Implementing Self-Determination: Perspectives from Eleven States

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Section I: What Is Self-Determination?

Self-Determination: A (Very) Short Primer

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What does self-determination mean in the context of a human services system?

Although there is no one definition of self-determination, there are key concepts and values that underlie most states' attempts to empower the persons with developmental disabilities who are consumers of services and their families. Every services system will operationalize self-determination in ways that make sense in it's own system but there are some themes around which self-determination revolves:

- Consumers and families make informed choices about their own lives
- Consumers and families have control over these choices
- Consumers and families have individual budgets with which to make decisions
- Supports and services are designed to fit the preferences and desires of consumers and families
- The intent and outcomes of supports and services are determined by consumers and their families (and chosen advocates)
- Self-determination is about sharing power and control and negotiating relationships among consumers, families, advocates, providers and support coordinators

What does this mean in terms of operating a human services system?

Self-determination is multi-dimensional. Implementing practices that enhance the possibility of self-determination means re-thinking and potentially changing many facets of the services system, from what responsibilities families share to how payment rates are determined for services. To each of the stakeholders in a system, implementing self-determination may mean different roles and responsibilities and different risks; self-determination does not mean a unitary response for all. Self-determination plays out for each person differently, based on the situation and preferences of that person. For one person, a willing and capable parent may take on much of the support coordination role: for someone else, who may not have close friends or family, a paid case manager—who understands how to assist people to make informed choices-may hold this responsibility. One individual may prefer to hire and fire their own support staff, another may prefer an agency to do this for them. A system based on self-determination permits supports and services to be configured and delivered in a multitude of ways by a variety of agencies and individuals.

Operationalizing and implementing self-determination takes time and commitment at every level. It is not a one-size-fits-all package; the details of how self-determination will work must fit with the aims, culture and resources within a state. While clearly states can and should learn from each other, how Washington decides to make self-determination a reality must be tailored to what Washingtonians want as well as build on the elements and structures of the current system that are working well. The details of self-determination in Washington must fit the culture and practices that are acceptable to stakeholders within the state.

What are key elements in operating a system that supports self-determination?

- There is an understandable and equitable method for allocating resources to consumers and families
- Money follows the person: that is, money is portable and does not "belong" to services providers nor case managers
- Rate setting, contracting and payment processes allow for individualization and flexibility
- Support planning is a partnership among consumers, families, providers, and support coordinators
- The frequency and intensity of support coordination is tailored to reflect the needs and preferences of individuals and families
- Quality assurance is multi-faceted and includes significant participation from consumers and families in deciding if the outcomes and quality are present in the supports and services used
- System rules and regulations, including provider standards, permit flexibility in designing supports and services and allow for creative approaches to supporting individuals. These approaches include enhanced roles and responsibilities for families and consumers in coordinating and directing supports and services (if they so choose) such as purchasing alliances, voucher or fiscal agent systems
- System practices create a more diverse marketplace where consumers and families actually have a variety of support and service options from which to choose
- There is strong commitment (including financial resources) to training for all stakeholders in the new roles and responsibilities that come with implementing self-determination, including state administrators, case managers, providers, consumers and families

What self-determination is not

- Self-determination does not mean no accountability for how and why public funds are being used
- Self-determination does not mean putting vulnerable people at serious risk in the name of choice and control
- Self-determination does not mean "whatever you want, at whatever cost"
- Self-determination is not just a little "tweaking"—it is major systems change that builds on what's already working within a system and re-engineers what's not

Section II:The Eleven States Surveyed

The States Surveyed

People in eleven states which had received Robert Wood Johnson (RWJ) self-determination grants were interviewed. States with a county or regionally based case management system were Kansas, Minnesota, Oregon, Vermont, and Wisconsin. States with a state based case management system were Arizona, Connecticut, Hawaii, Massachusetts, and Washington.

Many of the other eight RWJ grant states were contacted, but interviews did not take place. These states include Florida, Iowa, Maryland, Michigan, New York, Ohio, Pennsylvania, Texas, and Utah.

As shown in Figure 1, the eleven states surveyed had a variety of social service delivery systems. In some states a statewide administrative and case management system exists. In others, counties or regions are the administrative unit. Washington reports the largest number of consumers statewide. Only Massachusetts and Minnesota approach Washington's size.

The two states where Self-Determination is most advanced have a relatively small number of consumers—6,000 in New Hampshire and 3,000 in Vermont.

Figure 1

Background Information on States Interviewed

State	General System	Population (In Millions)	# Consumers Statewide	# in self-determination as of June 1998
Arizona	State	4.43	15,896	12
Connecticut	State	3.27	13,509	70
Hawaii	State	1.18	2,400	0 (start 7/98)
Kansas	Regions	2.57	8,000	40
Massachusetts	State	6.09	18,000	100
Minnesota	Counties	4.66	21,000	60
New Hampshire	Regions	1.16	6,000	Many
Oregon	Counties	3.20	12,000	15 + 75*
Vermont	Regions	0.59	3,000	Many**
WA - Island County	State	5.53	25,000	14
WA - Spokane	State	Same	25,000	20
Wisconsin - Dane County	Counties	5.16	1,500***	15

File source: data needs:\ Phone Survey\S_D#1.xls

** 15 in Multnomah County, 75 Family Support in Washington County*

*** 37 in a special project*

**** Dane County Only*

Brief Descriptions of Self-Determination in Each State

Note: All these descriptions are in terms of June 1998 when interviews took place.

Arizona

The focus is on grassroots consumer to consumer communication to empower adults in making choices. Year One was piloted in Phoenix; Year Two added Tucson to the Phoenix pilot in April 1998. Partnering takes place with Independent Living Centers (ILC), expanding the peer mentoring used in ILCs to people with developmental disabilities. 12 people were involved in June 1998.

Connecticut

A year and a half into their project, 70 people, primarily adults new to the system, are exercising self-determination with the help of support brokers at five pilot sites, one site in each state region. The 20% who are children have significant disabilities such as autism or severe medical problems. Most people live at home, and a few are moving into their own apartments; supports commonly requested are in-home support, transportation, and community skill support. The other project components are (1) intensive training of consumers to advocate for themselves and of providers and staff in ways to support self-determination and (2) a systems-wide review of changes needed to accommodate self-determination: fiscal, data, planning, and case management.

