of case management, and fiscal intermediaries. Some define self-determination more broadly or have linked the project with other initiatives, such as waiting list funding, systems change, managed care implementation, or consumer-directed services. Although our assessment strategy focused on these "tools," we did not discount those sites that are approaching self-determination in other ways.

Since the projects are progressing at varying rates, many of our assessment questions were premature in some sites. Quantitative results are presented here only for variables that most of the sites were able to answer.

Independent Variables

Variable 15: Participant Selection. One of the independent factors that should have a direct bearing on individual and systemic results is the methods adopted by the sites to select project participants. It appears that most states directed the initiative to individuals already receiving services, but were interested in some sort of change (e.g., Massachusetts, Texas). However, each state and/or locality applied their own specific screens. Some of the

Variable 15. Selection Process

	Number of Sites / Valid N	(%)
First come/first served	9/35	(25.7%)
Priorities determined	8/35	(22.9%)
Random	3/35	(8.6%)
None	4/35	(11.4%)
Other	11/35	(31.4%)

approaches included: transitional youth, self-selection through calling an 800-number, good match between mentor and mentee, individuals on waiting list, family support recipients, lottery system, "readiness" criteria, "slot" conversions, and range of high and low cost participants recruited for purposes of tracking cost and quality of life outcomes.

Variable 16: Basis for Individual Budgets. One of the biggest challenges facing the self-determination initiatives is the mechanics of creating an individualized budget. To approach a truly individualized budget, there are several prerequisites including the ability to track individual costs, the availability of software to store and analyze such information, and the creation of a planning process linked to resource allocation. Not surprisingly, most of the sites used historical costs as the basis for individual budgets since this method is the easiest to implement - at least for people already in the system. Some site respondents noted that they used the supports in the plan and aggregated the costs - an approach well-tailored for people coming off the waiting list. A small number of sites started the budgeting process with a threshold amount and built on this foundation depending on the nature of the individual's needs. An even smaller number used some type of formal assessment such as a "time study" or measure tied to functional or adaptive behavior or other factors).

Variable 16:

Methods Used to Derive Individual Budgets

	Number of Sites / Valid N	(%)
Use of historical or current budget; adjust according to supports listed in the plan	23/29	(79.3%)
Aggregate costs of supports listed in person-centered plan	14/28	(50.0%)
Two-tiered approach: start with base amount, add more if needed	8/28	(28.6%)
Use of assessment measure to specify budget	6/29	(20.7%)

Variable 17: Savings Incentives. This variable deals with the presence of incentives in the program for participants to spend less than their current allocation. Of the 30 sites responding, only six of 27 (22.2%) noted that they have incentives in place for participants and families to spend less.

Variable 18: Individual Budget Oversight. This variable refers to the process used by the site to oversee individual budget expenditures. In most sites, such oversight is somewhat ad hoc. Some examples include: use of vouchers Texas), comparison of expenditures against original budgeted amount, prior approval by county (Minnesota), spending monitored by case managers on quarterly basis,

limiting control to day/employment supports only, and tracking costs by category of support. Many sites were still in the early stages of the project and had not yet developed individual budgets.

Variable 19: Support Broker Entities. This variable explores the nature of the agency structures and staff activities associated with "brokering" functions. In the initial phases of the self-determination initiatives, most sites adapted their current case management structure and "retrofitted" it as service brokerage. As a consequence, less than a third of the service brokers are characterized as "independent." Even this figure does not necessarily reflect truly independent service brokerage since some brokers, such as those in Minnesota, work for the county. The remaining brokers are part of state systems (e.g., Massachusetts and Connecticut), or part of provider organizations (e.g., Pennsylvania, parts of New Hampshire, Wisconsin, and Vermont).

Variable 20: Identification of Service Brokers. This variable addresses the status of those filling the service brokerage role reinforces that fact that most sites used existing case managers in order to get their projects off the ground (e.g., Minnesota, Texas, etc.). However, it is anticipated that in the next phase of ongoing projects, there will be more support broker options and different organizational auspices.

The nature of the role also varies from site to site. In Delaware County Ohio, the "support broker" role is not tied to a specific position. The function also includes the "resource allocator" role in addition to negotiating and navigating the service system. In Kansas, a "mentor" plays a less active role. Mentors work with an individual and a "circle of support" to develop a supports plan. Afterwards, the circle is primarily responsible for carrying the plan out.

Variable 19
Support Brokerage Entities

	Number of Sites / Valid N	(%)
Independent support brokerage	10/31	(32.3%)
Internal state system	7/31	(22.6%)
Internal provider organization	7/31	(22.6%)
Considers "support brokerage" as a "role" that can be performed by anyone, not a "position". Included staff facilitators; mentors; circles of support.	17/32	(53.1%)

Variable 20
Who Performs the Support Broker Role

	Valid N	Average %
Existing case managers	29	76.0%
New position created and new support brokers recruited	16	25.3%
Family/natural supports	17	6.5%
New case managers recruited	16	2.8%

Variable 21. Constraints on Individual Budgeting

	Number of Sites/Valid N	(%)
Lack of participant understanding	17/23	(73.9%)
Lack of family understanding	16/23	(69.6%)
Inadequate training of support brokers	13/21	(61.9%)
Insufficient natural supports	18/32	(56.3%)

Variable 22 Authority of Service Brokers

	Number of Sites/Valid N	(%)
Can approves some or all of the budget	12/27	(40.4%)
Has no authority to approve the budget	10/27	(31.0%)
Can authorize a transfer of funds	4/27	(13.8%)
Can determine which purchases are OK or not OK.	1/27	(3.7%)

Variable 21: Budgeting Constraints. With respect to constraints on the service brokerage/individual budgeting activity, equal weight was given by the sites to lack of understanding among some participants, lack of understanding among families, and inadequate training among brokers.

Variable 22: Service Broker Authority. Another essential factor in the structure of service brokerage has to do with the extent of authority granted by the system to individual brokers. Approximately 1/3 of brokers has no authority to approve the budget. However, a substantial number have the ability to approve some or all of the budget and a smaller number can authorize the transfer of funds. Clearly, such power can be a two-edged sword. If the brokers have divided loyalties (participant versus the provider or funder), then power over resources could prove detrimental to the interests of the person. On the other hand, an independent broker with no power may also not be an adequate support to the individual.

Variable 23: Service Broker Choice. Another service brokerage variable has to do with the ability of the participant to chose his or her broker. Participants in 15/28 (53.6%) sites are able to choose the support broker. However, these results are somewhat cloudy given that in some sites (e.g., Minnesota), *theoretically* participants can choose, but *realistically,* it is not an option.

Variable 24: Structure of Fiscal Intermediary. Refers to the way in which fiscal intermediaries - where they exist - are organized and what kinds of agencies are carrying out the function. Sites revealed variance in how this function is organized. In an effort to get the projects off the ground, states used whatever came to hand as **a** fiscal intermediary. Minnesota, for example, uses the county agency as a fiscal intermediary; in New Hampshire it is the area agency. In Hawaii and Oregon, a new and independent structure was established to play this role.

Given that the conception of a fiscal intermediary is somewhat fluid at this point, there are still a number of individuals who are taking advantage of these structures (i.e., out of 23 sites responding, an average of 39.7% of participants currently use a fiscal intermediary).

Variable 25: Roles of Fiscal Intermediary. The responsibilities vested in emerging fiscal intermediaries are primarily aimed at payment of staff and dealing with tax filings. Fewer sites reported that fiscal intermediaries actually participated in hiring and firing decisions and negotiation of liability and disability insurance. Connecticut relies on fiscal intermediaries in that state to also bill Medicaid. To ensure that Medicaid reimbursement is sought, the Connecticut program requires participants with budgets over $5,000 to use a fiscal intermediary.

Variable 24
Structure of Fiscal Intermediary*

	Number of Sites / Valid N	(%)
Community organization	10/13	(76.9%)
Vendor created specifically for the project	3/13	(23.1%)
Government agency	1/13	(7.7%)
Microboards	0/13	(0%)
Purchasing alliances	0/13	(0%)

Variable 25
Roles and Responsibilities of Fiscal Intermediaries

	Number of Sites / Valid N	(%)
Pay staff	13/14	(92.9%)
Pay employment taxes	13/14	(92.9%)
Reimburse providers	13/14	(92.9%)
Preparation of state audit reports	10/13	(76.9%)
Preparation of participants' tax returns	10/14	(71.4%)
Filing workers' compensation claims	8/11	(72.7%)
Disability insurance	6/14	(42.9%)
Liability insurance	6/11	(54.5%)
Hiring/firing staff	1/14	(7.1%)

Variable 26: Advisory Committees. Another ingredient of the Demonstrations is an advisory committee or council made up of key constituencies - most specifically people with disabilities and their families. The following summarizes the responses from the sites regarding the presence and composition of advisory councils.

- 28/36 (77.8%) of sites have an advisory committee;
- Out of 26 sites reporting, participants make up an average of 28.2% of advisory committee members;
- Out of 24 sites reporting, families make up an average of 19.4% of advisory committee members.
- 2/33 (6.1 %) of sites hired participants as *unpaid* project staff; 4/33 (12.1 %) hired participants as *paid* project staff.

- 4/34 (11.8%) of sites hired family members as *unpaid* project staff; 5/34 (14.7%) hired family members as *paid* project staff.
- Roles and responsibilities of participants and families include:

education and training	public relations
mentors	making spending decisions
support groups	person-centered planning facilitators
panel discussants	project facilitators
conference presenters	

Participation of people with disabilities and families on advisory committees is clearly dependent on support in the form of resources (for transportation, etc.) and facilitation. While some of the sites provided support, others did not - even though consumers and family members were expected to take part. Conversely, Vermont was extremely supportive of such participation - even to the point of paying consumers more than they did direct support staff.

Variable 27: Nature of Training.
Efforts to provide participants, family members, support brokers, and providers with information about the project and how to participate effectively were another important variable. In addition to the usual trainers, many sites used family members and people with disabilities as trainers. For example, one county in Minnesota used family members to meet with other family members to "mentor" them regarding self-determination.

Variable 27: Types of Trainers Used by Sites*

	Number of Sites / Valid N	(%)
Participants and families	18/30	(60.0%)
Community organizers	15/30	(50.0%)
Fiscal experts	10/30	(33.3%)

*Others: accountants, project staff, mentors, New Hampshire project organizers, providers, self-advocates, person-centered planning experts, UAP.

Key constituencies who were the targets of training included:

- 30/35 (85.7%) of project sites trained participants and families.
- 24/32 (75.0%) of project sites trained providers.
- 21/26 (80.8%) of projects trained support brokers.

Further, all projects that reported receiving technical assistance from the National Program Office stated that the support was "extremely helpful." Some sites desired more assistance at the local project level.

Some of the topics covered during the training provided across sites included:

Major focus:

- general self-determination
- person-centered planning
- range of supports
- money management
- values
- community integration
- organizational change
- implementation issues
- developing networks

Minor focus:

- labor law
- liability
- managing payroll
- employee benefits
- MIS development

Other topics addressed:

vocational issues
personal outcomes
conflict resolution and mediation
self-advocacy
federal policy
history of the system
quality enhancement
shifting control
team building
group facilitation

Variable 28: Outreach. In addition to training, the sites used a variety of methods to "get the word" out regarding the self-determination initiative. Presentations proved to be the most popular methods but sites also used "new media" such as videos and the Internet. Other non-traditional activities included consumer booklets, self-determination game, rap song, family nights, bonus given to regional areas that put together a self-determination plan, self-determination newsletters, guidebook/compilations of stories highlighting participants, and use of an ICN network to hold satellite training across state.

