

**Minnesota's RWJF Self Determination Project:
The Current Program Model and
Some Recommendations for Revision**

**Submitted to Barb Roberts
Minnesota Department of Human Services**

as

**Report 1 for the RWJF Self Determination Formative Evaluation:
Evaluation of Minnesota's Self Determination Project structure to determine
the degree to which the structure has high potential to accomplish project
goals and promote self determination principles.**

**by
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Minnesota is in the process of implementing a Self Determination Project funded by the Robert Wood Johnson Foundation (RWJF). Self determination, as it is conceived in this project, is based on the principles of *freedom* to plan and live a life; *support*, formal and informal, to live the life one chooses; *authority* over the resources, both formal and informal, that will assist the person to live the life s/he chooses; and *responsibility* for accepting the benefits and risks for choices made and accountability for spending public money in ways that assure health and safety and that are life enhancing. A formative evaluation has been conducted to assess the potential of the project structure and work plan to accomplish project goals and promote self determination principles. This is a report on that evaluation.

To evaluate the potential of the project structure and work plan to accomplish project goals and promote self determination principles, we interviewed state and local project coordinators, obtained and reviewed many project documents, and constructed program logic models of the overall state level project structure and work plan and of each of the county structures and work plans. We solicited feedback on these models from approximately 25 national and state "experts" on either self determination or system change and people with general expertise in the developmental disabilities field. Follow-up was done by a post card and a subsequent telephone call. Some feedback was eventually obtained via a telephone interview. We ultimately received input from nine respondents in addition to members of the evaluation team. These respondents included:

Angela Amado, U of MN
Bob Brick, MN Arc
Ellen Cummings, Consultant, New Hampshire
Marc Fenton, Consultant, Massachusetts
Amy Hewitt, U of MN
Tom JoliCeur, Hennepin County
Sherri Larson, U of MN
National Program Office for Independent Choices, National Council on the
Aging, Inc.
Bob Prouty, U of MN

Recommendations contained in this report were also based on information contained in various position statements, reports and publications on the nascent system change in the developmental disabilities field. These included

- Findings from the evaluation of the Minnesota Performance Based Contracting Project.
- Independent Evaluation of the Monadnock Self Determination Project.
- Live Free or Die: A Qualitative Analysis of System Change in the Monadnock Self Determination Project.

- Beyond Managed Care, and Beyond Managed Care II (both published by the University of New Hampshire) and
- Keeping the Promise: Managed Care and People with Disabilities (A record of the process and recommendations of Minnesota's DD Community Stakeholders Group, published by ANCOR)

Implementing a program aimed at supporting self determination is a new activity in Minnesota as well as elsewhere around the country. Even general system change, of much significance, is uncommon. You, as participants in the Minnesota RWJF Self Determination Project, are in the forefront of these efforts. As such, there are not many people out there who have gone before and can tell you what should be done or what will work or will not work. Much of the feedback that we received from the "experts" was in the form of a question, e.g., "Would it work to..." "Does there need to be..." Many of the "experts" approached their review of the models with an expectation of what they can learn from us, e.g., "While many (entities) have promoted consumer choice of providers, few have relinquished fiscal controls. We are most curious what will result in terms of changing perceptions and relationships." Additionally, some of the feedback that we received was contradictory, e.g., one person suggested developing a project-wide work group to develop a Single Plan and coordinating those efforts with other groups in the state who are working on Single Plans. On the other hand, another person said, "Beware of the time invested in developing a single plan ISP. Do you want people's time and energy invested in more paperwork or in helping people get what they want? So what if it's a single plan for the same old life?" In addition to the difficulty in finding people with "the answers," the effort is complicated by the need for changes to fit the context (both geographic and cultural) in which they are implemented as well as the need to design those changes in a way that facilitates ownership by the stakeholders.

In spite of the fact that there are no definite answers or perfect models to copy, we have secured some suggestions from "experts" and other stakeholders, from other projects (particularly the PBC), and from a review of the literature. The predominant themes in those recommendations were:

- **Collaboration for maximum effectiveness.** Two primary reasons for maximizing collaboration were to increase efficiency and to maximize the benefits of diversity. The latter was evidenced in recommendations to collaborate with underserved minority populations, consumers, and direct service staff. The motive to increase effectiveness was seen in recommendations to collaborate with other state efforts, with all stakeholders at local sites, and with generic community resources.
- **Principle-based system.** Many respondents mentioned operating on the principles that have already been developed (DHS, DD Stakeholders' Group,

NH Self Determination Project) and perhaps consolidating them into a central focus and evaluating all decisions against the principles. Fairness and trust and operating on ethical standards were stressed.

- **Consumer empowerment.** Many of the comments were on keeping the focus on the consumers and what their needs and desires are. Cautions were issued about being sure person-centered planning and outcome-based quality assurance are flexible and individualized. Developing accessible and appropriate consumer support and education activities was stressed.
- **Need to develop entirely new kinds of supports.** Some ways to support development of new supports were to provide outreach and technical assistance to generic community providers, to provide the assistance, flexibility, and start up support to establish new innovative programs, to help minority groups develop provider agencies, to support change in existing supports by working with provider agencies, unions, community colleges (for training), registries, and to support legislative changes.
- **Community Development.** There were many references to promoting ties with the community. Some things that were mentioned were facilitating access to generic resources, facilitating community friendships, expanding support networks, and encouraging natural supports.

There are more suggestions here than you could possibly implement. Indeed, one respondent to the models of what you are doing now asked, "Is it really possible to do all of this within the time frame of the project?" But, of course, many of these recommendations will be discarded, some new things can replace existing things, and some things can be set aside for attention in another effort. You will, of course, need to accept these as just suggestions and decide whether they fit or not. Some may be good, some may stimulate other, better ideas, but we would guess the most value will come from using the models and the suggestions as a way for people in the project to review where they are and to decide where they want to go.

As Dakota County tells their consumers before signing them up for the project, this is a new way of doing things and we'll all be learning together~"If you're willing to take this ride with us, you're welcome." You have embarked on an adventure. You have a lot of support and good wishes but, unfortunately, no road map.

The first two sections of this report lay out models of the work plans and structures of the project at the state and local levels. Section I is the overall project work plan and Section II is the three local work plans. The models use as a framework outcomes that we found either explicitly or implicitly in the project goals and work plans. The outcomes are: I. Minnesota's Self Determination Project's success provides an impetus and a foundation for similar efforts across the state, II. Service approaches meet the needs of the geographic area being served, III. Access and resources for service delivery for persons with similar

area being served, III. Access and resources for service delivery for persons with similar needs are equitable, IV. Individuals and families control their own resources, V. Redesigned roles support local community and consumer control, and VI. Quality assurance reflects local community and consumer control. The six outcomes are divided into intermediate outcomes which are followed by activities that are either taking place or are planned at the project sites in order to achieve the stated intermediate and ultimate outcomes. These models were developed to facilitate analysis of the logic of the project plans and their potential to attain the projected outcomes.

The third and final section of this report gives recommendations for possible changes that project participants can consider making to the current models. These recommendations and suggestions also use the six ultimate outcomes and their intermediate outcomes as a framework. Because there was a lot of overlap in the suggestions between applicability to state or local projects and between applicability to the three local sites, all suggestions are combined under a given outcome.

We recommend that project participants and advisors use the program models to do their own critique of the program logic and the potential of these activities to reach these stated outcomes. Additionally, we recommend that project participants and advisors review the recommendations and suggestions, not only to determine their appropriateness for this project at this time, but also to spark new ideas which may be more appropriate.

Minnesota Self Determination Project

Section 1

Over-all Project Work Plan and Structure

This section is divided into 6 ultimate outcomes the project hopes to achieve. For each outcome, two or more intermediate outcomes are listed. Under the intermediate outcomes are listed the activities that the project is planning to, or has already carried out, both at the project-wide level and the local level. As you review the activities, consider the potential of these activities to achieve these outcomes, i.e.,

Activities

Intermediate
Outcomes

Ultimate
Outcomes



I. The success of Minnesota's Self Determination Project provides an impetus and a foundation for similar efforts across the state.