Hawaii

Starting July 1, 1998, adults currently enrolled in DD in two sites will be offered the opportunity to participate in the project. Recent legislation endorsed the principles of self-determination, with the individual as the decision-maker. A managed support organization will act as the fiscal intermediary, and case managers are being intensively trained to be support brokers. The hope is to involve over 125 people in the project.

Kansas

By June 1998 Kansas was into its second year of a RWJ grant, with pilot projects in two sites and two more sites about to open. A primary objective is to move the money and the decision-making as close to the recipient as possible. In Kansas there is a regional community developmental disabilities system, and case managers are employees of provider agencies. Independent facilitators may be hired as needed if the consumer or family chooses, facilitators may help consumers create active circles of support, coordinate services, and work with the budget allotted to them. A fee for service system is being used, with movement toward the use of a prepaid health plan.

Massachusetts

The RWJ two-year project has three components. (1) The Service Coordinator Group includes twelve Department of Mental Retardation staff who through using self-determination with an estimated total of 77 people will examine the issues surrounding brokerage and support development. (2) The Provider Group, made of two providers, has targeted a total of 37 currently served individuals for whom to develop customized supports. This process will allow the group to explore issues around how a system can make the transition from a slot-based to a choice-based orientation. (3) A community organizer will work with up to six Family Governing Boards created within urban minority communities in

the Greater Boston area, helping them to amass the skills they will need to make decisions about resource allocation and identifying and securing supports for families and individuals in their cultural communities. A board of citizens from Haiti has been doing this for over three years. The project anticipates engaging 250 families.

Minnesota

Key elements are education, system redesign, and the creation of individual budgets. The three project counties--out of 87 counties in the state--represent an urban, a rural, and a metropolitan site. Begun in February 1997, projects now involve 60 consumers aged 4 to 65 and of all disability levels. The target is 200 people by January 2000. System redesign is absorbing a lot of effort, and has yielded a Title XIX waiver amendment allowing consumer directed community supports, the first ever approved by the Federal government. Other states which have not succeeded in obtaining such waivered services as part of their waiver plans are watching with interest.

New Hampshire

New Hampshire is so proud of their Self-Determination implementation that they have a Web site at <www.state.nh.us/sdp>. A pioneer in this field, New Hampshire requested the Robert Wood Johnson Foundation to give project funds for the first time to programs serving people with developmental disabilities.

The original 3-year Robert Wood Johnson pilot project began in the Monadanock region in 1991. The results of the independent evaluation were impressive, showing a reduction in cost and a dramatic increase in the quality of life. This generated major RWJ support for the field of Self-Determination and funding for the projects described here and others around the country.

By 1998, all of the state's area agencies and the Division of Developmental Services are making changes to promote Self-Determination. New Hampshire's deeply ingrained tradition of local control has meant that each of the twelve area agencies has its own unique version; approximately half provide services themselves and half use vendors. The pace of change is affected a lot by the vision of the area agency staff and management and that organization's willingness to take risks.

Oregon

The Oregon Self-Determination Project in the Greater Portland Area focuses on a consumer-directed support brokerage called Self-Determination Resources, Inc. (SDRI). The SDRI Board of Directors has majority consumer representation. Fifteen customers who have private resources are being served in Multnomah County, and 75 customers are receiving family support in Washington County. In the first year of the project emphasis was on designing SDRI functions such as person-centered planning, brokering supports, fiscal intermediary and administrative employment supports, customer education and technical assistance, community development and customer-directed quality monitoring.

Vermont

A key element of self-determination is found statewide in Vermont, where a separate budget is attached to each person with developmental disabilities. Most people are choosing consumer management of services and working with established providers rather than consumer direction of services, where the consumer has the need, interest, and ability to actually control the service dollars and hire staff. The RWJ grant is being used to help create a broad range of networking and training activities to disseminate self-determination and to resolve technical issues which stand in the way of people's control of their service delivery. A vision suggested by the Vermont staff to the RWJ foundation is to support initiatives for expanding the concepts developed in self-determination to all types of health care services, with a focus upon patients rights.

Washington: Island County

The one-year RWJ grant (7/97 - 6/98) was used to work with fourteen families with young children under seven years old. Just entering the system, the families were mentored in taking the lead from the start in identifying service needs and finding supports rather than becoming dependents of the system. They were encouraged to look at both the resources available in their community and at the Developmental Disabilities service system. They developed strategies to voice their specific needs and to solve their own problems. The staff person hired for the project conducted long interviews with families and got to know them over several months. "Somebody hung in there long enough to validate what I'm thinking and feeling and to say, 'Why don't you try that'?", was a common reaction from families.

Washington: Spokane County

Spokane County moved into choice two years before receiving their one-year RWJ grant. In response to consumer requests for more control over their lives, the county changed the way it handled the employment/day program dollars—dollars under direct administration of the county. Budgets of $463 per person were created for those receiving services. People picked their own providers, and most stayed with their current provider—over the two years there was a 20% turnover rate. For the 20 people involved in the RWJ grant, there was a hope of creating individual budgets covering all their services. In the process, staff learned what it would take to create such budgets, and concluded that within a one-year project it was not possible to put them in place.

"Individual budgets are a key part of self-determination," Lynn Pippard said in an interview, "but a person can still be socially isolated." The focus of the project was the use of a community developer to address this issue, helping people make connections in their neighborhood. For example, she helped organize a monthly potluck at a community center where out of the 100 people, 20 were consumers, and all lived in the same area.

Wisconsin - Dane County

"Dane County in 1997 (Year I of the RWJ grant) followed a two-track approach to learning. On the one hand, it has undertaken an extensive planning process to put structures and policies in place to support self-determination for a large number of people. On the other hand, Dane County has been willing to go ahead and try to provide or begin planning for consumer control of support resources without waiting for a full structure to be in place, or for certainty about what the structure will look like. The direct experience of trying things

out has been important both to learning what issues need to be addressed in implementing self-determination, and to energizing the process with stories of real change in the lives of real people."