Variable 28
Strategies Used to Get the Word Out

	Number of Sites / Valid N	(%)
Presentations	32/38	(84.2%)
Articles	28/40	(70.0%)
Brochures	27/39	(69.2%)
Direct Mail	18/33	(54.5%)
Videos	11/38	(28.9%)
Internet	8/34	(23.5%)

Variable 29:. The next issue has to do the elimination, waiver or alteration of rules or regulations in order to facilitate implementation of self-determination. Some of the regulations/policies that were seen as in need of change included:

Variable 29
Use of Pure State and Local Resources

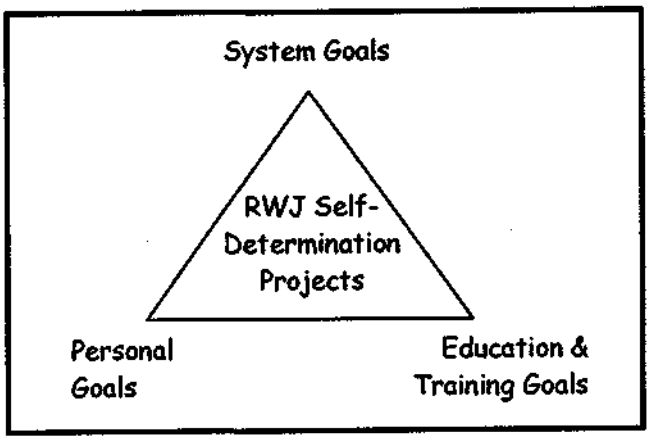
	Number of Sites / Valid N	(%)
Training	18/31	(58.1%)
Non-traditional purchases	16/31	(51.6%)
Fiscal Intermediaries	7/31	(22.6%)
Support brokers	7/31	(22.6%)

Other uses: peer support and self-advocacy initiatives, consultants.

- 13/18 (72.2%) of states reported funding as a constraint.
- 13/17 (76.5%) reported restrictions on the use of public funds.
- 10/17 (58.8%) of states reported hour/wage laws as a constraint.
- Other constraints reported:
  - categorical funding;
  - licensing regulations;
  - how to promote self-determination when there are others waiting for services;
  - waivers are too numerous and complicated; and
  - paperwork.

It was also interesting to note the ways in which states and sites used "pure" state funds - those funds that were not used to match federal funds (e.g., Title XIX). The fact that some sites used state funds to finance fiscal intermediaries and support brokers begs the question of how these functions will be funded in the future.

6 Findings: First Year Progress



Three fundamental goal clusters emerged from the 19 RWJ Demonstration Sites. These clusters include: (a) system-centered goals, (b) person-centered goals, and (c) education and training goals.

While progress was not even or easily achieved, the RWJ Demonstration Sites took significant strides toward achieving what they set out to do. Organizational and financing structures were thought through and established. A number of people began to receive supports based in self-determination principles. Policy and regulatory goals were pursued, and many people at all levels of the system became better informed about self-determination.

In this chapter, these clusters are described and findings related to each is offered. Some of these findings relate to the "dependent variables" or outcomes that were targeted directly during the site visits, while others reflect a more summary analysis.

Three Goal Clusters and Findings to Date

The goals pursued by the RWJ Demonstrations pertain to aspects of the service system and the lives of individuals with developmental disabilities. There were also project goals related to "spreading the word" about the Demonstrations, and building knowledge and skills among many pertaining to self-determination. Clearly, the truest test of the Demonstrations' concerns the impact on individual lives, an outcome that is targeted by the assessment undertaken by the Center for Outcome Analysis. This analysis reflects outcomes related to systems level changes and educational activities, as well as "proxy" participant outcomes.

Goal Area 1

System-Centered Goals

All 19 state project sites made it their goal to rearrange some or all of their associated state developmental disabilities service systems. The overall intent was to achieve widespread systems change related to self-

determination. Sites differed, however, regarding the projected scope and pace of change.

Review of the goals set by each state reveals two distinct strategies for systems change. The first, applied by most states, utilizes the RWJ initiative as a limited "learning laboratory" (e.g., Oregon, Massachusetts, Kansas, Pennsylvania). This strategy revolves around starting small, learning a lot, and putting the lessons to work elsewhere over time. States may have articulated a desire to expand the pilots to other sites, but the general intent was to gain experience and work out any technical difficulties with a small number of people before attempting to change over the entire system.

A second strategy, pursued by a few states or counties, was more ambitious. This approach bypasses or accelerates the piloting phase and involves changing entire systems over to a self-determination structure (e.g., Maryland, Michigan, Vermont, Winnebago and Dane Counties in Wisconsin). The intent is to set broad systems change vision, and align relevant administrative, fiscal and service practices with the new vision.

Aside from differences in strategy, the system centered goals that states planned to achieve included the following:

Involve self-advocates and family members in policy planning and implementation (e.g., Oregon, Iowa, Massachusetts).

Create a policy environment favorable to self determination, while eliminating current system barriers to self-determination. This may have included goals related to financing or rules and regulations, (e.g. Arizona, Iowa, Michigan).

Develop a working structure for delivering supports based in self-determiantion principles, including resolution of any technical difficulties. This was an essential systems goal articulated by all states. States may have included objectives related to setting personal budgets, establishing "broker" or fiscal intermediary functions, exploring news means for assuring quality or re-defining the roles played by the payer, support providers and participants, and establishing new standards for licensing and accreditation.

Expand system capacity by encouraging use of alternative or informal sources of support (e.g., Massachusetts, Vermont, Iowa).

Decrease overall costs for delivering services and/or improve cost efficiency (e.g., Arizona, Hawaii, Maryland, Massachusetts, Michigan, New Hampshire, Texas, Wisconsin).

Decrease wait lists by investing any savings in additional service capacity (e.g, Maryland, Utah).

Establish a system-wide culture that routinely delivers supports consistent with the principles of self-determination (e.g., Florida, Kansas, Wisconsin).

Goals like these were ambitious and were not all summarily achieved. Yet most states made significant progress on many of the stated goals. For instance, self-advocates and family members often were involved in policy planning and implementation, though not at all sites and the level of their participation varied. Likewise, all states succeeded at developing a working structure for delivering supports based in self-determination principles. The structures, however, varied in design and complexity. Additionally, sites worked hard - albeit without decisive impact yet ~ to widen the range of supports available to individuals, including use of informal or "non-traditional" supports, and to establish a policy environment more favorable to "self-determination."

Progress on other goals was more elusive. Goals related to serving specified numbers of people, decreasing costs or wait lists, or establishing a system-wide culture for delivering supports routinely consistent with self-determination were not immediately met during the first year of the projects. States typically made progress at a slower rate than was initially anticipated. This is not surprising since achieving goals like these will predictably take time and much additional effort. Indeed, in many states the planning process alone took up a good part of the first year.

Specific findings related to our site visits include the following:

Variable 30: Control of Funds. One of the key changes that would be expected as states move closer to self-determination is a shift in the control of funds from providers to individuals and families. The initial findings suggest that there is movement in that direction. Among those sites reporting, the proportion of people participating in the initiative who control their own budgets doubled in the first year. Given the range of approaches reflected in the various sites, the notion of "control" potentially varies from the "directing of resources" (i.e., deciding to whom and to what resources should flow as was the case in Texas) to "allocating resources," most notably through voucher based systems where disbursements are directed by the participant through a fiscal intermediary (e.g., Oregon, Dakota County in Minnesota, Wisconsin, Kansas).

Variable 30: Control of Funds

	Average % of funds controlled by participants	Average % of funds distributed directly to providers
At onset of project	20% (N = 15)	81% (N = 18)
At end of year one	41% (N = 16)	65% (N = 19)

Variable 31: Realization of Savings. An important potential outcome of the implementation of self-determination is a more efficient allocation of resources. The preliminary results suggest that about 1/3 of the sites have experienced some sort of savings. In some instances (Minnesota), the savings are kept in reserve for the individual as a sort of personal "risk pool." In Kansas individual service rates, keyed to a tiered system, are discounted 10% from the outset with another 10% held in "risk reserve." In other instances, such as Massachusetts and Oregon, savings are made available to support services for other individuals.

Variable 31 Realization of Savings		
Project has resulted in savings	8/21	(38.1%)
Project has not resulted in savings	12/21	(57.1%)
Don't know	1/21	(4.8%)

Variable 32 Case Manager Caseloads. A potentially interesting outcome is the differential in case manager/ service broker case loads between the self-determination initiative and the basic system. Case manager/ service brokers in the self-determination project not only began the program with lower case loads but also ended the first year with even lower case loads. This finding could mean that service brokers were given more "space" to gear up for the program and to concentrate on the transition that both they and the participants were about to make. Given that many brokers who were interviewed characterized the start up of the self-determination initiative as "labor intensive," these smaller case loads would be welcome. This finding is still inconclusive, however, and will be explored in Year 2.

Variable 32: Average Case Manager Caseloads		
	CMs involved In the project	CMs not involved in the project
At project onset	48 (N = 21)	67 (N = 16)
At the end of year one	46 (N = 21)	67 (N = 17)

Variable 33 & 34: Ability to Track Costs. As states and localities attempt to develop unique budgets to reflect the individual choices and participant preferences, it will be necessary to develop systems that track individual expenditures and allocations. The numbers of sites that reported the capacity to track individual costs went up slightly during the first year, however the ability to" deconstruct" costs and to reassemble allocations based on individualized plans is still an elusive goal in most

sites. The ability to track costs in relation of participant characteristics, service needs, and services utilization increased even more slowly.

Variable 33: Ability to Track Costs in Relation to Participant Characteristics, Services Needs, and Services Utilization

	Yes	Partial Ability
Project onset	5/28 (17.9%)	4/28 (14.3%)
End of year one	7/22 (31.8%)	5/22 (22.7%)

Variable 34: Ability to Track Costs to Serve Individuals

	Yes	Partial Ability
Project Onset	6/28 (21.4%)	5/28 (17.9%)
End of year one	10/27 (37.0%)	8/27 (29.6%)

Variables 35-37: Changes in Provider Configuration. A final cluster of possible outcomes of self-determination initiatives has to do with its impact on the configuration of the provider community. Potential influences include an increase in competitiveness, an increase in the number of provider agencies, and an expanded use of generic services.

Among the sites responding, there are clearly contradictory results with approximately half seeing and increase and another half sensing a decrease in provider competitiveness. With respect the numbers of providers, there appears to be a small increase in some sites - again a finding that is inconclusive at this point.

Finally, almost two thirds of the sites reported that the use of generic (alternative or "non-traditional" developmental disability services) increased. Specifically, Wisconsin and Oregon among other respondents reported using generic home/health services and other forms of home supports for participants enrolled in the program.

These findings, however, should be treated for what they are - tentative first year findings. Most sites were not fully up and running during the site visits. As a result, we are uncertain of what to make of these findings, but will target these and other related issues in the second year of the inquiry.

Variable 35 Projects' Perception of Competition Among Providers in Year One

Number of Sites / Valid N		(%)
Increased	14/31	(45.2%)
Decreased	16/31	(51.6%)
No change	1/31	(3.2%)

Variable 36 Average Number of Individual Provider Organizations

Project onset	20	(N = 16)
End of year one	27	(N = 15)

Variable 37 Projects' Perception of Changes in Utilization of Generic Services in YR One

Number of Sites / Valid N		(%)
Increased	16/25	(64.0%)
Decreased	8/25	(32.0%)
No change	1/25	(4.0%)

Goal Area 2

Person-Centered Goals

A chief feature of the RWJ initiatives revolved around serving some number of people within a self-determination supports structure. In addition, most states also aimed to increase the control individuals exerted over their supports and lives, improve individual quality of life, and increase individual use of alternative or informal supports.