Intermediate Outcomes:

- A) Project implementation and outcomes are evaluated to refine project as needed.
- B) Information about the principles, structure, work plan, and lessons learned in the project is disseminated to encourage and support similar efforts.

Project-wide Activities

The Project will:

- Develop and use self determination principles to support planning and implementing change.
- Develop and use topical frameworks to guide individual activities.
- Set up and coordinate a Workgroup and Committee structure to guide project activities.
- Develop and use a framework for communication/public relations.
- Use stakeholders and workgroups to evaluate the project on a quarterly basis.
- Contract with independent project evaluators to 1) evaluate the effectiveness of the project structure, 2) evaluate the effectiveness of consumer support activities, 3) evaluate the impact of methodologies used to determine individual budgets, 4) evaluate the effect of the self determination project on the quality of services and supports, 5) evaluate whether the project structure could be transferable to additional disability groups, and 6) coordinate with the RWJF evaluation contractor.
- Renegotiate and redesign traditional roles of government administrative employees as necessary to achieve project goals.
- Establish communication linking for project participants (i.e., video conferencing, retreats, meetings).
- Provide project presentations for interested audiences.

Additional Local Activities

The Counties will:

- Participate in project wide activities.
- Utilize project-developed principles and frameworks in developing local activities.

***Self Determination Principles**

Freedom. The ability of individuals, with freely chosen family and/or friends, to plan and live a life with necessary support.

Support. The arranging 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.

****Framework for Communication/Public Relations**

1. The audience will have access to the principles of goals.
2. The audience will receive information about the project wide activities and regional differences.
3. Ample time for presentation/discussion is important to assure the audience understands the scope and intent of self determination.

II. Service approaches meet the needs of the geographic area being served.

Intermediate Outcomes:

- A) Local entities have responsibility for local resources and the implications for their use.
- B) Local entities, supported by the state, have expanded capacity to meet the needs of local citizens.
- C) More individuals remain in the local community.

Project-wide Activities

The Project will:

- Pursue waiver amendments to give local entities the responsibility to assure supports are consumer directed and there are provisions for 1) consumer education and assistance in the areas of self determination and person centered planning, 2) mechanisms which allow consumers to exercise control and responsibility over their supports, 3) outcome based quality assurance methods, and 4) more flexibility to increase provider availability.
- Provide training and technical assistance for counties on options available under the waiver amendments.
- Provide technical assistance for counties to analyze resources available for implementing the MR/RC waiver amendments.
- Provide for or arrange for systems change/associated technical assistance to promote creative use of funds at the county level.
- Develop links with others working on increasing the availability of support persons to meet consumer needs.

Additional Local Activities

The Counties will:

- Build outreach activities for families and consumers on inclusion and use of generic community resources.

III. Access and resources for service delivery for persons with similar needs are equitable.

Intermediate Outcome:

A) A system for rational resource allocation are in place.

Project-wide Activities

The Project will:

- Pursue options for block granting of funds.
- Develop options for pooling resources for flexible use.
- Develop a funding allocation tool.
- Determine if methodologies are transferable to other funding streams through project evaluation.

Additional Local Activities

The Counties will:

- Pilot the funding allocation tool.
- Analyze waiting lists to better develop services.

Intermediate Outcome:

B) Individuals have access to culturally appropriate services.

Project-wide Activities

The Project will:

- contract for technical assistance for cultural considerations in areas such as access to services, building community connections, and person centered planning facilitation.

Additional Local Activities

The Counties will:

- Receive and utilize training to build community connections across all cultures which includes building support networks, utilizing Arcs, People 1st, and community organizations.
- Focus local consumer training and education on providing information and support in the context of a person's culture and values.

IV. Individuals and families control their own resources.

Intermediate Outcome:

- A) All expenditures are integrated into single budgets for flexibility, efficiency, and choice.
- B) Individuals and families have choice of service providers.

Project-wide Activities

The Project will:

- Develop a framework for tracking and dispersing funds.*
- Develop procedures and options to make individual resource allocation a viable alternative (tracking system, budget worksheets, employer of record/fiscal intermediary options).
- Develop software to track individual costs.
- Develop procedures for the development and implementation of individual budgets.
- Support managed care demonstration project efforts to provide individual consumer data.
- Support managed care demonstration project efforts for pooling resources and developing a capitation (for Blue Earth and Olmsted Counties).
- Initiate a legislative plan that supports consumer directed services and allows flexibility for monitoring, benefit portability, and decision making directed by the consumer.
- Evaluate current housing support funding streams and the status of incentives for promoting consumer controlled housing and determine the feasibility for developing legislation to increase flexibility and consumer choice in housing.

Additional Local Activities

The Counties will:

- Develop local procedures and options to make individual resource allocation a viable alternative (tracking system, budget worksheets, employer of record/fiscal intermediary options).
- Develop local procedures for the development and implementation of individual budgets.
- Assure that consumers know their support costs.
- Develop methodologies to simplify support purchasing through developing budgets that reflect needs and not funding streams.
- Analyze outcomes from the instruments and methodologies used.
- Promote the development of non-traditional service providers that consumers may choose/want.

Framework for Tracking and Dispersing Funds

1. Funds must be spent according to the consumer's plan.
2. Audits must be available and bills are checked against the consumer's plan
3. Funds must flow quickly.
4. Funds availability must be flexible and easy for the consumer to use.
5. Consumer fund allocations should be determined prior to planning.
6. An allocation mechanism that can be tracked must be used.
7. There must be a consistent and clear fund allocation method used.
8. Budget tracking must be ongoing.
9. There must be flexibility for the use of funds.

V. Redesigned roles support local community and consumer control.

Intermediate Outcome:

- A) Methods and support are provided to transition from obsolete services.

Project-wide Activities

The Project will:

- Develop a framework for education.
- Provide training for all involved.

Intermediate Outcome:

- B) Individuals and families are supported to assume new roles, e.g., controlling their own resources.

Project-wide Activities

The Project will:

- Seek MR/RC Waiver amendments to support consumer choice for individual service plan development.
- Develop a framework for Employer/Employee relationships.**
- Develop a Consumer Handbook for information about being an employer with review by a labor attorney and someone to ensure consumer accessibility.
- Develop a framework for consumer controlled housing, (not completed)
- Develop and implement an education plan to promote consumer controlled housing and to educate support persons on methodologies to support consumer choice.

Additional Local Activities

The Counties will:

- Provide consumer education and assistance to enhance self advocacy skills and informed decision making and to promote self determination principles.
- Support the development of community organizations to provide consumer support and to be utilized in advisory/steering capacities.
- Develop access to person centered planning facilitators to meet individual consumer planning needs.
- Provide education to support persons on assessing options outside the traditional "menu" of services.

Framework for Education

Education focus minimally encompasses: 1)Philosophy/principles, 2) Local capacity and access for consumer person centered planning facilitation which encompasses building self sufficiencies at the local level, 3) Mentoring and technical assistance for facilitators, 4) Education and support for consumer support networks, 5) Self advocacy, and 6) Community connections.

Framework for Employer/Employee Relationships

Consumers will have choices to handle employment law issues. Consumers may be the employer or the county agency will provide alternatives for handling employer of record, payroll, taxes, worker's compensation requirements and other related employment law areas.

V. Redesigned roles support local community and consumer control, (continued)

Intermediate Outcome:

C) Local entities are supported to fulfill new roles.

Project-wide Activities

The Project will:

- Develop a framework for liability. *
- Coordinate strategic planning for counties regarding liability issues.
- Contracted with a labor attorney to help with employment issues.
- Develop a framework for service coordination. (not completed)
- Recommend legislation to increase flexibility in the areas of MA Home Care and case management.