Quoted from March 31, 1998 progress report to the RWJ Foundation.

Characteristics of Self-Determination in the States Surveyed

Figures 2 through 4 summarize information about Self-Determination in the eleven states surveyed:

- Seven states gave consumers individual budgets with which to purchase services. Low and high budgets varied widely, with a median budget in New Hampshire of $37,000.

- Adults were the focus of Self-Determination efforts in most states.

- States differed regarding which clients were enrolled--current clients (4 states), new clients (2 states), or both current and new clients (5 states).

- Implementing Self-Determination statewide is a lengthy process. The people interviewed estimated that 5 to 10 years' time would be needed. In New Hampshire, whose first steps toward Self-Determination began in the early 1980s, another 4 years are thought to be needed for statewide implementation.

- High importance was placed on support brokers—whether case managers or contracted providers--who help link consumers to services.

- The residential location for Self-Determination varied. In some states, only family homes were included in projects; at the other end of the spectrum, other states included all residential settings available in that state.

- The supports brokered through Self-Determination in most states were very broad a diverse, particulatly in states like New Hampshire and Vermont where Self-Determination has been offered for many years.

Figure 2

Size of Individual Annual Budgets and Who is Included in Self-Determination

	Individual Annual Budgets:		***Who is included:***		***New clients? Current?***
STATE	***Low***	***High***	***Adults***	***Children***	***Both?***
Arizona	$10,000	60,000	yes	a few	both (started w/current clients)
Connecticut	$19,000	50,000	80%	20%	new
Hawaii	Still starting up		yes	a few	current
Kansas	$39,000	65,000	yes	one	both
Massachusetts	Still starting up *		primarily	a few	both
Minnesota	$3,000	106,000**	yes	yes	both
New Hampshire	$2,000	$150,000***	yes	yes	both
Oregon	Don't have them yet		yes	no	new (private pay families only)
Vermont	$2,100	90,000	95%	5%	current
WA - Island County	Didn't have them in project		no	yes	current
WA - Spokane	Didn't have them in project		yes	no	both
Wisconsin - Dane County	$20,000	$70,000	yes	no	current (all future clients will be offered S-D)

File Source: data needs:\ Phone Survey\S_D#2.xls

* Estimated: $3,000 - $15,000 with employment

** Some persons have no budget and are using self-determination methods for planning; county money is involved because a case manager is working with them

*** Median is $37,000; all regions are working toward 100% consumers with individual budgets within next 2 years and some regions were there as of June 1998

Figure 3

How Long to Esablish Self-Determination? Importance of Support Broker?

STATE	***How Long Will It Take to Establish Self-Determination Statewide?***	***Importance of Support Broker Function? 5= High, 1 = Low***
Arizona	5-10 years	5
Connecticut	10+ years	4
Hawaii	5 years	5
Kansas	5-10 years	4 to 5
Massachusetts	5-8 years	5
Minnesota	5-6 years	5
New Hampshire	4 more years	5
Oregon	6 years	4 to 5
Vermont	We are approaching it now	5
WA - Island County	5-10 years	4.5
WA - Spokane	5 years	5
Wisconsin - Dane County	5 years	5

File source: data needs:\ Phone Survey\S_D#3.xls

Figure 4

Residence: Support Types

STATE	**Residential Locations Included**	**Support Types**
Arizona	GH, semi-independent, own home	Very broad
Connecticut	Most are home, some in apartments	Respite, companion, supervised day program, equipment
Hawaii	Not started yet	Not started yet
Kansas	Own home or own apartment	Individualized programming
Massachusetts	All Residential Locations	Very broad
Minnesota	All Residential Locations	Very broad
New Hampshire	GH, FC, independent living, own home	Very broad and very individualized *
Oregon	Family homes	Information not available
Vermont	Family homes, apartments, AFH (1 per)	Very broad and individualized
WA - Island County	Family homes	Empowerment for parents in parent activism
WA - Spokane	Family homes = majority	Community building; day programs; employment
Wisconsin - Dane County	Supported living, a few family homes	Residential services, respite, day programs

File source: data needs:\ Phone Survey\S_D#4.xls

* For example, in a day program with 5 people, each will be doing different things during the day.

Section III:Perspectives on Implementing Self-Determination

Consumer Involvement

We have 100% consumer controlled advisory councils at each local project site. We are turning away from programming and now we are working with consumers to find individual activities for a valued day, which may or may not include traditional programming. This might mean purchasing a pet, if that's what they need and want, going to horse arenas to find a way to work with horses, or doing a job search at places like Target and grocery stores.

Sharon Johnson, Kansas

Our ability to provide specialized technical assistance in self-determination here in Vermont has been used so far for 37 consumers. Three people are involved in entrepreneurial ventures. Two are peer counselors to train other self advocates. One is a man who consults with public agencies in his community regarding accessibility. Recently he approached the high school regarding counseling youth about transition. He has used funds to help him create Public Relations materials to use with these organizations. Two other people heard about self-determination through public education and training, and chose to move out of family homes into apartments, finding roommates, creating budgets and supports. One father whose two children were over 22 years old approached us to see if he could do more of the service coordination himself. Because we can't pay families directly, he will hire his own case manager rather than using the case management provided by a local agency. Two consumers are asking to manage their own money, hiring their own case managers, choosing the staff to support them, and so on. We are working this out with them. I don't think most people will be choosing to take this route of actually directing their own services.

Michelle Sures, Vermont

Under self-determination, it's the consumer or their legal representative who is making the final choices. In the past everyone sat around, gathered information, and reached consensus. Now it's the consumer's role to make informed decisions and take responsibility, and there's a letting go process and a need to deal with risk in new ways.

Barb Roberts, Minnesota

For some years we have had vehicles to allow persons to contract for their own services and supports with a predetermined number of providers. Providers respond to an individual's own profile, or rather group of profiles, in an RFP format and individuals then interview the provider candidates and make their selection. The budgets represent a broad range of supports and costs.