Eighteen of the 19 states had as a goal to serve a specific number of people in more self-determined ways by the project's end. There was variance between what states sought to accomplish in this area. Some set conservative goals while others were more ambitious (e.g., Oregon expected to serve about 60 individuals in one pilot site, New Hampshire's mission was to serve 300, Utah aimed for 1,100).

For the majority of the states who had goals relating to increased personal control or empowerment, it meant that participants would control both their own service dollars and the choices affecting their lives. For example, Hawaii sought to "enable persons with developmental disabilities to make decisions on what supports and services they need, and how to allocate funds to obtain these supports and services." Florida, Michigan, Oregon, Maryland, and Pennsylvania are other states make similar declarations.

Several states expected that the individual's overall quality of life would improve when supports were planned and delivered in ways consistent with self-determination (e.g. Hawaii, Maryland, Michigan).

Several states articulated goals related to promoting greater partnership involving participants and their communities, including focus on utilizing informal supports. Florida, for example, aimed to support development of mutual relationships between community members and "generic community resources as personal and family supports". Massachusetts proposed to, "increase community capacity to serve as a natural resource to persons with disabilities." Iowa sought to encourage use of "natural supports and generic services."

Again, it can be stated that states made progress in achieving these goals, but after one year of work there is still much to do. Overall, states proceeded at a slower pace than what was initially planned. Planning takes time, especially when difficult structural and procedural issues are at stake. Further, such planning was simply pre-requisite to overcoming difficulties associated with actual implementation of the plan.

Taken together, these challenges proved formidable and states generally did not meet their stated year one goals related to serving a particular number of people within the Self-determination Demonstration. As a result, related goals tied to improvements in quality of life or promoting greater partnership involving participants and their_____

communities were not definitively achieved for the numbers of people anticipated. These findings should not be interpreted as negative or as a sign of "failure." To the contrary, with some exceptions, states steadily moved along their course and gained momentum as their first project year drew to a close. We anticipate more instructive findings in this goal area during our second year inquiry.

Goal Area 3

Education and Training

Several states set goals related to training and education related to self-determination. The intent and targets of such instruction, however, varied. All in all, most states emphasized that the overall purpose was to make people aware of the underlying principles and mechanics of planned systems change so that all groups could participate in the change effort.

Generally, instructional topics in most states included: (a) the underlying values of how self-determination; and (b) information pertaining to the workings of the initiative (e.g., person-centered planning, individual budgeting, support brokerage, and quality assurance).

Such instruction primarily targeted participants, family members, existing case managers, project team participants and staff, and service providers. Some states emphasized training for particular target audiences, though about half emphasized instruction for all target audiences (e.g., Oregon, Maryland, Massachusetts, Minnesota, New Hampshire, Ohio, Utah. Texas and Vermont).

Florida, Texas and Wisconsin had especially noteworthy goals around education and training targeted specifically to people with developmental disabilities. These states had goals around teaching participants how to make choices and communication of those choices - two skills required to make a self-determination structure work.

Generally, states were energetic in pursuing these goals. Sites created videos, brochures and other materials to build awareness for the Demonstration. Numerous presentations were given at conferences and other meetings. Moreover, targeted training was provided to a variety of audiences to "spread the word" about the Demonstration and solicit input.

However, two difficulties were observed. First, because the precise structure of each Demonstration took time to take shape, the "training" offered was often more grounded in the generalities of self-determination than in the specifics of how it would "work." This was especially true in the early stages of the Demonstrations and may acted to dampen support for the effort as some took a "wait and see atiitude."

Second, with notable exceptions (e.g. Wisconsin, Texas) training or educational awareness activities were not generally tailored for or directed at self-advocates. Family members, providers and advocates may have profited greatly from these activities, but not necessarily self-advocates. In this regard, during our site visits there was a growing recognition of the need to engage self-advocates more effectively.

7 Observations and Concluding Remarks

In addition to collecting information on project characteristics, activities and outcomes, we also spoke with many people who were associated with the Demonstrations. Collectively, these individuals represented a range of constituencies, including self-determination staff, service providers, administrators, self-advocates, family members, policy makers and so forth. These qualitative interviews yielded rich information on the actual implementation of self-determination practices. Project staff also deliberated over the findings and their implications, seeking to explore similarities or differences between sites and to gain further common insight.

Like all qualitative methods, however, there is an underlying assumption that those providing the information are representative of others who are similarly situated. Additionally, we recognize that throughout the year -- and even prior to the initial funding of the sites -- staff at RWJ Self-Determination National Program Office made a variety of strategic decisions related to the development of the demonstrations. Such decisions pertained to the administrative entity that could apply for RWJ funding (i.e., state agencies only), the substance of the technical assistance that was offered, the organization and conduct of national conferences, and other actions that guided site activities. Staff also commented that such decisions often reflected emphasis on a developmental sequence within sites that could take several years to play out. For instance, at the start emphasis may have been placed on resolving structural issues. Later on, the focus might shift to educating and involving self-advocates. Collectively, these decisions helped to define the substance of the demonstrations and influenced their development for the short and long term.

With these caveats in mind, our deliberations touched on many issues. Our resulting opinions are just that - opinion. The following discussion presents overall observations and themes drawn from these interviews as well as the structured data collection discussed above. Finally, preliminary conclusions that one can draw from the experience to date are offered.

Observations On The Progress of The Demonstrations

Several factors aided or hindered the progress made by the Demonstrations. It is important to note, however, that these factors were not necessarily equally observed in all states. Moreover, some factors may have acted as a boon in some states and as a hindrance in others. Or a factor may have acted as both a facilitator and constraint over time. Finally, these factors were all at work within a dynamic systems context (See

Chapter 4). In listing these factors, we seek only to describe each and note generally on what side of the ledger they fell. The graphic on the following page shows these key factors in relation to other study variables.

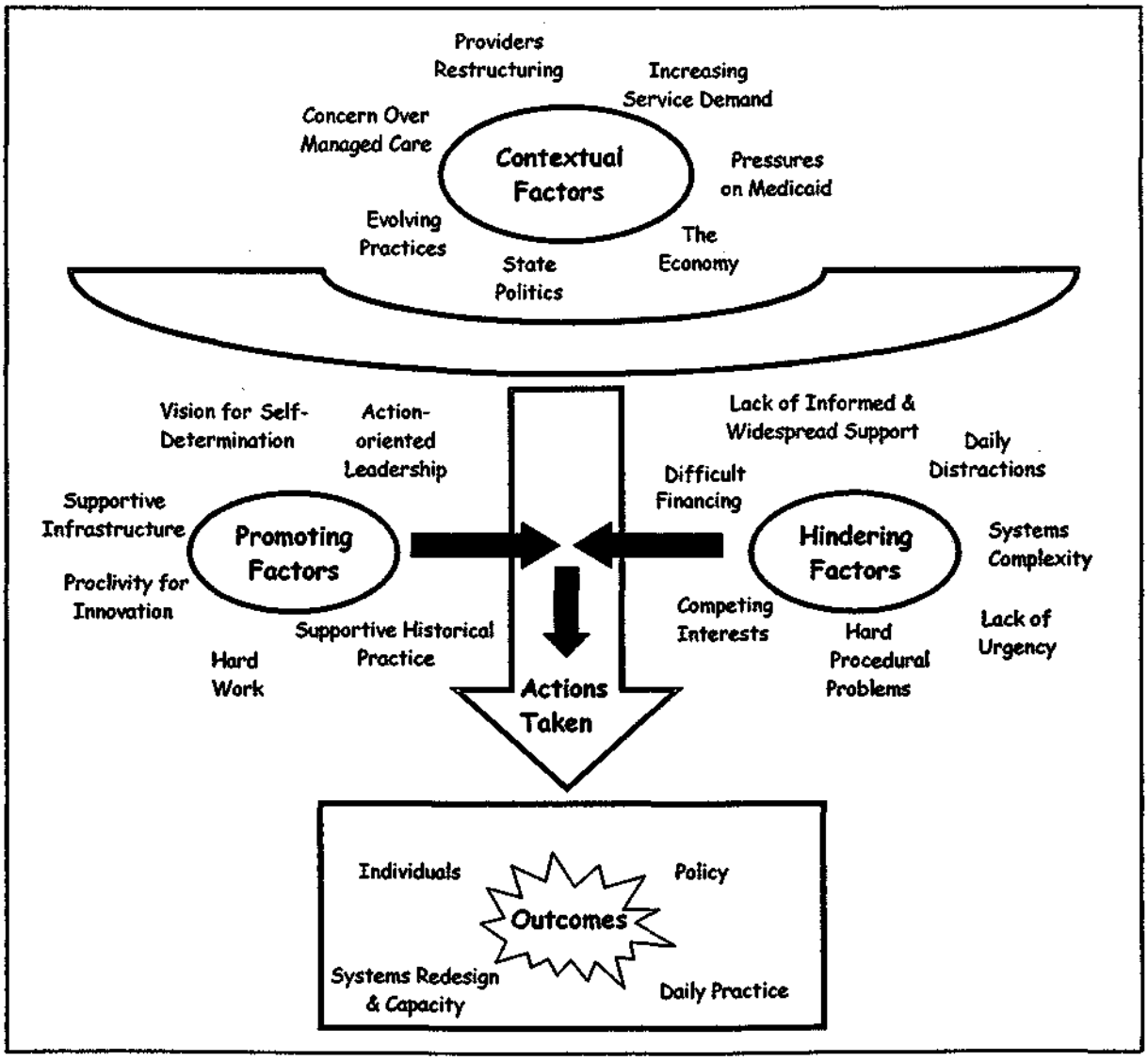
Factors Aiding the RWJ Demonstration Sites

We can discuss a variety of discrete factors that contributed to the success of the RWJ Demonstrations. Five, however, stand out:

A clarity of vision and action oriented leadership:

The presence of strong and enduring leadership at the state and/or local level was crucial to the success of the self-determination effort.

Contextual, Aiding and Hindering Factors Affecting The RWJ Self-Determination Demonstrations



A strong commitment among many to make self-determination work:

What becomes obviously apparent from our site visits is that many people across the country worked hard to make their projects succeed. We collected volumes of materials to illustrate the thinking and status of the projects. And we heard ample testimony to indicate that there is a staunch and strong resolve for making the self-determination projects work. Such commitment carried the projects throughout, and especially through times when the barriers to success seemed great.

The commitment demonstrated in the states was buoyed by the persistent and welcomed assistance provided by the Self-Determination National Program Office. Grant recipients often made note of the annual conferences, the information made available, and the onsite technical assistance as factors that contributed to success.

Supportive systems infrastructure:

The less complicated the task of building an infrastructure for self-determination, the more expeditious the implementation of the reform. In other words, where much of the "underbrush" had been cleared or where systems were relatively transparent (e.g., VT, KA), the process for self-determination was easier. Conversely, where systems were already complicated to negotiate, the process was slowed (e.g., PA, MA, OR).