Additional Local Activities

The Counties will:

- Provide training and support to service coordinators in order to assist consumers to arrange individualized supports and implement plans.
- Assess the need for changing representation for public wards and develop an action plan to address the outcome of the assessment.
- Research, promote, and support the development of non-public guardianship options for persons with developmental disabilities.
- Implement a single plan ISP.

Intermediate Outcome:

D) Service providers are supported to fulfill new roles.

Project-wide Activities

The Project will:

- Develop a framework for provider support.**
- Pursue MR/RC Waiver amendments to support consumer directed supports and creative service delivery.
- Make recommendations for legislation changes to increase flexibility and consumer choice in work environments.
- Invite work and day program organizations to participate in project-wide advisory groups to develop ideas for meeting consumer choice.

Additional Local Activities

The Counties will:

- Encourage stakeholders representing provider interests to develop strategies for transition and meeting individual consumer needs.
- Create and implement on-going provider education and technical assistance opportunities regarding self determination principles and customer service.
- Develop methodologies and implement those methodologies for increasing the options for providers to work for consumers and not the funding source.
- Invite provider organizations to participate in local advisory groups to develop ideas for meeting consumer choice.
- Work with work support providers to accommodate consumer requests for scheduling preferences, job choices, and work environments.

Framework for Liability

1. Liability issues will be addressed on an individual service planning basis.
2. Consultation with a contractor will advise on issues.
3. An "options list" will be maintained as a resource for individual issues.

Framework for Provider Support

1. Provider education and training will be addressed on an individual basis as it relates to the individualized needs of the consumer.
2. Providers will be encouraged to participate in "peer-support" networks. Topics for communicating and meeting could include re-focusing on approaching their business, how to satisfy the consumer, how to prepare for the future, and evaluating what supports are offered.
3. Incentive strategies for participation will be developed at the local level. _____

VI. Quality assurance reflects local community and consumer control.

Intermediate Outcomes:

- A) Quality assurance systems, designed within federal and state guidelines, are locally based and provide for consumer and family input.
- B) The quality assurance systems' definition of quality includes choice and control.
- C) Quality assurance *is* linked with quality improvement support systems.

Project-wide Activities

The Project will:

- Develop a framework for quality assurance. (not completed)
- Pursue waiver amendments in order to remove barriers to develop and use outcome based quality assurance methods.
- Implement rule consolidation legislation that moves from checklist licensing reviews to consumer outcome based reviews.

Additional Local Activities

The Counties will:

- Develop and implement quality assurance plans that include an evaluation and consumer satisfaction component.
- Include choice and control as part of their quality assurance plans.
- Utilize quality methodologies from PBC, Region 10 Quality Assurance Commission, Rule Consolidation, Project Assure, DHS quality initiatives, and their own development as an integral part of service delivery to project participants.

Overall Project Support Structure

- The workgroup and committee structure for the project as a whole consists of two committees and four or more topical workgroups. Coordination and facilitation of these groups is provided by a full-time Project Coordinator who is employed by the State Department of Human Services (DHS).
- The general advisory committee is called The Strategic Resource Committee and it consists of representatives of statewide groups including legal advocacy, provider organizations, consumer organizations, business, consumers, DHS staff, a legislator, and local project site staff. The purpose of this group is to share information about the project and local activities, to provide a forum for input regarding project activities, and to support self determination efforts on a statewide basis.
- The other committee is called The Information and Resource Committee and it consists of representatives of DHS, the participating counties, consumers, a provider, consultants, and representatives from two other state demonstration projects. This committee serves as a forum for DHS, the counties, and others to share information and provide updates as well as to problem solve on identified issues. It also serves as the contact group for consultants. Recently, they began inviting other counties to these meetings to increase awareness of self determination and to receive additional feedback of project activities.
- The workgroups serve to develop strategies in specific topical areas. Currently there are workgroups on Education, System Redesign, Individually Controlled Resources/Liability, and Housing. Other workgroups may be formed from time to time to address specific issues.
- The Education Workgroup is developing an education and outreach implementation plan to assure consumers, their support persons 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. Membership consists of representatives from the three project sites, DHS staff, and consultants.
- The System Redesign Workgroup provides direction and strategies to change the status quo of service delivery, increase flexibility, shift consumer supports control to the consumer, address barriers and work on changes that are necessary to make self determination a reality for persons with developmental disabilities. Membership consists of representatives from the three project sites, DHS staff, and consultants.
- The Individually Controlled Resources/liability Workgroup provides direction, strategies and consultation for the technical development for individually controlled resources including dispersing and tracking funds, liability and other issues which will allow consumers to have control over their resources for purchasing supports. Membership consists of representatives from the three project sites, DHS staff, and consultants.
- The Housing Workgroup was recently convened to address funding issues for individual housing, work with generic housing agencies, and develop a handbook for individuals and families. Membership consists of representatives from the three project sites, DHS staff, and consultants.
- An additional group, the DHS Support Staff Workgroup consists of DHS staff representing various state-wide initiatives and key areas targeted for redesign.
- In addition to the overall project structure, each participating county has a supporting structure of coordinators and committees and work groups.

Minnesota Self Determination Project

Section 2

Local Structures and Work Plans

This second section gives information about the local project plans. The first part gives information about the counties, their project structures, their criteria for participation, and their outreach. The second part gives the local work plans divided again by the six projected outcomes. As you review the activities, consider the potential of these activities to achieve these outcomes, i.e.,

Activities

Intermediate
Outcomes

Ultimate
Outcomes



Overview of Participating Counties

Dakota

Dakota is a large county in the south metro area which includes both suburban and rural areas. The Developmental Disabilities Division consists of 28 Social Workers plus case aids who serve over 1200 consumers. There are 30 licensed day and residential providers in the county and numerous family foster care providers.

Although Dakota County is not involved in the managed care pilot project as the other two counties in the Self Determination Project are, Dakota was recruited to participate in the project because of their experience with individually controlled budgets. Their Accounts Management Program started in 1990 with state family subsidy money and county DD funds and has grown from six people to about 350. Families submit an expenditure plan and receive their money quarterly. They do not have to turn in receipts. Although there is a policy that specifies how the money can be spent, there are very few boundaries. Some things that are acceptable are dinners out for Mom and Dad or weekends in a motel to swim for the whole family ("It's cheaper than respite.") This program has cut costs substantially and people are happy with it.

Olmsted

Olmsted County is located in the middle of a rural area in southeastern Minnesota. Its county seat, Rochester, is a medium size city which is the home of a major medical facility. Olmsted has between 500 and 600 open cases for consumers with developmental disabilities. These consumers are served by approximately 16 case managers, three day program providers, and five residential provider agencies, the public schools and a variety of other providers.

Olmsted's system change planning began in 1995 and has involved all stakeholder groups. In addition to the Self Determination Project, Olmsted is involved in the managed care demonstration and an alternative quality assurance demonstration, the Region X Quality Assurance Initiative. There is a great deal of overlap between the three projects and Olmsted sees them as one initiative with more than one funding source. Progress has slowed recently due to the change in leadership in the Developmental Disabilities section including a several month vacancy in this position.

Project Foresight is the name of the local project in the managed care demonstration and even though that project has shifted to include all disability groups, that name still applies to the developmental disabilities effort. Representatives of Project Foresight planning groups are serving on cross-disability work groups to help further shape this broader demonstration.

Blue Earth

Blue Earth County is located in a rural area of southern Minnesota. The county seat, Mankato, is a medium size city which is the home of a state University and serves as a "service hub" for the surrounding counties. Blue Earth has about 330 active consumers with developmental disabilities who are served by five case managers. There are six residential providers in the county and one vocational provider.

Blue Earth County is also participating in the managed care demonstration project. For this effort, they are partnering with two neighboring counties. The local project, Project Assure, has been in planning for four years. They see both of these projects as working together to increase self determination for people who receive services.