Hans Toegel, Massachusetts

Support Brokers

We hope, as a systems change, to change the understanding of the case manager role to helping people make choices rather than making those choices for them. Currently we have heavy caseloads and the mentoring project was not intended to be a time-saver particularly for our Support Coordinators (Case Managers).

Brian Lensch, Arizona

People need someone to help them understand and navigate the system.

Terry Cote, Connecticut

In Kansas, case managers have generally worked within regions for individual providers. Thus, we have consciously decided that case managers will not be involved in directing the self-determination process. Instead we're interested to see that the person and family members have a circle of friends or a support network to help with planning. This circle is informal and does not include staff from existing agencies. If needed, an independent facilitator can be hired to facilitate planning within a circle of friends.

Sharon Johnson, Kansas

Even people with significant disabilities can find their voice. It takes people who care profoundly to hear them. Those without someone closely connected to them may always need to have paid professionals in their lives. Service coordinators are critical to self-determination. They have experienced the first and most dramatic role changes, from people who put requests for the maximum amount of money for a consumer to people who negotiate with a whole circle of friends. They need to have facilitation skills and budgeting skills too. They are the people who make the link between the dollars and the dreams in the plans. And they are committed to facilitating what the consumer wants; for example, to have a meeting at Pizza Hut without the guardian present.

Mary Ellen Fortini, New Hampshire

You ask how important support brokers are in helping to realize self-determination in our state (rate 1=low to 5=high). I would say we value it at a 5. The manner in which we are proceeding to transfer decision-making and resource control to individuals and families, is substantially through our service coordinators (state positions). They are the only form of support brokerage we currently have and are the vehicles through which individuals plan and resources are identified and, under self-determination, funds are accessed (except for our Family Boards). At some later point, we may need to rethink this model as individuals and families become sufficiently familiar with the support system and funding alternatives.

Hans Toegel, Massachusetts

I rate case management as a 5. The three self-determination project counties do intake, eligibility determination, monitoring, and authorizing of funds. The consumer can choose their own service coordinator, and currently, with little experience, most end up choosing their case manager. In one project county, the county hired a service coordinator who looks at creative way to help case managers be service brokers.

Barb Roberts, Minnesota

Support Brokers, continued

Support brokers are very important. Families can have a difficult time working their way through any bureaucracy, both for generic services we all use and special services.

Deanna Hartwig, Oregon

Support brokers and empowering the consumer are the two most important things in self-determination. Brokers are an empowering tool for people who can help them access their dreams. If we were to come in with preconceived notions about services and service slots, we might as well not change the system.

Donna Winnick, Wisconsin

Support brokerage is key. If people aren't going to do things in the way they were formally done, the correct focal point is paramount. In the relationship with the person with disabilities, it is crucial that the support broker and the person are in synch. Things fall apart without the point person.

Michelle Sures, Vermont

Support brokers are very important. By this, I mean paid persons who truly have only the best interests of consumers at heart, work with them, think out of the box. Decent brokerage involves being in the neighborhood and having the time to work directly with consumers.

Lynn Pippard, Spokane County, Washington

People need someone they can talk to, who can help them figure out what they want and need without a lot of forms and evaluations—just a friend who lives in the community and knows it and knows how to hook people up. The broker helps the families who don't have negotiating skills. The support broker must live in the community so as to have an intimate understanding of community resources.

Jackie Henderson, Island County, Washington

Training

Education of consumers, families, and providers is a huge component of self-determination here in Minnesota. Consumers receiving Title XIX waivered services have a consumer education and training service option up to $2500 per person per year to pay for self-advocacy training and learning informed decision-making. This money pays fees, materials, and travel. We are committed to doing this because people don't have much experience with receiving training and with decision making. We have prided ourselves regarding choices, but, for example, the choice of Coke versus 7-Up is very different from being able to choose among many different things to drink.

Barb Roberts, Minnesota

Training, continued

We want to help people think outside the way they've been thinking, so we have a lot of training for consumers, parents, guardians, and agency staff. Developing good training for service brokers is a huge focus. Professionals, siblings, friends—all will be certified. The education process will take a long time; self-advocacy is a weak area.

Donna Winnick, Wisconsin

The case manager, in taking up the support broker role, has to learn how to dream.

William Christoffel, Hawaii

Cost

We are trying to support more people who require more intensive supports in the future. The DMR portion of budgets does not include the full costs: Title XIX home health aides, school programs and community supports. Current budgets range from $10-50,000 per year, most being in the low twenties.

Terry Cote, Connecticut

Support brokers are critical as advocates, developing person centered plans, organizing services. It's a more intense role and you will need more case managers; where you save is in the amount of services provided.

William Christoffel, Hawaii

You can count on costs going down if you are moving people from congregate to individual settings. Once everyone is in a community setting, don't expect savings. In New Hampshire there were a few people with dramatic changes of circumstances and you can't count on that.

Mary Ellen Fortini, New Hampshire

Regarding the savings in New Hampshire, they saved large amounts of money on a few people. Generally people want to spend all their money.

Donna Winnick, Wisconsin

Budgets are attached to people. One struggle is how to skim off enough money to pay for the infrastructure.

Michelle Sures, Vermont

Fiscal Models & Individual Budgets

We are using independent community based fiscal intermediaries. There is an agreed upon budget and lifestyle plan. Monies are to be forwarded to those providing services; some payment may be made directly to families too. Families sign the time sheets for the services received. We have a waiver amendment with broad definitions. We are working to protect families from rules and regulations that would hamper their ability to be involved. The fiscal intermediary would deal with these.

Sharon Johnson, Kansas

In New Hampshire with 12 area agencies you have more than 12 different fiscal models. Most regions operate with a couple of models, for example using an area agency fiscal intermediary for some people, and letting families act as managing employers if they so choose. Each family needs from us some or all of the following:

- Medicaid billing, IRS forms, help with the IRS
- An independent service broker who then helps form and facilitate the circle of friends
- Enhanced family care

Mary Ellen Fortini, New Hampshire

Here in Minnesota the Feds approved a Title XIX waiver amendment to the Home and Community Based Waiver program allowing consumer directed community support. It is not provider driven. This is the first such wavered service approved, and lots of states are watching us. The consumer is in the driver's seat. Ironically, we had more trouble in Minnesota getting this out of our department than HCFA had in approving it because we needed to include the detail that would be understood by all stakeholders that although the service is general there is a mechanism and a priority to assure health and safety. (See Appendix for a copy of the waiver.)