Supportive financing:

% Financing that emphasizes individualized, flexible supports is an important facilitating factor in the implementation of self-determination practices. Such financing is in great measure possible through use of a flexible Medicaid Home and Community Based waiver (Smith, 1997). This waiver, if carefully structured, potentially can accommodate much of the support a person may need. This was evident in states like Vermont, Wisconsin, Michigan, Kansas, and especially so in Minnesota where "consumer centered supports" were explicitly identified. This state also included "consumer education" as a waiver service to provide means for offering self-advocates important education on self-determination and other topics.

State or counties where generous resources were available to support individual budgets as well as small caseload size for service brokers had a distinct advantage in the move to self-determination. When overall spending is depicted as a proportion of statewide personal income that is devoted to developmental disabilities, seven of the RWJ Demonstration states (VT, MN, CT, NH, IA, MI and MA) were among the top 15 states in 1996 (Braddock et al., 1998).

Supportive history and a proclivity for innovation:

In several states, including New Hampshire, Oregon, Pennsylvania, Michigan and Vermont, the presence of a stable and comprehensive family support policy were important to the implementation of the self-determination projects. Family support programs have long sought to provide maximally flexible supports. Over 30 states already offer such support through some form of cash assistance, with nearly 20 offering direct cash grants (Agosta & Melda, 1995; Braddock et al., 1998). Innovation tied to individual budgeting or "brokering" are not new family support practices. As a result, these programs provided an example of the flexible use of resources and the emphasis on accommodating individualized needs.

In Michigan, Vermont, Pennsylvania, Kansas and New Hampshire a preceding or concurrent commitment to system reform based in self-determination principles was an enhancing factor in the initiation of the Demonstrations. Such reform may have included a managed supports waiver, long term policy and programmatic reform, or a multi-year plan.

Connecticut, Vermont, Oregon and Wisconsin were some of the states whose self-determination efforts benefited from a foundation of practice based on person-centered planning technique, a practice that is crucial to the clarification of individual preferences and choices.

Florida, Maryland, Michigan, Texas and Wisconsin had previously been "CSLA" states - a status that allowed them to use Medicaid Title XIX funding for individualized residential settings in a very flexible fashion. The CSLA program was also premised on many of the same principles that guide self-determination efforts.

Factors Hindering the RWJ Demonstration Sites

The Demonstration Sites encountered a variety of obstacles in pursuit of their goal. Seven such factors include:

The relatively short duration of the RWJ grant awards, and for some states the relatively modest amount of the award.

States (with the exception of New Hampshire) were awarded grants of one, two or three years in length. Additionally, the award amounts -- related to their duration ~ ranged from $100,000 to $400,000. Certainly, states appreciated the assistance. However, the challenges these states faced in making system change were formidable. Placed in perspective, these grant awards may have been too small (e.g., as in the cases of Washington and Florida) and insufficient in

duration to assure dramatic and enduring change. On the other hand, in settling on this approach the National Program Office made a strategic decision that may have - in the short term -- paid off better some states than others. The overall effect of this strategy may take several years to unfold, and so assess.

In a related observation, several states staffed the "RWJ Demonstration" with new "project-only" hires. In fact, as the Demonstration project's RWJ funding wound down, questions were often raised about the future of such ad hoc staff and their project. In some states, these staff and their work were at risk of being marginalized. Because they had no permanent or structural authority or status within the state or local systems, these staff were vulnerable. Where this occurred, the capacity for Demonstration staff to lead and act effectively was undercut.

An absence of a sense of urgency for change:

One of the most crucial ingredients to the success of any significant change initiative is a strong sense of urgency for making change. Kotter (1995) rates an absence of urgency as the leading cause of failure in such initiatives.

In the mid-1990s, the potential for Medicaid reform, the possible application of managed care strategies, and the growing waiting list for services did much to stimulate a willingness to change developmental disabilities systems. Program structures related to self-determination provided a basis for making change that was consistent with best-practice ideals and demands for cost efficiency (Agosta &Kimmich, 1997).

More recently, however, concerns over Medicaid reform and managed care have dissipated and several states have initiated efforts to reduce wait lists (e.g., in RWJ states such as FL, MA, PA, UT, OR, NH). As a result, the willingness to adopt radical solutions to seemingly intractable problems has decreased. Such a lack of immediacy means that self-determination is unfolding in a more incremental fashion.

An embryonic and still emerging constituency to support the Demonstrations:

"Self-determination" is thought by many to be an irresistible concept that requires no argument or justification. It is. Yet, at the time of our first year assessment, we did not observe a widespread constituency for the systemic changes sought by the Demonstrations. Energy for the effort was young and still emerging.

Certainly, self-advocates and family members were typically, but not always, involved with project planning and advisement. The associated enthusiasm for the project, however, did not easily or readily spread out among broader

numbers of people. This was especially noticeable among self-advocates as we observed that as an organized constituency self-advocates played a limited role in the Demonstrations. Recall that fewer than one-half (7/18) of the participating states report the presence of statewide self-advocacy organizations (Variable 11; p. 34), and fewer (4/17) contracted with a self-advocacy organization to provide training or technical assistance on self-determination (Variable 13; p. 36).

This is not to suggest that individuals with developmental disabilities do not want to control their lives. They do, and say as much. Nor does it suggest that the individuals associated with the Demonstrations were unaware of the need to engage self-advocates and family members in the change process. Much effort was exerted toward this goal.

At the time of our first year assessment, however, it was apparent that while "self-determination" enjoys broad appeal, its associated implementation and systems transformation had not yet truly engaged large numbers of self-advocates or family members. Again, in settling on its first year strategies, National Program Office staff, while recognizing the importance of self advocates to the effort, understood that strong grassroots participation might be slow to develop and that increased involvement from self-advocates might not be seen until the second or third years. Still, during the first year, in most states the Demonstrations appeared to be more a result of what professionals were doing to adjust the system than what self-advocates and families were demanding be done. There may be several explanations. For instance:

- Self-advocates may have been pre-occupied with other priorities (e.g., closing state institutions in favor of community systems) and could not turn their immediate or full attention to the Demonstrations.
- Policy makers, unpracticed at involving self-advocates in shaping disability policy, may not have done enough to: (a) assure that self-advocates were amply represented (and supported) at policy making sessions, or (b) inform and engage self-advocates as an overall constituency for self-determination.
- The changes necessary to implement self-determination can be threatening to many established interests or traditional constituencies (e.g., service providers, some family groups). Some of these groups (most notably some service providers) showed little enthusiasm for changes related to of self-determination, and did not work to promote the concept. In fact, state Demonstrations were sometimes met with outright resistance.
- Most of the Demonstrations were construed as "pilots" or "learning laboratories." As a result, from the start potential support for the effort was limited because the pilots themselves were limited. While there may have

been general widespread interest in the concept -- and sites were quite vigorous about "spreading the word" -- most self-advocates and family members were not operationally engaged in the pilots.

We noticed, however, that interest in the Demonstrations seemed more vigorous among younger self-advocates (e.g., individuals transitioning from school or young adults) or families of young children living at home. Such generational differences are not easily explained and warrant further study.

Most sites did not immediately target individuals who were already receiving residential or day-time services, focusing instead on families who were already receiving family support services or new service recipients taken off of the wait list. Moreover, the allocations associated with these service recipients were generally modest in comparison to allocations for individuals served in traditional services (e.g., ICFs-MR, day habilitation). In essence, the standing "slot system," and its associated providers and service recipients remained largely unaffected by the Demonstrations. These practices, while perhaps pragmatic in face of local resistance or uncertain project structures, failed to actively engage most service recipients.

The initial working structures developed by these Demonstrations depart significantly from the status quo, and can be quite complicated to understand and manage. New words were introduced (e.g., broker, intermediary, risk) and multiple structural variations were considered. The resulting "apparatus" of self-determination may in some cases simply outweigh its procedural appeal. Until project structures get simpler to negotiate or more familiar, self-advocates and family members may prefer to stay with their current service configuration. This may be especially true where people are relatively satisfied with their current services.

While recognized as an important element to success, engaging self-advocates and family members in large numbers may not have always received top priority. During the first year, the sites did exert great energy for "spreading the word." A primary focus, however, was on the formidable task of making the projects operational (e.g., hiring staff, establishing an advisory committee, wrestling with many knotty issues). There were many issues to work out within stringent timelines. Past the first year, greater focus may be placed on engaging self-advocates and family members as a vigorous constituency for change. Further, this constituency may itself emerge on its own and with its own voice for self-determination, especially as the Demonstrations take root and expand. As illustrated later, we intend to examine this issue in detail during our second year assessment.

Difficult issues to resolve regarding the mechanics of self-determination:

The idea of "self-determination" may appear simple and irresistible but beyond its broad stroke appeal, it has proven difficult to define with consensus agreement, operationalize and put into practice. This should not surprise any, given that one purpose for the demonstrations was to identify and resolve the procedural issues related to self-determination.

Frankly, one reason for such difficulty pertains to a fundamental resistance among some to the idea of ceding authority over allocations to self-advocates and family members. Service providers were not immediately enthused over the idea of "competing" for the business of participants. Fiscal managers expressed concerns over the absence of satisfactory "audit trails" or the "appropriate use" of public funds. County and state government wrestled over a re-interpretation of their respective roles. Case managers wondered how their efforts differed from those of "brokers." Issues like these touch on the locus of control in systems, and on the flow of money and power, topics that inevitably result in argument and resistance to change.

Aside from these matters, states encountered an assortment of brain teasing issues. Examples include:

- Coping with an evolving definition and understanding of what "self-determination" means. The National Program Office provided guidance on this matter, though in the field there is an ongoing dialog over the meaning of the concept, and the interpretations of its supporting principles. So far, much of the discussion surrounding self-determination seems keyed to the "personal liberties" side of the equation, based in the belief that individuals have a right to control their own life. Yet there are other civil liberties that must be taken into account. Just as important as the idea of personal freedom are notions such as non-discrimination or "equal treatment." These other concepts bring up the notions such as the "collective well-being" or equity. Aside from a commitment to "personal freedom and control," decision-makers must also assure that that the service system is "fair" to all and has the common benefit in mind.

- The means for compiling person centered plans and budgets. While states are familiar with person-centered planning, the idea of pairing this planning with an allocated budget was novel (See Agosta & Kelsch, 1999). Our observations suggest that this particular issue is among the most difficult for states to resolve. There are two fundamental and related issues to work through: (a) Should individuals be informed of the allocation amounts, and if so, when? and (b) How should allocation amounts be set?

1. Sites needed to decide whether individuals were going to be told of their allocation amounts at all, and if so, when would they be told -- before or after the personal planning process. Some argue that individuals should be given a pre-set budget or budget range to plan around, so that they may plan while knowing what resources are available. While this approach maximizes personal power, it subtracts discretionary power from system administrators. Critics also claim that people would likely plan to spend their full amount, resulting in few savings.

   An alternative strategy is to defer any discussion of an allocation until after a personal planning process where needs are identified and budgets built to match the stated needs. Proponents maintain that the tactic is maximally "person centered" and allows systems planners to move dollars where they are needed. One drawback is that individuals are planning "in the blind" and that too much discretionary power may rest with the planning coordinator (i.e., the "broker") and the funder.

2. Additionally, sites needed to establish a process for setting an allocation or at least an allocation "ceiling." There are currently two schools of thought for setting budgets. One approach is based on quantitative measurement where individuals are assessed regarding their demographic characteristics (e.g., age, diagnostic criteria), functional capacity (e.g., daily living skills, extraordinary medical, physical or behavioral challenges), available resources, and other variables, including informal or alternative resources that the individual can utilize instead of publicly financed services.