The mission statement of Project Assure is to make certain that eligible participants have:
FREEDOM to plan and live a life of their choosing,
AUTHORITY to control available resources necessary to live that life,
RESPONSIBILITY to accept the benefits and risks of those decisions,
ACCOUNTABILITY in spending public resources in safe and life-enhancing ways, while assuring that the necessary services are available to support these rights.

Overview of Participating Counties

Dakota

The goals that Dakota has for their participation in the project are:

- To demonstrate a positive shift in peoples' lives with broader and more flexible options.
- To demonstrate where blocks are in the current system so they can be removed.
- To learn whether or not having direct control over resources has an impact.
- To show that managed care can be participant-driven.
- To shift power from the system to the person.
- To shift the focus from the system to relationships.
- To make the system more equitable-less of a "haves and have nots" imbalance.
- To incorporate the processes developed in the project into the regular operations of the DD unit (not a set-aside).

Dakota has established the following principles to guide decision making:

1. Relationship principle: We believe that people plan with and are supported and facilitated best by those who know and care about them - that relationships are more important than rules.
2. Simplicity principle: We believe when consumers and families must interact with the bureaucratic helping systems, things should be made as clear, streamlined, and simple as possible. This allows a focus on the consumer's

Olmsted

Olmsted's goal is to change the service delivery system by shifting the power to consumers. From this power shift, the other parties (counties, case managers, service providers, families, and the community) become equal and are expected to change the way they operate and to adapt to the individual's plan. Olmsted expects to learn what the barriers are in the system and what needs to change one person at a time and then will try to generalize to make broader changes where appropriate. It is expected that this model will help them to drive change at the state level as well.

Blue Earth

Overview of Participating Counties

Dakota

needs rather than on how to deal with formal helping systems.

3. Human need principle: We believe that ALL people have the same human needs, as described in Maslow's hierarchy. (They speak of this as "removing the disability filter.")
4. "What Works" principle: This project is a process of success, failure, learning and getting better. It's now about finding the "right answer;" it's about finding out what works.
5. Transition principle: We believe it is important that the current system not be seriously destabilized. We are engaging in an evolutionary process of change.
6. Equity principle: We believe people with similar needs should have similar financial resources with which to obtain their support.
7. Change principle. We believe change is okay and in fact expected as roles change and power shifts to families and people with disabilities, that this project is about thinking outside the box and that communication is key.

Olmsted

Blue Earth

Project Structure

Dakota

Project support consists of:

- A full time Self Determination Project Coordinator and supporting management staff.
- A Steering Committee to provide guidance for the SD grant. Consists of county supervisors and case managers, parents, 1 consumer, and providers. Average attendance is 18 - 22. The county presents activities and decisions to them and gets feedback.
- Two self-advocacy groups serve as consumer advisory committees. They go to them for guidance on issues that impact individual consumers.
- Working with the local Arc for guidance and planning for them to be the conduit for self determination information after the project.

Olmsted

Project support consists of:

- Self Determination Project Coordinator (1/2 time, funded by RWJF funds)
- Self Determination Service Coordinator (Full time, funded by RWJF funds and Project Foresight funds) to provide support to individuals and their teams in the planning and implementing stage and to "mentor" case managers.
- Project Foresight coordinator and various supporting staff also assist with SD project activities.
- Project Foresight Advisory Committee. Has been meeting for three years to plan for that project. It has been expanded to also advise the SD project. Originally it had three work groups. The Finance Work Group finished its work. The Quality Assurance Work Group became the Region X Quality Assurance Advisory Committee. The Service Delivery Work Group continues. This committee consists of Residential, Day, and PCA providers, family members, Arc representatives, county representatives, and a Public Health Nurse. There was a consumer on this group but s/he moved to the Quality Assurance group.
- Service Delivery Work Group. This group was charged with developing a new model for service delivery from intake through quality review.
- The Region X Quality Assurance Advisory Committee provides input for the quality assurance part of the SD project.
- People First sub-committee. They also serve an advisory function to the project but chose to do so as a separate group.

Blue Earth

Project support consists of:

- A full time coordinator whose position is completely supported by grant funds
- An Advisory Council, which includes staff of service provider agencies, parents, persons with developmental disabilities, and a county case manager.
Although this advisory council is the only committee or workgroup specific to the Self Determination Project, there is considerable coordination with the committees and workgroups for Project Assure, the managed care project that the county is also participating in. These are:
 - The Service Workgroup which has a large, monthly meeting to which all stakeholders are invited. It serves as a forum to share information about the project and to advise other workgroups.
 - The Service Design Workgroup. This is an active group that has developed many of the changes, e.g., the single plan, the waiver variance requests, provider profiling, and the alternative quality assurance program.
 - The Case Management Workgroup which is made up of case managers from all three of the managed care counties.
 - Transitioning Workgroup is working with the budget allocation tool.
 - The Implementation Team is made up of people from all disability groups from all three managed care counties. They are working on the budgeting and other areas that overlap with the managed care project.

Criteria for Participation

Dakota

For the first year, a participant must be a client of Dakota County Social Services Developmental Disabilities Section and Dakota County's financial responsibility.

A participant, their parent(s) if a minor child, and/or guardian/conservator if they have one must:

1. with whomever they choose - develop, revise and update as needed, a Personal Support Plan following established guidelines for addressing health and safety, and support wanted/needed.
2. make arrangements for obtaining and paying both formal and informal providers of goods and services.
3. not use funds to pay Home Health or other County fees. County fees are set by the County Board and are required for County funded services within established policy.

In addition, the participant must use funding sources other than Home Health or ICFs-MR due to federal funding constraints.

In the second year, the criteria is being expanded to anyone who is a client of Dakota County regardless of funding source. There will be limits, however, to what they can do when federal funding is involved.

Olmsted

Who can Participate in Olmsted County's Self Determination Project?

- Anyone with a developmental disability or related condition who Olmsted County has financial responsibility for.
- Anyone who, with assistance as needed, is willing to:
 - Using an individualized planning method, creatively plan for their needed supports.
 - Develop and monitor an individualized budget
 - Receive a reduction in funds to 90% of current allocated funding level. 5% will be placed in a general "risk pool" for emergencies.
 - Assist in making changes in the current system.
- Children and families, school age students, and adults of any age may participate.

Blue Earth

Participants must...

- Meet Rule 185 definition of eligibility for services.
- Be the financial responsibility of Blue Earth County and live in or receive services within the geographical area of Project ASSURE*.
- Agree with the established principles of Self-determination. They should be willing to work to affect system change while recognizing changes are likely to be incremental.
- Be committed to the belief that given the opportunity and needed supports, they can arrange their resources in ways that are cost-effective, resulting in a higher quality of life.

There are no limits concerning age, level of disability, etc. A wide representation of persons will be encouraged as the project expands.

(*To start, they will only be accepting consumers for whom Blue Earth is the county of responsibility. Later, they hope to open it up to consumers who live in their county but are the financial responsibility of the two counties who are their partners in the managed care demo.)

Outreach and Participation

Dakota

- Information meetings/presentations. Had three information meetings-invited 1200 people-included everyone in the system. About 80 people came but got a lot of calls. There was a lot of excitement. Most of the families who have support through Home Health were excited about it, but they can't do that now. Gave out application forms and got 34 back (including 4 kids on Home Health), got 5 more later. Planned to take 20 participants, but decided to take them all. Some had to drop out due to family problems. They're going to do another group later. (They felt it was important to go directly to consumers rather than just through social workers.)
- An informational brochure was developed and distributed prior to the information meetings. It gives a brief overview of the project and self-determination principles and provides a name and number to contact for further information.
- A second round of information meetings is planned for the second year.

Participation

As of March, 1998, there are 24 consumers in the project and 17 plans have been approved. Six of these live in group homes and the rest live in the family home. Applications are being accepted for Year Two.