To be able to use the new waivered services, the three counties in the project had to do a number of things; it was both a carrot and a stick for them. They have to provide consumer education in Self-Determination and in person-centered planning. They have to have procedures and criteria for allocating resources, and a quality assurance system must be in place. Two of the project counties are also in a managed care demonstration, and are developing an assessment tool for resource allocation. The other county has its own tool. All this is very experimental.

An example of a changed service to a family is that of a woman with a disabled child. A Personal Care attendant would come in two to three times a week so she could go out and do laundry, this at $10-15 an hour. From their budget the family chose to buy a washer and dryer so the attendant didn't have to come in. Using Medicaid for such purchases is in policy discussion at the federal level. This kind of thing may make the Federal government nervous because it is so new and there are debates on what types of supports should be available and paid through public funds. The counties have to be very careful with this and may choose to use county funds instead of federal funds for purchasing some supports; it has to be very individually need based and made part of true person centered planning.

Barb Roberts, Minnesota

Each of the three pilot counties in Minnesota does individual budgets differently. In allocating a budget, two counties took a historical approach. The third county allocated 90% of the historical budget to each person and put 10% in savings and a risk pool. The way the budgets are developed and implemented differs. For example, in the metropolitan area there is a checkbook system. The person writes out checks based on the plans, and directly pays the provider. Eligibility can be affected if a person has funds beyond a determined limit. Mixing federal funds and a person's own funds may create problems for keeping the support

funds and personal funds separate. If there is too much money in the checkbook that is not defined correctly, eligibility may be affected and the person will not be eligible for medical assistance. As an authorizing agent the county actually is holding the checkbooks, but the checks go through a regular bank and are set up as a type of voucher system. This was complex to set up, and there are a number of monitoring functions behind the scenes. The nice thing is, this doesn't distinguish the different money sources but melds them together from the point of view of the consumer. The county does the tracking of the various funding streams.

Barb Roberts, Minnesota

I hope that in Oregon with the closure of a large ICF-MR that we will have additional money for individual and family support, and that the self-determination related brokerage called Resources Inc. could continue to offer supports.

Deanna Hartwig, Oregon

Monitoring

When I look at a region, if 30% of the consumers are in any one model of support, I ask, "Are you doing it for convenience and for inexpensive care and because it's easier for the area agency, or because people want this?" You need to constantly audit and question. No one model should be permanent; a model isn't self-determination, the underlying values and community inclusion are self-determination.

Mary Ellen Fortini, New Hampshire

In order for counties to authorize funds for consumer directed community supports as part of the Title XIX waiver, we had to put in place a quality assurance system in the three pilot counties.

Barb Roberts, Minnesota

We haven't figured out yet how to provide quality assurance for consumers managing their own care. What if someone buys CDs instead of paying staff? We are working on the issue. As for the 13 area agencies in the state who have service contracts (Vermont state employees provide no services), they are still responsible for service quality in their areas.

Michelle Sures, Vermont

Managed Care

I think of self-determination as a backlash to managed care, which has a much different sense of priorities. Self-determination puts quality and services first, and also looks at cost. A big part of it can be cost reduction through quality. Managed case focuses on saving money, and if we get quality, it's good. In New Hampshire, the adult/elderly care is going towards self-determination.

Mary Ellen Fortini, New Hampshire

Self-determination is very difficult to implement, but one motivation in doing this is to forestall something worse, to create a barrier against the other managed care trend to limiting choice and doing services on the cheap and by slots.

Donna Winnick, Wisconsin

The Change Process

The system redesign element is huge. This is a very regulated state. In the first year it was lots of work sorting this out, and very frustrating.

Barb Roberts, Minnesota

For case managers, a huge role change is involved from I know best with a meek, accommodating consumer to the case manager being a facilitator and helper. Instead of managing people, the case manager helps people get what they want. To change attitudes and roles is very hard.

Barb Roberts, Minnesota

The Self-Determination Project took a look at the four principles of self-determination and amended them. This gave the group ownership; it was tedious, and took a long time to get the exact words. Since then our stakeholder groups and steering committee have helped us figure out all kinds of things—how to handle the liability pieces, the insurance piece, and how to pay people.

Barb Roberts, Minnesota

This systems change is from the state and from the grassroots. I'd like to see the consumer directed service philosophy penetrate DD, Mental Health, substance abuse, children's services, and to stay. Implementation is hard at this point. I do this on top of my regular job, and its very labor intensive. I'm doing consulting half of the time. In general, everything has been much harder to implement than we anticipated. For example, using a temporary hiring agency and lining things up the way we want. we're putting out another RFP for people to do background checks, set up health insurance and workers compensation.

Donna Winnick, Wisconsin

Conflict is involved in our changes. In Multnomah County, where we have a RWJ grant, the brokers working out of Resources Inc. are not a big threat to the current system. The case managers, however, would love to do what the brokers and the family support people do, and there is conflict here. I'd love to see case managers have lower caseloads and be able to have and do what the family support managers and brokers do.

Deanna Hartwig, Oregon

As a result of our project, here in Island County we started thinking differently and doing business differently. All of the adult service providers became much more attuned to what people needed versus what they happened to have or what people used to do. People in service agencies enjoy including people more in the development of their service.

Jackie Henderson, Island County, Washington

We do continual planning and outreach. This is a big cultural change and systems change. It's very time consuming; you have to be vigilant. If you think you have the answer, you probably don't. Yet it's a very exciting time; we'll see how far we can get. Changes could easily take ten years.

Terry Cote, Connecticut

I relied heavily on the DD council to provide input because the bureaucracy was more ingrained.