   Once the assessment is completed, a composite score is tallied and associated with a budget amount. The statistical relationships can grow complicated, utilizing historical rates or other systems variables and correlation analyses. Budget amounts can be set differently for each person, or individuals can be assigned to groups with an associated budget.

   A potential advantage to this method is that everyone goes through the same formal assessment process, and if the measuring tool is well tested it can be made statistically reliable. Proponents argue that it is a "fair" or equitable way to set budgets. Additionally, from the start system administrators have precise knowledge of the resources allocated to each individual, and so the amount allocated overall. Detractors note that the system cannot be truly "person centered" since any measuring tool and its resulting statistical scores cannot possibly take into account the full circumstances of individuals. Inevitably, some will be allocated too much money while others too little.

The second approach is to create a budget that is based on a personal planning process that specifies the individual's needs and preferences. Personal budgets are developed based on the cost of needed services and other factors, including use of natural or alternative supports. Budget amounts may be calculated based on historical rates for services or what the service may be purchased for locally. Once a budget figure is reached, it may require approval by an oversight authority. This added step is necessary so that the sum of the individual budgets does not exceed the total budget for all participants.

An advantage to this budget setting method is that it allows individualized flexibility. The participant's life is planned and then financed according to the individual's needs. On the other hand, this method could become tedious -- and costly - because of the planning time required, the number of people who could become involved, and number of times the individual's budget proposal might be rejected before it is accepted by the funder.

Frustrations may also arise just by virtue of not knowing how high a budget can reach. Finally, there is concern over how equitable this approach is when played out over time and large numbers of people. Ultimately, individual budgets may depend on how assertive one is during the planning process or on the skills or preferences of the planning coordinator.

This overall issue and the decision process within Demonstrations was especially troublesome in states where historical means for setting individual rates are cumbersome and contentious. In states like these, there is no equitable or commonly agreed "starting point" to begin discussions over setting personal budgets.

- Settling on the role and functions of the "service broker" as opposed to traditional "case management" or "service coordination" and placing it efficiently -- with financing - within the present system.

- Determining the most efficient means for managing and accounting for person-centered budgets and resulting spending.

- Working through the legal and tax implications of individuals managing their own budgets, and the structure and responsibilities of fiscal intermediaries.

- Deciding on what to do with any savings that may be realized from the initiative. Can or should savings be shared with participants or reallocated to fund other people or other systems interests?

- Settling and growing comfortable with the new roles that must be played by government, individuals, families and providers. This was especially troublesome where state and county government needed to think through and establish new roles.

- Deciding on how to manage financial and personal risk. Should a "risk reserve" be established? If so, how should it be financed and managed?

- Thinking through and developing new ways to manage information and. assure health and safety of individuals, and monitor supports quality.

Those states that had to build an infrastructure for self-determination from scratch had a more difficult time in implementing the reforms.

Because the transformation of a service system requires some new skills and competencies, success in large measure is contingent on a critical mass of individuals who are committed to self-determination principles. This includes, among other matters, a commitment to ceding authority to self-advocates and family members, and the willingness and skills to be flexible and take reasonable risks. In some states, such expertise is thin.

The National Program Office on Self-Determination provided assistance to offset these difficulties, and it was greatly valued. Program Office staff went on-site to provide information, speak with great numbers of people (e.g., policy makers, self-advocates, family members, providers) about self-determination, share experiences from other states, mediate disagreement, and otherwise help the Demonstrations along. And the sites learned much from one another. After all, it was expected that the individuals working within the Demonstrations would identify, wrestle with and resolve numerous issues through their own effort. In turn, these individuals often made their experiences and expertise available to others. Many respondents, however, stated that would welcome more assistance on the "nuts and bolts" of self-determination.

Difficult and uncertain financing for self-determination:

As stated earlier, the idea of self-determination needs no argument. Yet the structures used to operationalize this idea require financing. Medicaid funding is an essential element of developmental disability systems; Medicaid finances about 75% of all developmental disability services nationally (Smith & Gettings, 1998). This resource -- managed by the Health Care Finance Administration (HCFA) ~ has not always been quick to accept and fund innovation in the field. This is not a criticism of HCFA, but a reminder that Medicaid is a well-regulated resource, requiring federal and local cooperation coupled with well-defined accountability. While states have found numerous ways to utilize Medicaid (i.e.,

most notably through use of Home and Community Based waiver) flexibly to meet individual needs, the waiver is not infinitely elastic. And its elasticity can vary by state.

Indeed, some states experienced significant barriers to financing the self-determination initiative. Paying for the broker service in tandem with case management or for fiscal intermediary services, for example, proved troublesome. Likewise, the very idea of individuals having personal budgets needed to be distinguished from a personal cash grant. HCFA does not permit direct cash payment to individuals, but rather considers personal budgets as "approved allocations." Further, it is understood that not all supports are "Medicaid reimbursable," a simple fact that led to discussion over what is or is not "off the menu" in state systems. To contrast, other states, such as Minnesota, Michigan and Kansas, have found ways to manage their Medicaid financing with enough flexibility to promote, not hinder, self-determination.

Day-to-day distractions associated with administering state systems:

Aside from attempting to initiate significant systems change, state and local authorities needed to cope with the ordinary high demands of administering the service system. Union demands, tensions surrounding closing a state institution, individual crises, demands from those on service the wait list, Medicaid financing difficulties, and more are all standard fare for system administrators. At times these other concerns simply took priority, diverting resources and staff time from the Demonstration project.

Those states where case manager case loads were high (e.g., Washington, Hawaii, Oregon, La Crosse County in Wisconsin) had more difficulty ensuring the individual attention necessary to realize the outcomes of self-determination. This circumstance may have contributed to tension between case managers and "brokers."

Competing local interests:

In some states (e.g., Hawaii, Massachusetts, La Crosse County in Wisconsin, Oregon) the presence of a self-determination initiative within a larger bureaucratic structure caused some resentment and resistance. Case managers, for instance, wondered why the self-determination program was being brought in to do what some thought they were already trying to do. Likewise, there was sometimes contentious discussion over a re-definition of roles played by various levels of government or sections within bureaucracies.

The passive and/or active resistance to change by providers was a distinct constraint -- especially when the proportion of funding implicated by the change

was also apparent (e.g., independent brokers or new fiscal intermediaries). It is not clear whether states will maintain a reliance on existing structures or will instead focus on establishing new ones.

To a great extent, the notion of self-determination and its associated administrative mechanisms operate within the purview of the traditional service system. In fact, the efforts are relatively small in comparison to the dollars spent across entire service systems. As a result, rather than using the self-determination demonstrations to help *transform* the entire system, there is the danger that the demonstrations will simply become one more option within the larger system. Within this context, it will be interesting to note how states cope with a range of potential social, legal, fiscal and administrative barriers to change.

Self-advocates consistently indicate that they very much want to be in control of their own life. Yet, the organized self-advocacy community has not been a consistent and engaged partner of the self-determination demonstrations across the states and local sites. Most sites, however, have included self-advocates in the planning process. And all agree that self-advocates are an essential constituency in this effort. We anticipate that the extent of their involvement in the projects may well increase in years two and three. Still, during the first year we conclude that self-advocates ~ as a constituency ~ had not become completely engaged in these demonstrations or in the overall move to transform systems to promote self-determination.

Most states and local sites are, not unexpectedly, coping with the complexities of implementing the components of self-determination. Examples include difficulties over setting individual budgets, managing risk, allocation tracking mechanisms, equitable linkage of resources to need, assuring quality, and the reconfiguration of management information systems.

There is little doubt that the self-determination initiative has contributed to the enhancement of progressive reforms already in process in many states. It has also provided a methodology in several states for carrying out parallel initiatives such as the wait list reductions (e.g.. Maryland, Oregon), or for effectively responding to demands for reform tied to cost containment (e.g., Wisconsin, Michigan).

The movement toward self-determination is an evolutionary process that will require changes in attitudes and culture as well as in the organization of systems and in the more precise allocation and tracking of resources.

Fully realized, the self-determination initiative can potentially stimulate the use of more non-traditional providers, the increased utilization of generic services and the blurring of categorical boundaries in the service system.

Given the rich experiences of the states and local sites during Year One of the project, there are several important issues to monitor during the next phase of the impact assessment:

The paths states take to resolve the many operational riddles that confounded planners in Year One, including examples such as: (a) the evolution of the role of service broker, its level of independence and authority, and who pays for it, (b) setting person-centered budgets, (c) the diversification of the fiscal intermediary function, the formal roles of this entity, and the auspices under which these roles are carried out, and (d) quality monitoring.

The extent to which the self-determination effort moves beyond a limited demonstration to an approach that develops momentum throughout the system;

The ways in which self-determination initiatives cope with "success" - including how its proponents preserve the person-centered character of the process, deal with provider resistance, and with challenges from emboldened opponents;

The central components of self-determination that can be consistently applied across all settings;

The changes that are actually made in the traditional or existing service system to enable self-determination to be carried out, including what is done to overcome various legal, social, fiscal and administrative barriers; and

The presence of sustained leadership at all levels (e.g., state, county, individual) for self-determination.

These are only some of the issues that will be the focus of the Year 2 Impact Assessment. Based on the discussions of the our Project Advisory Committee, however, we will also concentrate on one key implementation issue: the extent to which designers, planners, administrators, and supporters of self-determination initiatives have been successful in involving people with disabilities as trainers, advisors, participants, constituents and evaluators of the self-determination initiative. We also expect that this focus will allow us to explore the connection between the Self-determination initiative and the formal self-advocacy system within a state and the productivity of these relationships.

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Appendix A:

List Of Study Variables

The Robert Wood Johnson Foundation
Self-Determination Initiative

Evaluation Strategy

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge MA 02140
617-876-0426

April 13,1998

Approach

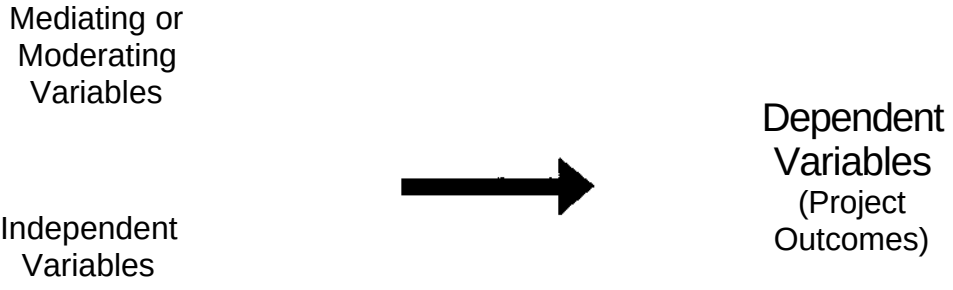
The evaluation strategy is designed to:

- Assess whether the projects reach their particular goals in a cost-effective fashion;
- Document the changes that take place at the state and local level, including the constraints and obstacles encountered, and the relevant national policy issues;
- To assess whether self-determination approaches result in increased choice and power among project participants, and the creation of individual supports (COA).

To achieve these evaluation goals, information will be collected to address five fundamental questions:

1. What was the program theory, implementation strategy and planned outcomes of each project? (What was the project's "logic model"?)
2. What actions did the projects actually take to achieve their goals?
3. What actions went smoothly and well?
4. What obstacles or constraints were encountered?
5. What were the results of the actions taken?