Olmsted

- Olmsted has a contract with the Arc for 10 hours per week to increase awareness and education for people with disabilities and their families about the changes. They thought people might be more responsive to Arc than to the county. The Arc, assisted by the project coordinators, have held two information meetings which were well attended, are doing outreach, writing newsletter and newspaper articles, and are looking for people to serve on the advisory committee. They are also developing a survey to gain insight on how Arc and Project Foresight staff can best serve families and individuals in becoming familiar with the new program.
- The county also sponsored informational meetings for various stakeholders in the developmental disabilities system.

Participation

As of 4/98, there were between 8 and 10 people in the SD project. Four live in licensed facilities, two people live or have lived in foster care settings, the rest live with their families.

Blue Earth

The county has distributed information about the demonstration to individuals and families primarily in three ways.

- First, they created a booklet explaining self-determination in general and the demonstration project in particular and mailed it to all consumer! and their families or guardians.
- The project coordinator also meets individually with service providers and school districts to explain the project and, in turn, ask them to distribute information to individuals and families.
- Finally, the local Project Coordinator co-sponsored a Family Forum with the local Arc to explain the meaning and importance of self-determination for persons with developmental disabilities, and the opportunity to participate in this demonstration project.

Participation

As of March '98, 15 consumers and families have officially joined the project. The living situations of these consumers include family homes, ICFs-MR, Medicaid Waiver group homes, and one adult living independently.

Projected Outcomes and Local Work Plans

- I. The success of Minnesota's Self Determination Project provides an impetus and a foundation for similar efforts across the state.

Intermediate Outcomes:

- A) Project implementation and outcomes are evaluated to refine project as needed.
- B) Information about the principles, structure, work plan, and lessons learned in the project is disseminated to encourage and support similar efforts.

Dakota

The coordinators and managers from all of the counties are involved in making presentations about project activities.

Olmsted

The coordinators and managers from all of the counties are involved in making presentations about project activities.

Blue Earth

The coordinators and managers from all of the counties are involved in making presentations about project activities.

The two counties that are partnering with Blue Earth in the managed care demo are planning to incorporate self determination principles in their work in that project.

Through the project coordinators' involvement in the managed care project, ideas about self determination are being considered and adopted in systems serving other consumer groups. For example, a managed care work group assisted a group of mental health consumers to set-up a "consumers as providers" initiative in the mental health service system.

II. Service approaches meet the needs of the geographic area being served.

Intermediate Outcomes:

- A) Local entities have responsibility for local resources and the implications for their use.
- B) Local entities, supported by the state, have expanded capacity to meet the needs of local citizens.
- C) More individuals remain in local community.

Dakota

Dakota County Providers Training Group which consists of providers and county representatives who get together periodically to plan training. There is a group working on developing community crisis services.

Olmsted

The Olmsted Personnel Initiative started about March, 1997. The emphasis is on providers working together to recruit, train and retain direct support staff. Recently, People First joined the collaborative and assists in recruiting and developing training plans.

The Regional Crisis Project is a collaboration of southeastern Minnesota counties, service providers and state DHS staff. The purpose is to build local crisis services to replace the Regional Treatment Centers as the only option for people with developmental disabilities who are in crisis. Providers are being trained in many aspects of preventing, planning for, and managing crises. Another emphasis is on developing some local emergency respite beds to use in times of crisis. Transportation issues task force considers new options for expanded use of public transportation.

Blue Earth

Blue Earth County facilitated a "Frameworks for Accomplishment" process with many local stakeholders to plan what services for persons with developmental disabilities are needed in the local area and how these services should be delivered. Blue Earth has a Training Collaboration of local providers who jointly plan training. They put on a Spring and a Fall Conference. Blue Earth County is part of a regional collaborative working on developing local crisis services.

III. Access and resources for service delivery for persons with similar needs are equitable.

Intermediate Outcome:

A) A system for rational resource allocation is in place.

Dakota

Dakota county has developed their own allocation instrument, the Individual Budget Allocation Matrix, to be used for new people and for people with changing needs. (People currently in the system will receive their historical costs.) It is a simple one page, two part document that divides funding into two categories. The "general needs grant" is a fixed amount for support that differs only whether the client is over 18, between 18 and 22, or under 18 (to reflect the need of adults for work supports). The "supervision needs" allowance has twelve levels-six levels of care and supervision which are further differentiated by whether the client is out of the family home or not. Each of the twelve statuses carries a given dollar amount. This tool does not consider room and board costs.

A Financial Allocation Instrument is being developed as part of the managed care demonstration to determine individual budget allocations. When Olmsted's Project Foresight begins, everyone's budget will be based on this instrument regardless of historic costs. They acknowledge that people already in the system will need a transition time and that there will need to be a provision for reassessment if a person's needs change substantially.

Blue Earth

Blue Earth county is also a partner in developing an assessment tool as part of the managed care demo. This instrument will determine a budget amount for individual consumers based on their actual needs for support rather than on the historic costs of the services and supports they have received. They see it as a long transition before everyone's budget is based on this instrument. The legislation for the managed care demo specifies that counties must insure the current level of service for people.

Intermediate Outcome:

B) Individuals have access to culturally appropriate services.

Dakota

Olmsted

Blue Earth

- Use of individual budgets and increased use of person-centered planning in all of the project counties should cause services to become more individualized and allow for cultural preferences.
- All counties should benefit from the project-wide contract for technical assistance for cultural considerations.

IV. Individuals and families control their own resources.

Intermediate Outcome:

- A) All expenditures are integrated into single budgets for flexibility, efficiency, and choice.
- B) Individuals and families have choice of service providers.

Dakota	Olmsted	Blue Earth
<p>Because Dakota County is not participating in the managed care demonstration project, their flexibility will be limited to state, local, and Medicaid Waiver funds, i.e., not Home Health or ICF-MR funding.</p> <p>Individual self determination budgets for current consumers are set at 100% of historical costs. Neep people and people with changing needs will have their budgets determined by the Individual Budget Allocation Matrix.</p> <p>The "Personal Expenditure Plan" is used for projecting individual costs by designated funding areas, i.e., informal supports (non-licensed and less than \$1000 per quarter), semi-formal supports (non-licensed and more than \$ 1000 per quarter), formal supports (licensed vendors), and generic supports. (The designations have to do with contractor/employee status.) It is a one page document which is completed, along with the "Personal Support Plan," as part of the individual SD planning process.</p> <p>Consumer expenditures are to be planned around consumer needs without regard to coverage by their particular funding source. Dakota has developed methodologies so that reimbursements are done</p>	<p>Under the managed care demonstration project, Olmsted will be able to pool all funds into a single funding stream to increase flexibility and local control.</p> <p>Individual SD budgets are set at 90% of historical cost "to spark creativity." (From the savings, 5% is placed in an emergency fund.) This is viewed as a temporary practice until the managed care demo begins and the assessment tool is used to determine everyone's budget.</p> <p>They provide historical spending information to individuals both in the project and not.</p> <p>Developed a Budget Worksheet to be used to break down historical costs by providers.</p> <p>Developed an "Individual Budget Worksheet" for projecting individual costs by designated funding categories. Used by providers in responding to RFP. Purpose is to break down what costs are for and allow for comparison between proposals.</p> <p>The Waiver Management Team reviews the plan and authorizes expenditures. This is also an interim procedure until the managed care demo.</p> <p>Roughly, their criteria are: a) Is it within the person's budget? b) Does it meet minimum health <u>and safety needs?</u></p>	<p>Under the managed care demonstration project, Blue Earth will be able to pool all funds into a single funding stream to increase flexibility and local control.</p> <p>Individual SD budgets are set at 100% of historical costs.</p> <p>Families who receive county funded respite care are now given the option of receiving a cash grant to purchase the types of respite they desire rather than being limited to using approved vendors who have traditionally billed the county directly for services rendered</p> <p>Individuals receiving waived services and members of their families are being provided individual budgets to purchase the services they desire. This change is making it possible for consumers and family members who receive waived services to design alternative living and employment options according to their personal needs and desires.</p> <p>Offering individual budgets to consumers and families receiving services through Home Health, ICF-MR, and other programs will become possible as the managed care demo is <u>implemented.</u></p>

IV. Individuals and families control their own resources.

Intermediate Outcome:

- A) All expenditures are integrated into single budgets for flexibility, efficiency, and choice.
- B) Individuals and families have choice of service providers.

behind the scenes and if the person's funding source does not cover the expense, it is covered with county funds.