William Christoffel, Hawaii

"The devil's in the details." One issue is resolved, then twenty spring out of that. The big issues turned out tiny, and vice versa.

Sharon Johnson, Kansas

Resistance to Change

There was lots of provider distress and resistance when the shift to self-determination started. My staff meets with providers regularly, and the anxiety level is coming down, although some providers are still nervous. People mostly want to choose their own case manager; few want to manage their own care. Provider capacity will be affected if lots of dollars are pulled out.

Michelle Sures, Vermont

It’s an ongoing challenge for all of us, families, providers, and state agencies, to help those who have been within the existing service system to think in other parameters. For newcomers, it’s not always such a big leap.

Sharon Johnson, Kansas

So far, there has been little resistance. Releasing control is the issue. We’re such paternalistic agencies with well defined infrastructures. For years, we’ve had individual budget money in small sums ($3-5,000) available through our Family Support program. Now that more money is involved, there is more tension.

Hans Toegel, Massachusetts

Arizona’s project is in its infancy stage. (They are partnering with Independent Living Centers, and setting up a peer mentoring system.) We’re finding that consumers have been entrenched, relying on providers and group homes to make decisions. Persons with disabilities who have been entrenched in non-participatory environments find it hard to conceptualize how to be a friend. People go to the provider they know first for advice, and trust a peer mentor only after a lot of interaction. People have been taught to be dependent, and it’s hard for them to take the leap. There seems to be an invisible barrier. They get close, pause, maybe do it in a few months.

Brian Lensch, Arizona

Resistance to Change, continued

The Department is trying to get everyone's funds more portable and flexible.

Terry Cote, Connecticut

What We Would Do Differently if We Started Over

I would make sure that all the stakeholders are sitting at the table. This includes consumers, family members, providers, but other people too such as community members, for example, a representative of the housing authority. These should be local people. Not all have to come every time, but all need to take part in the systems change, not to us but with us. It's important to look at the bigger community and address the issue of not creating a new isolation, and assess whether the community is ready to be inclusive.

Mary Ellen Fortini, New Hampshire

We're a year and a half into our projects, and I don't think we would do anything differently. Certainly we've had to change our path as circumstances changed.

Barb Roberts, Minnesota

We wish we could have gotten this going sooner, and started sooner with getting a broker agency going. Maybe we should have eased out the residentially based case managers.

Donna Winnick, Wisconsin

1) Start on time!
2) Do more groundwork with providers so stronger alliances are built rather than folks being anxious about what might happen. It would be nice if it could be more amicable.
3) As in many states, the whole issue of communication is complex. How do you make sure that the right people get information and that it filters down to the middle level managers who make things happen rather than the director. Teaching consumers and parents how they communicate effectively is important.

Michelle Sures, Vermont

We haven't been very good at engaging our consumer community. We'll use this grant as a chance to do more of that. Other states have consumer advisory boards.

Hans Toegel, Massachusetts

I would have involved consumers in a significant leadership role right from the start.

Terry Cote, Connecticut

It's a long process, actually very difficult, and longer than I ever thought. You have to let the existing contracts run out. I would have started in only one area and would have taken a closer look at the contracting situations right now, how they're being done and the constraints. I would plan for ways to get people beyond the parents involved.

William Christoffel, Hawaii

Evaluation

General Comments: Most sites are relying on Robert Wood Johnson-contracted evaluators to evaluate their projects. In many sites, evaluation activities were just beginning in June 1998. Two evaluation firms are involved, each in different states: HSRI and the Center for Outcome Analysis. See Appendix B for more details.

The University of Minnesota is doing a formative evaluation of systems change, and giving us feedback about how the three counties are doing. We get lots of feedback from stakeholder groups and steering committees, which are involved with just about everything. As for HSRI and the Center for Outcome Analysis, they have just started. This is a real problem with them starting so late. They are trying to do a pre/post survey but people are well underway already.

Barb Roberts, Minnesota

In addition to the RWJ evaluation, we are doing some on our own. The Center on Human Policy at Syracuse is our learning community. They were here for a site visit in mid-May 1998, and will produce a preliminary report, with a follow-up at the end (probably June 2000). Also, my teams send out follow-up surveys to people who contact them, and the surveys come to me. So far so good, but it's too early to judge. Among the 36 people completing surveys, some dramatic things have happened, and this helps create a statewide impetus.

Michelle Sures, Vermont

The University of Oregon is developing an evaluation instrument to assess the brokerage project.

Deanna Hartwig, Oregon

Final Words from New Hampshire

Choice is not control. If you are offering a list to choose from, this is choice, it isn't control. It's the difference between going to a restaurant and going to a grocery store to get your meals. In the restaurant, there is a fixed menu. If you shop for yourself, you can plan a meal suited to your dietary needs, your favorite foods, and your ethnic preferences.

Family members tell me they fear that self-determination is this year's fad. I tell them, "This isn't a model, this is a set of principles regarding how to think of and interact with people with disabilities." If it's a model, we have failed. The values are deceptively simple and easy for everyone to endorse: We value including people with disabilities in our community. But when you start to make the systems shift and real changes, a lot of resistance emerges.

Mary Ellen Fortini, New Hampshire

Appendix A: List of People Interviewed

ARIZONA

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VERMONT

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WISCONSIN

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Appendix B: Information Sources on Self-Determination

Two Web Sites on Self-Determination

<http://www.self-determination.org>.

The Robert Wood Johnson foundation is funding this web site run from the University of New Hampshire.

<http://www.state.nh.us/sdp>

This is the State of New Hampshire's site on self-determination.