It is understood that that the projects differ from one another, and that each is unfolding within its own unique context. As a result, to address these questions the evaluation team must collect information to describe: (a) a variety of contextual factors (i.e., *mediating or moderating variables),* as well as, (b) the precise actions that were taken by the project to evoke the desired results (i.e., *independent variables).* To complete the picture, the team will also collect data related to the outcomes of the project (i.e., *dependent variables).*



Three Types Of Variables

Each of these variable types are listed below, along with the primary topics of interest that fall under each. Subsequently, these topics are broken down further to show many of the particular variables that will be tracked.

1. Mediating or Moderating Variables

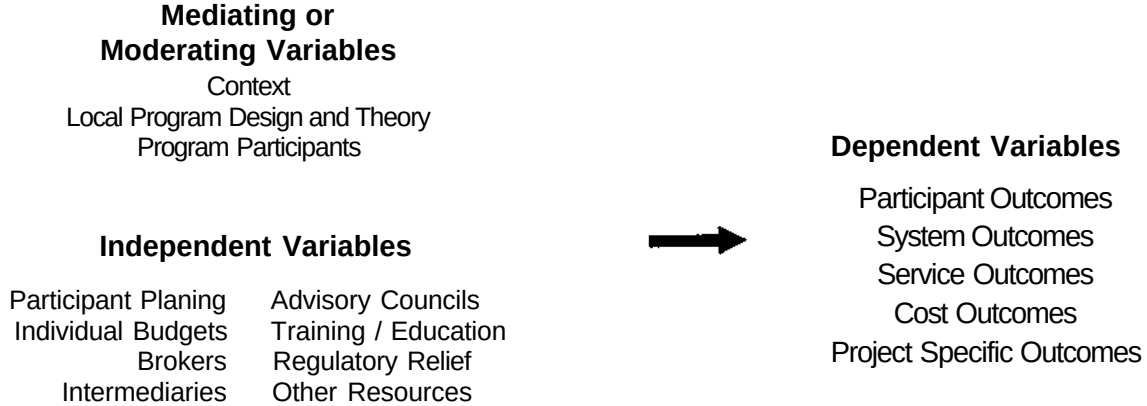
- Contextual factors: Describes the existing developmental disabilities services system.
- Local program design and underlying program theory: Describes the values or principles that underlie the project and the project's structure.
- Program participants: Describes the individual participants that are targeted by the project.

2. Independent Variables

- Participant planning: Describes practices used to develop a plan for providing the individual with services and supports.
- Individualized budgeting: Describes the procedures used to decide what amount of money each participant receives, and how this money is distributed.
- Service brokers: Describes agency structure and staff activities associated with "brokering" functions.
- Fiscal intermediaries: Describes the structure and functions of organizations that are used to manage the budgets that are allotted to participants.
- Advisory Councils: Describes the presence and effectiveness of advisory committees.
- Training and Education: Describes efforts to provide participants and family members with information about the project and how to participate effectively.
- Regulatory relief: Describes efforts to eliminate, waive or alter rules or regulations.
- Identification of non-traditional resources: Describes efforts to access additional money or other sources of support for participants.

3. Dependent Variables

- Participant Outcomes: Describes impact on participants with developmental disabilities.
- System Outcomes: Describes impacts on the overall developmental disabilities system.
- Service Outcomes: Describes impacts on the traditional service provider system.
- Cost Outcomes: Describes impacts on the costs of serving individuals.
- Project Specific Outcomes: Describes unique impacts anticipated by particular Projects.



Listing of Particular Variables By Type

Information will be collected on numerous variables related to the three categories shown above. The data collected may be quantitative or qualitative, and the means used to acquire needed information may or may not require direct involvement of local project staff.

1. Moderating & Mediating Variables

A. Contextual Factors

Configuration of state system (e.g., county-based, local non-profit, state regions)
Characteristics of the existing relevant Medicaid waivers (e.g., type of waiver(s), numbers of people served, fiscal investment, extent of flexibility, service array, federal/state matching ratio)
Momentum already present in the state that is consistent with the Self Determination Project (e.g., as evidenced by: (a) state's relative position to other states regarding investments in supported employment or living, (b) number of people in institutions relative to state population, (c) presence of independent variables prior to project)
Capacity of existing administrative structures to accommodate parameters of the Self Determination Project (e.g., management information systems, quality assurance, case management)
Continuity of leadership (e.g., tenure of the state or county decisionmakers)
Extent of stated commitment to the Self-Determination Project

- Extent of collaborative planning and decisionmaking for the Self-Determination Project, involving self-advocates, family members, government officials, providers, and advocates).
- Sense of urgency associated with the Project (e.g., existing mandates associated with application of managed care strategies for long term supports)
- Consumer/family demand for inclusion in self-determination demonstration
- Extent of consumer/family involvement on local provider boards
- Level of dissatisfaction with the status quo
- The presence of other potential catalysts (e.g., lawsuit, presence of active relevant legislation, DOJ inquiry)

B. Local Program Design

- Underlying values espoused by the Project (e.g., definition of self-determination, other principles advanced by the Project)

Number of years project funded
Extent of RWJ funding (total)
Funding and/or inkind resources contributed from state, county or other sources
Amount per person state is making available
Number of people that the Project intends to serve
Locus of leadership (e.g., where does leadership come from)
Nature of the Project organization and coordination (i.e., planned flow of authority and resources)
Characteristics of Project site(s) (e.g., local economy (if applicable), rural vs. urban)
Scope of the Project - statewide vs. local pilots

- Services/supports available (configuration of services when the Project started)
- Extent to which the Project program allows for choice - what is on/off the menu? (e.g., constraints on choice)
- Safeguards planning for health and safety of individuals and to assure that complaints or grievances are appropriately heard.
- Average wages, benefits, turnover rates of direct care staff in project
- Nature and extent of marketing and public awareness activities

C. Program Participants

- Consumer characteristics (current vs. waiting list, age, level of disability)
- Nature of selection process (e.g., priorities, self-selection, etc.)
- Previous residential environment (e.g., public institution, group home, family, etc.)
- Previous vocational environment (e.g., sheltered workshop, supported employment, day habilitation).

2. Independent Variables

A. Participant Planning (COA)

- Perceptions of consumers regarding their participation in the planning process
- Presence of person-centered planning approaches
- Correspondence between the plan and what was delivered
- Perceptions of case managers
- Extent of participation in decisions regarding budgeting
- Extent to which consumers/families choose the fiscal intermediary
- Factors to help or hinder practices related to this independent variable

B. Individualized Budgeting

- Method used to determine capitation amounts
- Number of people in demonstration program with individual budgets (COA)
- Method (if any) used to maintain a "risk pool" for unexpected or extraordinary costs
- Method(s) used to distribute resources through individual budgets (e.g., cash grants, vouchers, third part payments)
- Factors to help or hinder practices related to this independent variable

C. Service Brokers

- Organizational structure used to provide broker services (e.g., independent service brokerages, existing case managers)
- Range of responsibilities of service brokers (e.g., planning, budget setting, securing services and supports, developing natural or generic supports, project evaluation, negotiation with service providers)
- Number of participants per service broker
- Factors to help or hinder practices related to this independent variable

D. Fiscal Intermediaries

- Proportions of participants who use a fiscal intermediary.
- Organizational structure and legal status of the intermediary (e.g., government agency, vendor or provider agency specially created for the Project, standing community organization providing intermediary services)
- Functions performed by the intermediary and for what number of participants
- Proportion of fiscal intermediaries that are also service brokerage agencies
- Factors to help or hinder practices related to this independent variable

E. Advisory Councils

- Presence of a project advisory council
- Proportion of membership that are people with disabilities/proportion who are families
- Frequency of meetings
- Compensation (if any) for participation (e.g., stipend, mileage, meals, lodging, child care)
- Substantive nature of the role played by the Council
- Factors to help or hinder practices related to this independent variable

F. Training Of Families, Participants, And Providers

- Numbers of families, consumers and providers trained
- Extent of training (e.g., number of hours, days, etc.)
- Participation of families, consumers, and providers in the design of the training
- Topics covered during training
- Consistency of training curricula with self-determination goals and objectives based on a review of training schedule.
- Formal evaluations of training by consumers, families and providers if available
- Factors to help or hinder practices related to this independent variable

G. Regulatory Relief

- Key informant perceptions of level of regulation
- Rules or regulations eliminated, waived or relaxed for the Project
- Re-writing the HCBS waiver
- Factors to help or hinder practices related to this independent variable

H. Process For The Identification Of Non-Traditional Funding Sources

- Average proportion of individual budgets supported by non-traditional funds (COA)
- Factors to help or hinder practices related to this independent variable

I. Role & Extent of Involvement of the RWJ National Program Office

3. Dependent Variables (Project Outcomes)

Note: Evaluation hypotheses are listed (in italics) under each variable heading, with specific variables listed under each hypothesis.

A. System Outcomes

1) *Funds will be allocated to individuals consistent with the terms of the Self Determination Project.*

- In the target area and at the project's onset, the number of individuals receiving services and supports consistent with the terms of the Self Determination Project.
- The number of people that the project predicted it would serve in this way.
- In the target area and at the project's end (or at time of data collection), the number of individuals receiving services in supports consistent with the terms of the Self Determination Project.
- The proportion of those served and the number of people predicted (note: proportions greater than 1.0 suggest systems penetration).
- The number of people statewide who receive services similar to those targeted by the Self Determination Project.
- The proportion of those served by the project and those who receive services similar to those targeted by the Self Determination Project.

2) *In the target area, cost efficiencies realized by the Self Determination Project will be re-invested to serve individuals on the waiting lists (i.e., Wait lists will be reduced).*

- In the target area, the number of individuals on waiting list at beginning of project
- In the target area., the number of people moved off the waiting list.
- The number of people on the waiting served by the Self Determination projects

3) *Dollars that are ordinarily distributed directly to providers by contract by state or county funders, will be separated from these providers and placed under the control of participants.*

- In the target area and at the project's onset, the amount of money that is used to serve people with developmental disabilities.
- In the target area and at the project's onset, the amount of this money that is: (a) under control of participants, or (b) distributed directly to providers by contract by state or county funders.
- In the target area and at the project's end (or at time of data collection), the amount of money that is: (a) under control of participants, or (b) distributed directly to providers by contract by state or county funders.
- Changes in ratios or proportions related to these variables.

4) *The presence of "service brokering" will influence the structure and functions of the existing case management system.*

- Changes in case management structures and functions.
- Number of case managers acting as service brokers at project onset and end.
- Case manager caseloads

5) *State and county decision makers will be committed to expand and/or solidify the Self Determination Project statewide.*
   - The perceptions of key informants regarding implementation of self-determination principles in larger system.

6) *Fiscal policy related to revenue generation will be changed to promote program approaches that are consistent with the Self Determination Project.*
   - Changes in Medicaid policy (i.e., state/local administering rules, preparation of new or amended Medicaid waivers).
   - Using additional state or local revenue as match within the Medicaid waiver program.
   - Redistribution of existing resources.

7) *Quality Assurance Systems will change in favor of measures tied to individual circumstances, with decreased reliance on prescriptive approaches.*
   - Status of the Quality Assurance system at the beginning of the project (e.g., measures used related to individualized health and safety, licensing accommodations, other assurances of service quality)
   - Observed changes to the Quality Assurance system at the project's end (e.g., measures used related to individualized health and safety, licensing accommodations, other assurances of service quality)
   - Use of person centered participant or family monitoring
   - Use of direct feedback from participants regarding their satisfaction with services and supports they receive
   - Perceptions of case managers, providers and other key informants

8) *Changes will be made in state or county management information systems to accommodate approaches consistent with the Self Determination Project.*
   - Changes to track the costs to serve individuals (as opposed to historical rates tied to categorical funding formulas)
   - Changes to track these costs in relation to participant characteristics, service needs, and service utilization.