Expenditure Plans are approved by a team consisting of the social worker, the supervisor, and the SD coordinator.

Funds are distributed through the Self Determination Voucher Account. This is a checking account, owned by Dakota county but in the participant's name and on which the participant/designee is a signer. (This is similar to a treasurer of an organization who would have authority to write checks but would not own the account). The account does not say "Dakota County" on it. There are a lot of checks and balances on these accounts. Initial deposits are county money and then the county seeks reimbursement where appropriate.

Consumer Report Guide is being developed with the Arc. Will provide information about formal support providers and be in several accessible formats. It will provide information such as a description of their services, staff turnover rates, licensing information, and Incident or Vulnerable Adult Reports. This report will be disseminated by the county and the Arc.

c) Is it a reasonable use of public funds (not really defined yet)? Until the single funding stream which will result from the managed care initiative begins, the group also has to look at the limitations set out for the Waiver program. The Waiver Management Team consists of about 5 county people including a supervisor and case managers.

Policies are emerging as they go along. "We couldn't have predicted what people will ask for and the implications of that." There is a work group developing parameters.

There are plans to develop a Consumer Report Guide.

Blue Earth is developing a Provider Profile Manual. It will have basic information such as an overview of the organization, their mission statement, any specialties, position descriptions, and references. It will not have licensing information, incident reports, Vulnerable Adult Reports, or staff turnover rates but they will offer to make this information available for those who want it. This publication will also include suggested questions for consumers and families to ask prospective providers.

- A Service Fair for consumers and their family members is being planned in conjunction with the local Arc chapter. Providers, including schools, residential, vocational, and home health, have been invited to set up displays for families and consumers to visit. Another part of the day will be devoted to roundtable discussions.
- Variances to Minnesota's Consolidated Standard requested by this county will allow service providers additional flexibility in providing services in different ways or in different locations in order to meet specific requests of individuals or of their family members.

V. Redesigned roles support local community and consumer control.

Intermediate Outcome:

A) Methods and support are provided to transition from obsolete services.

See designated categories under B, C, and D.

Intermediate Outcome:

B) Individuals and families are supported to assume new roles, e.g., controlling their own resources.

Dakota	Olmsted	Blue Earth
Person-centered Planning <ul style="list-style-type: none">• Information is provided at orientation meetings about the different forms of person centered planning and "Planning Considerations" (a list of the 30 Outcomes developed by The [Accreditation] Council) is distributed.• Dakota has numerous person centered planning facilitators available. They have tentative plans to do more facilitator training.• PCP is offered at consumer information meetings. Connection to planning facilitators is made if desired.• Personal Support Plan. A one page document with five questions: What does the participant want to do or accomplish? How will the participant be supported? How is there reasonable risk of freedom from abuse, neglect, exploitation and danger to self/others? How is medical care provided? Who will provide what support (find? coordinate? payfor?)?	Person-centered Planning <ul style="list-style-type: none">• They have trained about 50-60 people to be facilitators during 1997 and early '98.• They see person-centered planning not as a "thing" but as a way to find out what people want and need and to plan how to get it. They place more emphasis on implementation ~ "in a community centered way."• A pre-planning phase focuses on educating the consumer that they will be heard and that they do have choices and helping them find out who they trust and who is their "community."• Pre-planning activities also focus on training all of the parties that will be involved in the new procedures and expectations.• There is an expectation that the system will react with not whether, but "how can we do it?"	Person-centered Planning <ul style="list-style-type: none">• Consumers and family members have participated in training regarding person-centered approaches to service planning.• Approximately 45 people have been trained to be person-centered planning facilitators. This includes all county case managers and representatives from all of the local provider agencies. Education <ul style="list-style-type: none">• A Family Forum was held with the local Arc to provide information about the project.• Two mailings have been sent to all consumers and families explaining the concept of self determination and the changes available through the project• A bi-monthly newsletter is sent out from the managed care project.• A contract is being developed with the local Independent Living Center to develop a self-advocacy curriculum and to provide training.

Education

- An informational brochure was developed and distributed prior to the information meetings. It gives a brief overview of the project and self determination principles and provides a name and number to contact for further information.
- Group orientation for participants. Discussion on individual budgets, planning processes, Personal Support Plans, project policy, Participation Agreement, project guidance, and participant support. County social workers were required to attend with participants on their caseload.
- Individual orientation is delivered while developing plan as needed
- Ongoing consumer support meetings to provide regular opportunities for participants to get together to discuss their experience.
- An Application for Participation in the project consists mostly of statements about project expectations and asks consumers to assess their comfort or support needs with each.

Fiscal supports

- A handbook of employment related issues was developed project-wide for individuals who may want to directly hire their support staff. This has been reviewed by an attorney and adapted for consumer appropriateness.
- "Employer of Record" contract with a support provider to handle personnel matters, e.g., payroll, unemployment taxes, withholding tax, for people who choose to hire supports and need assistance with employer/employee functions.
- A Participation Agreement is signed which describes project expectations and parameters. It is made very clear that this is a new way of doing things and the county, the participant, and those

Education

- The Arc, assisted by the project coordinators, have held two information meetings which were well attended, are doing outreach, writing newsletter and newspaper articles, and are looking for people to serve on the advisory committee. They are also developing a survey to gain insight on how Arc and Project Foresight staff can best serve families and individuals in becoming familiar with the new program.
- Informational handouts on self determination are distributed.
- A newsletter on the project is put out every other month and is distributed to all interested stakeholders.

Fiscal supports

- A handbook of employment related issues was developed project-wide for individuals who may want to directly hire their support staff. This has been reviewed by an attorney and adapted for consumer appropriateness.
- An RFP has gone out for a "Fiscal Intermediary" or an "Employer of Record" to process paper work (Social Security, Workman's Compensation, etc.) for individuals wishing to hire their own supports.
- Olmsted plans to do background checks on people hired by the consumer. This will include neighbors and friends—not sure yet about family members.
- Orientation to individual budgeting is informal at this point and handled by the SD Service Coordinator and case managers.

Other supports

- Olmsted has a contract with the local self advocacy group to review consumer training materials for readability and appropriateness.

- Further printed information is being developed to help families and consumers learn about and understand services and funding.
- Individual education and support are provided through project planning and participation.

Fiscal supports

- A handbook of employment related issues was developed project-wide for individuals who may want to directly hire their support staff. This has been reviewed by an attorney and adapted for consumer appropriateness.
- Blue Earth County has arranged for a provider agency to act as an "Employer of Record" for individuals or families interested in selecting their own in-home or employment support persons but not in meeting all the legal requirements of hiring and compensating support people.

Other supports

- The local project coordinator has assisted individuals with developmental disabilities in the area to start a self-advocacy group. This group is holding monthly meetings and recently elected officers.

- who provide support will be "learning together."
- Individual support is provided as needed.
- Consumers are given a document entitled "Bank Account Process" which explains the process of maintaining the checking accounts and the roles of the county and the participant.
- They will be seeking consumer direction for further training and education.

Intermediate Outcome:

C) Local entities are supported to fulfill new roles.

Dakota

The regular county social worker keeps the SD case with support from the SD Coordinator. There will need to be a county social worker involved to do certain administrative and eligibility things and monitor health and safety, but not necessarily to find resources and coordinate services. Dakota sees social workers as becoming a resource too and shifting from being "givers" and "controllers" to "helpers." However, people have the option to designate and pay for a private "support coordinator," e.g., a mother can pay herself for this function. The county is looking at strengthening the case management facilitation role. They are arranging for training.