Other Places to Contact for Information on Self-Determination

In addition to the web sites above, check with:

- RWJ Self-Determination Project, (603) 228-0602 or email administrator MarthaYoung at <mry@hopper.unh.edu>
- Syracuse University Center on Human Policy, (800) 894-0826 or (315) 443-3851 or <http://soeweb.syr.edu/thechp>
- University of Minnesota Institute on Community Integration (612) 624-6300 or <http://www.ici.coled.umn.edu>
- HSRI (Human Services Research Institute) (617) 876-0426 - This institute is one of two organizations evaluating the RWJ projects.
- Center for Outcome Analysis (610) 520-2007 - This center is one of two organizations evaluating the RWJ projects.
- TASH (The Association for the Severely Handicapped) (206) 443-9592

Appendix C: Examples of New Hampshire's Consumer Empowerment

Quoted from Mary Ellen Fortini, New Hampshire:
An example of consumer empowerment is a woman who has decided she doesn't want 'The State' in her life. In some ways she is our best example of how much a person can change their supports through Self-Determination. She's in her early forties and has gone from a $10,000 per year budget to a $4,000 per year budget. It took a year to get everything in place. She chose a friend to provide the supports she needs.

This woman lives in a small town, and has a daily routine. She walks to the general store for coffee, where a group gathers every morning. She knows all the news about the town. During the day, she stops in a predictable sequence of places. People call and ask about her if she doesn't show up. She lives in an apartment attached to a house, and the family checks in with her. She's also across from the fire department and the chief checks in with her too. She is very well regarded in town. She knows everything that is going on, she sends cards to people who are sick, she helps with community activities, and she visits people in the hospital. Bonnie will contact her case manager to tell her, "I met with my circle and this is what I need and what it costs."

In parts of New Hampshire there has been a real shift in power and control. There has been a commitment to moving these out of professionals' hands and into consumers hands. Many consumers do not communicate verbally, and some of their most challenging behavior is a voice struggling to be heard. We need to learn to hear what's being said instead of trying to stop it. Thus certain regions here are committed to moving away from behavioral techniques for controlling behavior. They believe that you cannot simultaneously support empowerment and control behavior.

An example is a man who eight years ago had 3 on 1 staffing 24 hours a day, 7 days a week, and was in four point restraints when he was in the state hospital because he was so violent and aggressive. He was released in October 1990. When he moved to the community, his staff had agreed to take the risk of working with him using the 'gentle approach' and seeking to understand him. They accepted the fact that he might hurt them until they learned how to hear him. In the process, he hurled one woman through the air, but she kept on working with him. As of two years ago, this man had his own business cutting cordwood out in the community.

Appendix D: Fact Sheet January, 1998: Minnesota's Self-Determination Project

A Developmental Disabilities Project Partnership
Blue Earth, Dakota, Olmsted Counties and DHS

Frequently asked questions about Minnesota's self-determination project:

What are the purposes of self-determination projects?
The purposes of self-determination projects for persons with developmental disabilities are to enhance options to choose supports, housing options and employment possibilities, and improve quality of life while doing so cost effectively. The projects also create a foundation to support change and instill creative thinking for supporting persons with developmental disabilities. Emphasis is placed on individuality for supports, services, housing options and employment. Nationwide support for self-determination projects has been made available through the National Office of Self-Determination for Persons with Developmental Disabilities, a national program of the Robert Wood Johnson Foundation.

Is Minnesota the only state that is participating in a self-determination project?
In February 1997, Minnesota was chosen as one of 18 states to receive a self-determination grant, and one of nine to receive a full three year grant of $400,000.

Is project participation available statewide?
Currently Blue Earth, Dakota, and Olmsted Counties are participating in the Project. During the three year grant period, outcomes in these locations will be evaluated to determine the feasibility of using self-determination approaches statewide. All counties are encouraged to adopt self-determination principles and methodologies. Information sharing and educational materials will be available statewide.

Who is eligible to participate?
Blue Earth, Dakota and Olmsted counties, as project participants, will select interested persons with mental retardation or related conditions to participate, for whom they are the county of financial responsibility. Selection of individuals will be based on participation criteria developed by the county.

What are the key principles of self-determination?
Freedom
The ability for individuals, with freely chosen family and/or friends, to plan and live a life with necessary support.

Support
Arrangement of resources, both formal and informal, that will assist an individual to live a life he or she chooses.

Authority
Individuals will control resources, both formal and informal, that will assist them to live a life they choose.

Responsibility
Acceptance of the benefits and risks by an individual for choices made, and accountability for spending public money in ways that assure health and safety and that are life enhancing.

How is self-determination different from current service delivery?
Self-determination allows opportunities to support persons with developmental disabilities in a manner that is individualized and creative. Although there is no single definition of self-determination intervention, primarily because it *is* different for every individual, it provides a "new way of thinking" in respecting individualized choice and control. Current service programs that require individuals to "fit" into the programs may not allow for individualized choice or control. Normalization takes on an expanded meaning to include not just having an informed choice, but control over true informed decision making. Community integration expands to include individualization in living and working in communities, not in program systems. Adhering to the principles of freedom, support, authority, and responsibility promotes control over resources, purchasing, and decision making that can be life enhancing.

What is the primary focus in the implementation of self-determination principles in Minnesota?
Minnesota's Self-Determination Project's goal is to improve management and administration of services, service financing and design, access to services, and quality assurance. Outcomes will focus on consumers having increased choice of supports and will have control over their supports..

The project will focus on education, system redesign, and technical development for individually controlled resources.

Education Component

The education component consists of assuring that consumers, their supports, and the community receive and understand information regarding self-determination, how to make informed choices, person-centered planning approaches, quality assurance issues and other related topics.

System Redesign Component

The system redesign component focuses on evaluating current regulations and policies, identifying barriers and challenges, and working on changes that are necessary to make self-determination a reality for persons with developmental disabilities. Emphasis is on simplification, assuring health and safety, and supporting consumers.

Technical Development for Individually Controlled Resources

Technical development for individually controlled resources will allow individuals to have control over their resources for purchasing individualized supports.

What progress has been made during the first year of the project?
The first year of Minnesota's Self-Determination Project has emphasized technical development for implementation. Activities concentrated on the following: Person centered planning, consumers developing their own budgets, consumers choosing service coordinators, tracking and dispersing funds, education plans/activities and materials development, bringing together advisory groups, developing quality/evaluation plans, approval of federal home and community-based services waiver amendments to promote self-determination principles, presentations and public relations events, systems analysis and data collection, and site specific procedures, policy and local implementation.