B. Services Outcomes

1) In the target area, the provider market will change.

- Competition among providers.
- Number of individual provider organizations.
- Consolidation, network development, mergers, buy-outs, entry of out-of-state for-profit providers.
- Perceptions among participants and families regarding extent of choices among providers.
- The exercise of choice among participants and families, as reflected in their changing service providers (i.e., the actual movement of money).
- Perceptions among service providers regarding their likes & dislikes related to the Project.

2) *In the target area, there will be organizational reconfiguration at the provider level (e.g., self-managed teams, changes in middle management, changes in training, involvement of consumers and families in governance, etc.).*
   - Perceptions among key informants at the state and provider level.

3) *In the target area, the use of generic providers will increase.*
   - Perceptions of case managers/service brokers regarding changes in the utilization of generic services.
   - Changes in individual supports as indicated by COA data

4) *In the target area, there will be shifts in utilization/configuration of services.*
   - Utilization patterns in the target area (e.g., residential, vocational).

C. Participant Outcomes (COA data, plus key informant interviews)

1) *Control over life will increase.*
2) *Community integration will increase.*
3) *Perception of quality of life will improve.*
4) *Health and safety will be protected.*
5) *Access to needed supports will improve.*

D. Cost Outcomes (COA data)

1) *For people already in service, average cost/person will decrease.*
2) *For new people served, average cost/person will be less than average cost/person currently in system.*
3) *The use of unpaid supports will increase.*
4) *The costs of providing services under terms of the Self Determination Project will be no greater than under the "traditional" system (i.e., Project programs will be cost neutral).*
5) *The costs of fiscal management under terms of the Self Determination Project will be no greater than under the "traditional" system (i.e., Project fiscal management will be cost neutral).*

E. Project Specific Outcomes

Projects may have anticipated outcomes that are not described above. The evaluation team will examine each Project's proposal and subsequent reports to determine if any potential outcomes should be added to our list or noted separately for a Project.

Appendix B:

RWJ Project Evaluation Coding Form

RWJ PROJECT EVALUATION - CODING FORM

State: __ __ (two-letter code) **Dates of site visits/interviews:**

Form completed by: __ __ __ (initials)

Instructions: If the project is composed of a number of local sites, write the site names in the boxes below, and record separate answers in the appropriate column for each local site demonstration, where applicable.

	Questions/Codes	State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	MODERATING AND MEDIATING VARIABLES							
	Contextual Factors							
CF01	*What is the configuration of the state MR/DD system?*							
	1 = combined with MH and/or SA 2 = separate department 3 = part of health department 4 = umbrella human service agency 5 = in transition 6 = other (describe)							
CF02	*What is the configuration of the sub-state system?*							
	1 = county-based (public agencies) 2 = local non-profit (private agencies) 3 = state regions 4 = other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
CF03	*How is the service population defined?*								
		1 = MR 2 = DD							
CF04	*How long has the state commissioner served? (total number of months)*								
CF05	*How would you characterize the "culture" of the state system?*								
		1 = "let all flowers bloom" (least regulated) 2 = collaborative / consensus oriented 3 = highly regulated							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	In the year prior to the start of the self-determination project, were any of the following elements in existence?								
CF06	0 = No 1 = Yes	Plans for long-term managed care for people with DD							
CF07		Relevant legislative mandates (e.g. person-centered planning)							
CF08		Pre-existing self-determination activities (broadly defined)							
CF09		Specific initiative to address waiting list							
CF09b		Major community-oriented law suit							
CF10		DOJ inquiry							
CF11		Statewide self-advocacy movement							
CF12		Family-directed family support options							
CF12b		Other (describe)							
CF13	*Was this a CSLA state?*								
	0 = No 1 = Yes								

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes			State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Is your state implementing, or do you have plans to pursue managed care strategies for the following populations and types of care?	**Long-Term Care**		**Mental Health Care**		**Substance Abuse Treatment**				
		2 = Yes 1 = Plans 0 = No	If Yes, % Covered	2 = Yes 1 = Plans 0 = No	If Yes, % Covered	2 = Yes 1 = Plans 0 = No	If Yes, % Covered			
CF15-CF15e	**SSI**									
CF16-CF16e	**SSDI**									
CF17-CF17e	**Dual Eligibles**									
CF18-CF18e	**Elderly**									
CF19-CF19e	**MR/DD**									
CF20	*Is managed care having an impact on self-determination activities?*									
		0 = No 1 = Yes								
CF21	*If yes, explain:*									

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Has your state committed to developing or implementing the following waivers for persons with DD?								
FP01	0 = No 1 = Yes	Medicaid 1915C							
FP01b		Pre-paid health plan (PPHP) amendment to 1915C waiver							
FP02		Medicaid 1915B							
FP03		Medicaid 1115							
FP03b		50/200 Waiver							
FP03c		Medicaid 1915G (targeted case management)							
FP04		Other (describe)							
FP05	*Number of people served under the main waiver for persons with DD receiving long-term supports:*								
FP06	*Date of first waiver (month/year):*		/						
FP07	*Federal/State matching ratio:*		/						

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	How does the current waiver affect the implementation of the following practices?								
FP09	1 = current policy supports this practice 2 = current policy presents a barrier to this practice 3 = policy has no effect 9 = N/A	Wide array of supports							
FP10		Reimbursement for support coordination							
FP11		Reimbursement for individualized residential supports							
FP12		Reimbursement for individualized vocational services							
FP13		Use of nontraditional providers							
FP14		Participant-authorized payment agreements							
FP17		Other (describe)							
	Project Design and Implementation (Local Program Design)								
PD01	*Original goal - scope of project:*								
		1 = statewide 2 = local							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
PD01b	*If project is being conducted in local pilot sites, what is the degree of autonomy among the sites?*								
		1 = all sites are managed centrally 2 = sites have some autonomy and variation in approach 3 = sites are basically autonomous 9 = N/A, statewide project							
PD02	*Number of years project funded (initially):*								
		1 = one year 2 = 18 months 3 = two years 4 = three years 5 = over three years							
PD02b	*Was the timeline of your project extended?*								
		0 = No 1 = Yes							
PD03	*Extent of RWJ funding (total):*		$						
PD03b	*Has the project stayed within budget?*								
		0 = over budget 1 = on target 2 = under budget							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
PD09	*Has self-determination expanded beyond RWJ projects?*								
		0 = no expansion 1 = yes, to other limited sites 2 = yes, as part of a limited statewide initiative 3 = yes, expanded statewide 9 = don't know, cannot determine							
PD14	*Are the original author(s) of the project proposal involved in the implementation?*								
		0 = No 1 = Yes							
	Administrative constraints encountered:								
PD15	0 = No 1 = Yes 9 = N/A, not relevant to project	Accounting systems don't accommodate individual budgeting							
PD17		CM caseloads							
PD18		Waivers not flexible							
PD19		Lack of availability of support providers							
PD20		MIS							
PD21		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Have there been any of the following changes in fiscal policy?								
PD22	0 = No 1 = Yes 9 = N/A	Changes in state/local administering rules							
PD23		Preparation of new or amended DD waivers							
PD23b		Creation of person-centered funding vs. service-focused funding							
PD23c		Creation of capitated funding schemes at substate level							
PD24		Using additional state or local revenue as match within the Medicaid waiver program							
PD24b		Creation of a unified funding base within DD system							
PD24c		Creation of cross-categorical integrated funding streams							
PD25		Other (describe)							

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
PD26	*The perceptions of key informants regarding implementation of self-determination principles in larger system.*								
	Regulations that constrained self-determination:								
PD27	0 = No 1 = Yes	QA							
PD28		Funding							
PD29		Hour/wages laws							
PD30		Restrictions on use of public funds							
PD31		Other (describe)							
	Involvement of Participants in Policy Development								
IP01	*Presence of an advisory council or project committee:*	0 = No 1 = Yes							
IP02	*Proportion of membership who are people with disabilities:*	999 = No council	%	%	%	%	%	%	
IP03	*Proportion of membership who are families:*	999 = No council	%	%	%	%	%	%	
IP04	*Frequency of meetings:*								
		1 = monthly 2 = quarterly 3 = semiannually 4 = annually 9 = N/A, no council							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Compensation (if any) for participation:								
IP05	0 = No 1 = Yes 9 = N/A	Stipend							
IP06		Mileage							
IP07		Meals							
IP08		Lodging							
IP09		Child care							
	Substantive nature of the role played by the Council:								
IP10	0 = No 1 = Yes 9 = N/A	Advises on training							
IP11		Participates in evaluation							
IP12		Assists in revising goals/objectives							
IP13		Recommends state or local policy changes							
IP14		Other (describe)							
IP15	*Any participants hired as project staff?*	0 = No 1 = Yes, unpaid 2 = Yes, paid							
IP15a	*Any families hired as project staff?*	0 = No 1 = Yes, unpaid 2 = Yes, paid							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
IP15b	*Other roles played by participants? (describe)*								
IP15c	*Other roles played by family members? (describe)*								
	Project Leadership								
PL01	*Where does leadership for the project **primarily** come from?*								
		1 = sub-state entity 2 = local advocacy organization 3 = service/support provider 4 = coalition 5 = state level							
		6 = other (describe)							
	Does the project have a contract with a self-advocacy organization?								
PL04		0 = No 1 = Yes							
	Participant/Family Demand								
CD01	*Is there a waiting list to participate in the project?*	0 = No 1 = Yes							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Characteristics of the Project Site								
	Are any of the following items "off the menu" (i.e. excluded from individual budgets)?								
CS06	0 = excluded 1 = approved 2 = nothing is excluded 9 = N/A, no individual budgets	Vacations							
CS07		Transportation							
CS08		Home ownership							
CS09		Business investment							
CS10		Education/training							
CS11		Pets							
CS12		Other (describe):							
	Presence of health and safety safeguards (for participants):								
CS13	0 = No 1 = Yes	Included in person-centered plan							
CS14		Individual health and safety plans							
CS15		Traditional QA regulations							
CS16		Crisis line/backup system							
CS17		Other (describe):							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
CS18	*Nature of grievance mechanism:*								
		1 = governed by regular grievance process 2 = process tailored to self-determination 3 = no formal grievance process							
		4 = other (describe)							
	Staffing issues - constraints to implementation at local level:								
CS19	0 = No 1 = Yes	Staff recruitment							
CS20		Staff retention							
CS21		Staff training/values							
CS22		Staff salaries							
CS24		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Nature and extent of marketing and public awareness activities:								
CS25	0 = No 1 = Yes	Articles in local media, including Arc newsletters							
CS26		Brochures							
CS27		Videos							
CS28		Presentations at "professional" meetings							
CS28b		Presentations targeted to community audiences							
CS29		Internet							
CS30		Letters to potential participants							
CS31		Other (describe)							