Resources for county case management will not be included in the individual budget amount; however, people can use their individual grant to purchase other support coordination if they choose. The county will retain the role of determining eligibility, determining individual budgets, and approving and evaluating support plans.

Olmsted

A goal is that people will be able to choose to do service coordination themselves or hire someone to do it, but the county is not offering a choice now. The Service Delivery Work Group recommendation was to not have County Case Managers other than for the provision of financial eligibility and administrative functions. The county is still considering to what extent they can move in this direction. Considerations are financial and Rule 185. At this point, Olmsted plans to deal with the issues around service coordinator choice one person at a time as they come up. They do have one contracted case manager; this happened before the project. The county is stressing finding private guardians and conservators for people on public guardianship.

A Single Plan "which will replace the multiple plans adults have had in the past from their residential provider, work services provider, and Olmsted County" will be developed collaboratively between case managers and service providers.

Blue Earth

The traditional county case management role will be split into two separate functions, service coordination and support plan facilitation. While the Service Coordinator role must be filled by a county staff member, consumers and families may chose anyone, including themselves, to act in the role of Support Plan Facilitator. Consumers and family members have been provided information on public guardianship and the limitations it places on decision-making by consumers and families as well as information on alternatives to public guardianship. They are now actively trying to find alternatives for those who have no interested family or friends. Development of a Single Service Plan will unify the service needs of an individual consumer into a single document

Intermediate Outcome:

D) Service providers are supported to fulfill new roles.

Dakota

Providers serve on the Steering Committee to provide guidance for the SD grant. Dakota had a separate orientation for service providers. The director of the DD Division spoke with providers at a meeting titled "Self Determination Implications for Providers." He discussed the changing roles, rules, and relationships and asked that they first look at *how* something might be done and not just say no. Working with providers individually and in group meetings to facilitate flexibility, e.g., letting people go to the DAC part time, and to view their roles as support and facilitation rather than that of director and decision maker. Developed a collaboration with the Dakota County Providers Training Group which consists of providers and county representatives to decide how to spend training budget. They did a joint workshop (SD Project and the Dakota County Providers Training Group) on "Building Inclusive Communities." Everyone was invited—families, consumers, providers, county, advocacy. Dakota plans to close or downsize ICFs-MR. Three large ICFs, with 12, 16, and 40 people, will close.

Olmsted

Providers serve on the Advisory Committee to provide guidance for the SD project. Informational sessions for providers were held during which project staff reviewed Project Foresight, the Region X Quality Assurance Initiative and the Self Determination Project. Coordinators have spoken at providers' meetings and community groups. The county is partnering with service providers regarding training to enhance the change to self determination and individual budgets and dealing with these changes. They sent a letter to providers requesting volunteers and four responded. Training will focus on these providers although it will be open to everyone. Although Olmsted does not have a formal plan to close ICFs-MR, they are telling service providers that in the future if someone leaves the facility, they probably will not authorize filling that bed. They have actively supported providers to close two ICFs in the past year—one for 20 people, the other for six.

Blue Earth

Service provider agency staff are included as part of local project advisory council.

- ' Service provider agency staff have received training in using person-centered approaches to service planning with consumers and families.
- ' Local project coordinator has met individually with service providers and school district staff to educate them about the demonstration, and encourage them to pass information on to consumers and families. Project coordinator is regularly holding roundtable discussions to provide education and support to direct service staff involved with the project. Variances requested to Minnesota Consolidated Standard will allow individuals and their support team members greater flexibility in terms of where and how services can be delivered by a licensed service provider.

VI. Quality assurance reflects local community and consumer control.

Intermediate Outcomes:

- A) Quality assurance systems, designed within federal and state guidelines, are locally based and provide for consumer and family input.
- B) The quality assurance systems' definition of quality includes choice and control.
- C) Quality assurance is linked with quality improvement support systems.

Dakota

Developing a quality evaluation protocol modeled after that used by the Interagency Early Intervention Committee (IEIC). This is basically an interview process for a sample of consumers focusing on selected outcomes.

Dakota has an annual or bi-annual case audit for every person who receives services. This consists of the county supervisor interviewing the social workers about their case loads. Questions are asked about the satisfaction of the social worker with supports, which people want to move, and what unmet needs there are. This information is used at both the county level to develop resources and at the individual service level to resolve the issues.

Olmsted

Olmsted County is part of the Region X Quality Assurance Initiative in which:

- Legislation was enacted to authorize and fund a pilot project for an alternative quality assurance system.
- A contract has been awarded to develop an evaluation instrument. It will focus on outcomes and use interviewing. It will look at individual organizations as well as the service system as a whole.
- The quality assurance program will be a substitute for DHS Licensing, but Licensing will have oversight responsibility. The group is working on a Federal waiver to eliminate the need for Health Department monitoring.
- This quality assurance system will only be used for organizations who provide a certain dollar amount of service. For service providers under that amount, the service coordinator and support team will monitor.

Blue Earth

An alternative quality assurance program is being developed by a workgroup. Variances requested to Minnesota Consolidated Standard will allow individuals, with their support team, greater flexibility in terms of how their services will be monitored and evaluated, will allow services to be evaluated on the basis of outcomes in people's lives rather than on the existence of processes, and will allow provider agencies to be accredited by independent accrediting bodies in lieu of some state oversight.

Minnesota Self Determination Project

Section 3

Some recommendations for revision of the current project workplan and structure to enhance the potential to accomplish project goals and promote self determination principles.

This section is divided into 6 ultimate outcomes the project hopes to achieve. For each outcome, two or more intermediate outcomes are listed. Under the intermediate outcomes are listed the recommendations and suggestions that were obtained as part of this evaluation. Please review these suggestions and consider their potential to enhance the likelihood of reaching the intermediate and ultimate outcomes. Use them also to spark your creativity to develop other potentially helpful modifications to the project.

Activities

Intermediate
Outcomes

Ultimate
Outcomes



I. The success of Minnesota's Self Determination Project provides an impetus and a foundation for similar efforts across the state.

A) Project implementation and outcomes are evaluated to refine project as needed.

1. Specify upfront what criteria will be used when the stakeholders and workgroups evaluate the project on a quarterly basis.
2. Address why outcomes were successful or not successful, i.e., what factors have affected them that are not transferable or useful to others, e.g., a committee may have been successful primarily because its members were best buddies.

B) Information about the principles, structure, work plan, and lessons learned in the project is disseminated to encourage and support similar efforts.

1. Respondents expressed appreciation for the project's emphasis on sharing the learning and promoting self determination statewide. One said, "I agree that the project will promote additional efforts statewide. As we have opportunities to learn about aspects of the plans in each of the project counties, we will find ourselves thinking about how that could work in our own sites. Similarly, it will provide direction on where not to go or what to avoid."
2. Develop a clear strategy for expanding self determination to other counties and a targeted and intentional dissemination plan. The dissemination plan should include what information various stakeholders need, how it could best be packaged for them, and with what frequency it should be disseminated to them. One suggestion for expanding to other counties was to have a project county "mentor" one or two other counties that are behind them in their system change efforts.
3. DHS should develop a plan, specifically to continue, but also to expand the accomplishments of this project. Stakeholders, both those involved in the project and those watching for its expansion, would lose trust in the state if this effort is allowed to die out and this loss of trust would inhibit future efforts at system change. Threats to stakeholder trust include the project being implemented but not significantly impacting the

self determination of individuals with disabilities and their families or promising that system changes will be implemented but then letting them fade away over time. This plan for continuation and expansion should address the need for technical assistance, funding, regulatory changes, as well as dissemination of project lessons.

4. Information that is disseminated should address incentives for developing a system based on self determination.
5. There should be clearly stated management responsibility for implementing and coordinating the planned tasks.