How do I get more information?
For more information contact Barb Roberts, State Self-Determination Project Coordinator, (612/296-1146 or e-mail: barb. roberts@state. mn. us).

Appendix E: Minnesota's Title XIX Waiver: Sections Relating Ammendments and Self-Determination

Minnesota's Title XIX Home and Community Based Services
Waiver for Persons with Mental Retardation or
Related Conditions:

Selected sections showing the amendments
for self-determination project counties

The full text of the waiver is available from Research & Data Analysis,
Department of Social and Health Services

Amendments to Home and Community-Based Services for Persons with Mental Retardation or Related Conditions (MR/RC Waiver)
April 1998

Purpose:

- Strengthen the role of family, friends, and generic community supports
- Promote consumer self-determination and full inclusion
- Increase flexibility of service delivery and funding
- Allow additional support/service options within the current allowable resources

Amendments:

1) Modify funding/service limits that exist within the current federal plan. Service payments continue to be managed by local county agency within their established allowable average

- Housing access - remove $500 limit
- Caregiver Training and Education - increase yearly limit to $2500
- Respite care - remove limit of 90 days or 2160 hours per year
- Live-In care giver rent and food expenses - allow for reimbursement of an unrelated caregiver expenses when he/she resides in recipient's home

2) Allow coverage of the following additional services. Service costs and unrelated caregiver expenses when he/she reside in recipient's home

- Extended PCA
- Chore services
- Transportation
- Consumer training and education
- Consumer-directed community support

3) Provide the Commissioner the authority to award waiver openings to local agencies which create efficiencies by effective service development. Under written agreements the state may allow local agencies to serve a limited number of additional persons within its total allocated dollars when a local agency has:

- attained institutional discharge goals,
- develops planning mechanisms to meet current recipients changing needs,
- provides for consumer-directed service delivery,
- pursues quality assurance mechanisms beyond basic health and safety.

Consumer Directed Community Support

Consumer-directed community supports are services which provide support, care and assistance to an individual with a disability, prevent the person's institutionalization and allow the person to live an inclusive community life. Consumer-directed community supports are designed to build, strenghten or maintain informal networks of community support for the person. Consumer-directed community supports include the following specific activities at the request and direction of the consumer or his/her legal representative:

1) Provision of services and supports which assist the person, family, or friends to:
   - identify and access formal and informal support systems;
   - develop a meaningful consumer support plan; or
   - increase and /or maintain the capacity to direct formal and informal resources.

2) Completion of activities which assist the person, his/her family, or his/her friends to determine his/her own future.

3) Development of person-centered support plans which provide the direction, assistance and support to allow the person with a disability to live in the community, establish meaningful community associations, and make valued contributions to his/her community.

4) Ongoing consultation, community support, training, problem-solving, and technical assistance to assure successful implementation of his/her person-centered plan.

5) Development and implementation of community support strategies which aid and strengthen the involvement of community members who assist the person to live in the community.

The consumer, his/her legal guardian, and the county agency will assure that consumer-directed community supports are not duplicative of any other service provided to the person. Components of the consumer-directed community supports will be documented as necessary to prevent the person's institutionalization in the individual service plan/personal support plan. Additionally, the county agency shall document how the community support services enable the person to lead an inclusive community life, build a viable network of support, and result in outcomes specified by the consumer or his/her legal guardian.

Payment parameters

Minnesota will cover consumer-directed community support services in areas of the state in which local agencies have memorandums of understanding with the state agency to demonstrate the feasibility and effectiveness of consumer-directed community supports. Local agencies offering consumer-directed community support services will:

- provide consumer education and assistance in areas of self-determination and person centered planing,
- incorporate practices to develop and implement consumer-directed community support options in their local written procedures and criteria for the allocation of home and community based waiver resources,
- establish mechanisms which allow consumers to exercise control and responsibility over their supports, and
- refine outcome-based quality assurance methods.

Local agencies' written procedures and criteria will specify their responsibilities to provide information about consumer-directed community support options, to assist consumers in accessing and developing the desired support(s), and to assist in securing administrative assistance to implement the support(s). Authorization of resources for the purposes of purchasing consumerdirected community support services will be made on the local level based upon factors

outlined in the agency's written procedures and criteria. These factors may include the person's functional skills, his/her environment, the supports available to the person, and the specialized support needs of the person. Costs associated with consumer-directed community support will be managed within a county's unique allowable average to provide the flexibility to meet the preferences and needs of persons in the most effective and efficient manner.

Provider Qualifications

Consumer-directed community services will be provided by entities which meet the unique recipient needs and preferences of the consumer as specified in the person's individual service or personal support plan. Local agencies are responsible to work with the consumer and his/her legal guardian to assure that the consumer-directed community supports meets the recipient's health and safety needs, consumer preferences, and are directed at the desired consumer outcomes.

Consumer Training and Education

Consumer training and education is a service designed to help a person with a disability develop his/her self-advocacy skills, exercise his/her civil rights, and acquire skills that enable him/her to exercise control and responsibility over the supports he/she receives. Areas of training and education which achieve these outcomes will be documented as necessary in the person's individual service plan or personal support plan. Local agencies will assure that the consumer and his/her legal guardian receives necessary information on training and educational opportunities. Documentation of the outcomes and benefits of the person's participation in specific education and training will occur in the individual service plan or personal support plan.

Consumer training and education will be provided by individuals, agencies or educational facilities which have expertise in areas such as consumer empowerment, consumer-directed community supports, self-advocacy, community inclusion, relationship building, problem solving and decision making.

Medicaid covers enrollment fees, materials, transportation, hotel and/or meal expenses related to participation in the consumer training and education. Resources to allow a consumer to attend a needed training or educational experience may be prior authorized by the local agency. The local agency, as an enrolled Medicaid provider, will submit claims for this service to MMIS. Payment may be directed to the consumer by the local agency to allow him/her to receive the needed training or education. Documentation of expenses may include the course syllabus, workshop description, or training objectives. Receipts for allowable fees and expenses must be submitted to the local agency to verify accurate payment. Payment will not exceed $2500 per recipient annually.