CS32	0 = No 1 = Yes 9 = N/A	Receipts required (state funds only)							
CS33		Yearly audits of budgets							
CS34		Pre-authorization required for certain purchases							
CS34a		Use of vouchers							
CS35		Fiscal intermediaries required							
CS36		Incremental payments/ disbursements							
CS37		Other (describe)							
	If pure state or local money is being used, what is it being spent on?								
CS38	0 = No 1 = Yes	Fiscal intermediaries							
CS39		Nontraditional purchases							
CS40		Service brokers							
CS41		Training							
CS42		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	INDEPENDENT VARIABLES								
	Individualized Planning and Budgeting								
	Extent to which planning process was translated into individual budget (how is the budget derived):								
PB01a	0 = No 1 = Yes	1 = use of historical or current budget, adjust according to supports listed in plan							
PB01b		2 = use of assessment measure to specifically set budget							
PB01c		3 = two-tiered approach (start with base amount, add on more $ if needed)							
PB01d		4 = aggregate costs of supports listed in person-centered plan							
PB02	*Any incentives for participant/family to spend less?*	0 = No 1 = Yes							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Constraints on individual budgeting process:								
PB03	0 = No 1 = Yes 9 = N/A, no individual budgets	Lack of participant understanding							
PB03b		Lack of family understanding							
PB04		Inadequate training of brokers							
PB05		Insufficient natural supports							
PB05b	*Any methods used to maintain a "risk pool" for unexpected or extraordinary costs?*	0 = No 1 = Yes							
PB05c	*What methods are used to distribute resources through individual budgets?*								
PB05d	0 = No 1 = Yes	cash grants							
PB05e		vouchers							
PB05f		third party payments							
		none							
		other (describe):							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Distribution of Resources for Individualized Budgets								
DR03	*Average amount and/or capitated budget per participant:*		$						
DR03a	*Range of budget amounts:*	*Minimum:*	$						
DR03b		*Maximum*	$						
DR04	*Is there a maximum amount/outer limit per person?*	0 = No 1 = Yes							
DR05		*If yes, amount:*	$						
	Support Brokers								
	Which of these organizational structures are used to provide broker services: (i.e. What options do people have?)								
SB01a	0 = No 1 = Yes	1 = independent support brokers							
SB01b		2 = internal - part of provider organizations							
SB01c		3 = internal - part of state system							
SB01d		4 = internal - part of county system							
		5 = other (describe)							
SB01e	*Indicate which support brokerage structure is dominant (enter number):*								

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
SB01f	*Can participants choose their support brokers?*	0 = No 1 = Yes							
SB02	*Extent to which the system delegates freedom and authority to support brokers:*								
		0 = none 1 = can approve some of budget 2 = can approve all of budget 3 = can authorize transfer of funds 4 = can determine which purchases are O.K. or not							
	Range of responsibilities of support brokers:								
SB03	0 = No 1 = Yes	Planning							
SB04		Budget setting							
SB05		Securing services and supports							
SB06		Developing natural or generic supports							
SB07		Project evaluation							
SB08		Negotiation with service providers							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Who are the support brokers (list percentage for each category)?								
SB09a		existing case managers	%						
SB09b		new case managers	%						
SB09c		new position created, new recruits	%						
SB09d		family members /natural supports	%						
SB09e		others (describe)							
	Constraints on support brokerage process:								
SB11	Rate 1-4 (1 = not a problem, 4 = major constraint)	Not enough support from system							
SB12		Inadequate training							
SB13		Caseloads too high							
SB14		Lack of authority							
SB15		Lack of knowledge of potential supports							
SB15a		Case management system still traditional							
SB16		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Fiscal Intermediaries								
FI01	*Proportions of participants who use a fiscal intermediary.*		%						
	Organizational structure and legal status of the intermediary:								
FI02a	0 = No 1 = Yes	1 = government agency							
FI02b		2 = vendor or provider agency specially created for the Project							
FI02c		3 = standing community organization providing intermediary services							
FI02d		4 = microboards - receive cash and use to serve one individual							
FI02e		5 = purchasing alliances - receive capitated amount, serve groups of individuals							
FI02f	*Indicate which fiscal intermediary structure is dominant (enter number):*								

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Functions performed by the dominant fiscal intermediary structure:								
FI03	0 = No 1 = Yes	Paying staff							
FI04		Filing workers' compensation							
FI05		Hiring/firing							
FI05b		Paying employment taxes - FICA, FUTA, SUTA							
FI05c		Disability insurance							
FI06		Liability insurance							
FI07		Preparing state audit reports							
FI08		Preparing participants' tax returns							
FI09		Reimbursing providers							
FI10		Other (describe):							
FI11	*Proportion of fiscal intermediaries that are also service brokerage agencies:*		%						

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Training Of Participants and Families								
TC01	*Has training been provided to participants and families?*	0 = No 1 = Yes							
	Types of people used as trainers								
TC03	0 = No 1 = Yes	Participants and/or families							
TC05		Community organizers							
TC06		Fiscal experts							
TC07		Other (describe)							
	Topics covered during training								
TC11	0 = no 1 = yes, some training on this topic 2 = yes, topic was a major focus of training	Labor law							
TC11b		Managing payroll							
TC12		Employee benefits							
TC13		Liability							
TC14		Money management							
TC15		Range of supports							
TC16		General self-determination							
TC17		Person-centered planning							
TC17b		Community integration							
TC18		Values							
TC19		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Training Of Providers								
TP01	*Has training been offered to providers?*	0 = No 1 = Yes							
	Types of people used as trainers								
TP03	0 = No 1 = Yes	Participants / families							
TP05		Community organizers							
TP05b		Organizational / management consultants							
TP06		Fiscal experts							
TP07		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Topics covered during training								
TP11	0 = no 1 = yes, some training on this topic 2 = yes, topic was a major focus of training	Organizational change							
TP12		Implementation issues							
TP13		Developing networks							
TP14		MIS development							
TP15		Range of supports							
TP15b		Staff recruitment							
TP15c		Staff training							
TP15d		Community integration							
TP16		General self-determination							
TP17		Person-centered planning							
TP18		Values							
TP19		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Training Of Support Brokers								
TS01	*Have support brokers been trained?*	0 = No 1 = Yes							
	Types of people used as trainers								
TS03	0 = No 1 = Yes	Participants / families							
TS05		Community organizers							
TS06		Fiscal experts							
TS07		Other (describe)							
	Topics covered during training								
TS11	0 = No 1 = Yes	Labor law							
TS12		Payroll responsibilities							
TS13		Liability							
TS14		Money management							
TS15		Range of supports							
TS16		General self-determination							
TS16b		Implementation issues							
TS17		Person-centered planning							
TS18		Values							
TS19		Other (describe)							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
TS08	*Has the National Program Office provided technical assistance or training for the project?*	0 = No 1 = Yes							
TS08b	*If yes, rate helpfulness of NPO assistance, 1-4 (1 = not helpful, 4 = extremely helpful).*								
	DEPENDENT VARIABLES (PROJECT OUTCOMES)								
	System Outcomes								
	The number of participants receiving services and supports through the self-determination project.								
SO01	Note: list cumulative figures.	At project onset:							
SO02		End of Year 1:							
SO03		End of Year 2:							
SO04		End of Year 3:							
	The number of people the project originally predicted to serve in this way.								
SO05		End of Year 1:							
SO05b		End of Year 2:							
SO05c		End of Year 3:							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	The number of people being served through the project compared to the number of people predicted.								
SO06		End of Year 1:	/						
SO07		End of Year 2:	/						
SO08		End of Year 3:	/						
	The number of participants who were not previously receiving services compared to the total number of participants.								
SO09		End of Year 1:	/						
SO10		End of Year 2:	/						
SO11		End of Year 3:	/						
SO19	*Has the project resulted in savings?*	0 = No 1 = Yes							
	If yes, where are the savings being invested?								
SO21	0 = No 1 = Yes 9 = N/A - no savings yet	Waiting list							
SO22		General fund							
SO23		Risk pool							
SO24		Administrative costs							
SO25		Other							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Of the services and supports provided through the project, estimate the percentage of funds that are: (a) under the control of participants or (b) distributed directly to providers through contracts with state or county funders.								
SO30a	At project onset:	(a) participants:	%						
SO30b		(b) providers:	%						
SO31a	End of Year 1:	(a) participants:	%						
SO31b		(b) providers:	%						
SO32a	End of Year 2:	(a) participants:	%						
SO32b		(b) providers:	%						
SO33a	End of Year 3:	(a) participants:	%						
SO33b		(b) providers:	%						
	Number of case managers acting as service brokers.								
SO38		At project onset:							
SO39		End of Year 1:							
SO40		End of Year 2:							
SO41		End of Year 3:							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Caseloads of case managers involved in the project:								
SO42		At project onset:							
SO43		End of Year 1:							
SO44		End of Year 2:							
SO45		End of Year 3:							
	Caseloads of case managers NOT involved in the project:								
SO42A		At project onset:							
SO43A		End of Year 1:							
SO44A		End of Year 2:							
SO45A		End of Year 3:							
	Ability to track costs to serve individuals (as opposed to historical rates tied to categorical funding formulas):								
SO46	0 = No 1 = Yes 2 = Partial	At project onset:							
SO47		End of Year 1:							
SO48		End of Year 2:							
SO49		End of Year 3:							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Ability to track these costs in relation to participant characteristics, service needs, and service utilization (describe):								
SO50	0 = No 1 = Yes 2 = Partial	At project onset:							
SO51		End of Year 1:							
SO52		End of Year 2:							
SO53		End of Year 3:							
	Services Outcomes								
	How has competition among providers changed?								
SV01	(use these codes) + = increased - = decreased 0 = no change N = not available	End of Year 1:							
SV02		End of Year 2:							
SV03		End of Year 3:							
	Number of formal, individual provider organizations:								
SV04		At project onset:							
SV05		End of Year 1:							
SV06		End of Year 2:							
SV07		End of Year 3:							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes		State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	*To what degree has there been any **collective** reorganization of providers (e.g. network development, mergers, buy-outs, entry of out-of-state providers, integration with other community agencies)?*								
SV08	0 = none 1 = some reorganization 2 = extensive reorganization	End of Year 1:							
SV09		End of Year 2:							
SV10		End of Year 3:							
	Perceptions of case managers/service brokers regarding changes in the utilization of generic services.								
SV16		End of Year 1:							
SV16b		End of Year 2:							
SV16c		End of Year 3:							

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes	State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes	
	Changes in utilization patterns in the target area - increase/decrease/no change:					Project Onset	End Year 1	End Year 2	End Year 3
SV17	Large (>16) state-operated residential facilities								
SV18	Large (>16) privately-operated residential facilities								
SV19	Medium (7-15) public and private residential licensed group home facilities								
SV20	Small (<6) public and private licensed residential group home facilities								
SV21	Foster care/family homes								
SV22	Other residential programs owned/operated by public/private agencies, including apartments (non-participant controlled housing)								
SV23	In-home supports furnished to primary participants in their own residence (supported living)								
SV24	Family support (services delivered in the family home; cash subsidies)								
SV25	Service coordination/case management								
SV26	Facility-based vocational services (sheltered workshops, work activity centers)								
SV27	Group vocational/employment services (enclaves and mobile crews)								
SV28	Individual integrated employment supports (supported employment, job coach model)								
SV29	Facility-based non-vocational services (day habilitation, day treatment, "seniors programs", etc.)								
SV30	Non-facility based/non-residential community participation/training services								
SV31	Other community integrated activities (health club memberships, etc.)								
SV32	Clinical services (therapies, behavior management, psychological services, etc.)								

RWJ PROJECT EVALUATION - CODING FORM

	Questions/Codes	State-wide	Site 1:	Site 2:	Site 3:	Site 4:	Site 5:	Notes
	Project Specific Outcomes							
PS1-PS3	*Projects may have anticipated outcomes that are not described above. List any potential outcomes that should be added to our list or noted separately for this project.*							