II. Service approaches meet the needs of the geographic area being served.

A) Local entities have responsibility for local resources and the implications for their use.

1. Are any of the counties analyzing waiting lists? This could be very important information in order to prioritize needs, creatively develop stop-gap supports, and assess future demands on the system.

B) Local entities, supported by the state, have expanded capacity to meet the needs of local citizens.

1. It may be helpful to clarify whether cost savings is a priority of this project, and if so, how high a priority is it? If one of the driving forces behind managed care and individual budgets is to save money, shouldn't all of the counties (not just Olmsted) be discounting the historic cost of services? The original Self Determination Project in New Hampshire offered individual budgets of 75% of currently allocated resources or 75% of the average amount allocated to persons with similar characteristics. Further, if there are cost savings, what plans exist to reinvest them to better serve the needs of all persons with developmental disabilities?
2. If greater reliance is to be made on accessing generic community resources, there will need to be outreach and technical assistance to generic community providers. Access and acceptance may not occur without facilitation. Quality assurance for these generic resources will need to be addressed as well.
3. There's not much in the plans about developing community friendships. One respondent stated s/he did not see evidence of "shifting the focus from

system to relationships." How many more relationships do people have?
How many more paid relationships are in people's planning circles?.

4. A recommendation was made to incorporate activities to encourage natural supports into the project.

C) More individuals remain in the local community.

1. Project counties are commended for collaborating with other counties to develop crisis services.
2. Perhaps active monitoring of the circumstances of people on waiting lists would be beneficial in order to avert potential crises.
3. Creative family supports and encouraging family involvement starting with early intervention services and continuing across the lifespan will increase the likelihood that families will stay involved with their family member. Strong family support can sustain people through life's crises and transitions, provide close relationships, and facilitate community involvement.

III. Access and resources for service delivery for persons with similar needs are equitable.

A) A system for rational resource allocation is in place.

1. One of our respondents recommended developing parameters for appeals with respect to resource allocation decisions. There is a high potential for well-educated, middle class or higher people to get more money because they will create better articulated appeals. This was also a principle for managed care set forth by the National Association of State Directors Developmental Disabilities Services (NASDDDS): "Appeal and grievance rights/procedures must be specified in advance. These rights and procedures must provide for the timely resolution of complaints and offer assurances that individuals will not be placed in jeopardy while disputes are being resolved. Grievances that cannot be resolved through timely, direct negotiations between the disputing parties should be referred for independent mediation/arbitration."
2. One respondent felt it was important to assure that block granting of funds requires some basic expectations of service delivery and that Federal funds participation is not lost
3. How should current service recipients be treated once a block grant is implemented? Will they be forced to accept less money to accommodate addressing waiting lists or to allow others to pool resources?

4. The Minnesota Developmental Disabilities Community Workgroup recommended the development of ethical resource allocation standards and practices as Minnesota is able to take control of eligibility and service bundling. They pointed out that decisions will need to be made about the appropriateness of spending relatively lavishly on some individuals while others receive nothing. This process should be undertaken by a group of stakeholders statewide including an appropriate number of those on waiting lists.

B) Individuals have access to culturally appropriate services.

1. Respondents had many complements on the inclusion of cultural supports in the project plan.
2. Try to have culturally specific person centered planning facilitators trained and available to accommodate local needs. If that's not possible, you could try to contract with an appropriate facilitator from another county. At the least, facilitators should have diversity training and be aware of their own cultural assumptions and values.
3. Counties should address who their minority groups are and what their issues are and plan to address their diverse needs and diverse views of self determination. Is it possible to help more minority groups develop provider agencies—perhaps a charter school type of arrangement?
4. It may be useful for each local advisory group to take some time to consider which groups of people in their community represent minority, or under-represented, groups in implementation of this project and develop plans to better include their perspectives.
5. It is important that members of relevant cultural groups be included in adequate numbers on local and state-wide advisory and work groups.
6. The DD Community Workgroup noted the opportunity, with increased county control, "to tailor service design, delivery and resource allocation to poorly served, especially minority communities." Some of their suggestions were to "sit down with minority communities to better understand why they underutilized services and service resources," to contract "with local community agencies to manage social service resources for certain groups," and "for the state to work directly with certain minority communities whose boundaries may transcend the boundaries of counties or to assist multiple counties to come together to plan more appropriate and accessible services for Minnesota's minority communities."

IV. Individuals and families control their own resources.

A) All expenditures are integrated into single budgets for flexibility, efficiency, and choice.

1. Some suggested considerations in developing an allocation tool:
 - How should historical service utilization and cost be used?
 - Should funding be developed on an individual client basis or comparable cohort of clients? If cohort, what criteria should be used to determine the cohort?
 - Should family resources be included in the capitation calculation? Should there be expectations of family contributions?
 - What are the consequences of over spending the capitation and who bears the risk?
 - How are outcomes related to resource decisions, if at all?
 - How are the savings used?
 - What level of efficiency is expected from this approach?
2. A respondent who was familiar with the NH project commented on the funding allocation tool: "Two people with the same characteristics may cost very different amounts of money. Determining an allocation based on who they are now may be way too much for who they become with a self determined life. Allocations should be flexible and reassessed periodically."
3. Consider having non-county people on the teams to approve expenditure plans.
4. Those associated with the New Hampshire Self Determination Project felt that a risk pool was an essential ingredient, at least as a transition measure until people knew what to expect. This provided security to consumers who might otherwise be afraid to try the reduced budget, it provided security to providers who were caught with half-filled facilities, and it provided security to the local managing entity against unforeseen expenses.
5. Another respondent said, "Having money available in a risk pool will encourage people to take the risk of trying less expensive forms of support. A combination of allocating a percent of historical costs and having the money available if it becomes necessary is probably a good way to go."
6. One respondent reported that there is currently managed care software available for developing individual budgets.
7. The project's definition of self determination is debatable. It would be interesting to ask whether providing individuals control over money really does

offer people a sense of self determination. If not, what else would? *(This could be a consideration in the evaluation of the impact of individual budgets.)*

B) Individuals and families have choice of service providers.

1. There might be a need for more project activities to support individuals and families to have choice of service providers. For example, working with unions, agencies, community colleges (to do training), legislative changes, staff registries, etc. etc.
2. The DD Community Workgroup recommended that the state play a "role in assisting management entities to maximize consumer choices and increase cost-related competition among social and health services providers by providing the assistance, flexibility and start-up support needed to establish new, innovative programs."
3. It could be very helpful to gather and disseminate cutting edge ideas from other demonstration projects across the county so people know what the "possibilities" are.

V. Redesigned roles support local community and consumer control.

A) Methods and support are provided to transition from obsolete services.

1. Often service providers and case managers have perceptions of regulations that are much more restrictive than the regulation needs to be. Perhaps workgroups could meet for the purpose of untangling this for some of the regulations that are perceived to be barriers to self determination. One example is examining and questioning the need to obtain background checks on "friends."
2. DHS should design a "user-friendly" process for requesting variances and consider a mediation provision when they are denied.
3. It might be beneficial to develop a project-wide workgroup to create a "Single Plan" document, including representatives from the Ramsey County PBC workgroup and any other stakeholders experienced or interested in developing their own Single Plan. This would concentrate expertise and make it available to all and disseminate what has been learned to other counties. On the other hand, one respondent questioned the value of working on a Single Plan at the expense of directly working to improve

consumers' lives. A caution in choosing to create a single plan to be shared across the three project counties is that it will require a commitment to work collaboratively in creating the plan and an acceptance that, as in all collaborative ventures, it will take a good deal of time and no county may get exactly what it wanted in the final product.

4. One respondent said, "There is a great deal of overlap in the skills that the various stakeholders will need. Training is more powerful when you train people in different roles at the same time. This helps create a learning community, facilitates people learning from each other, and helps keep the focus on the person with a disability."
5. The project evaluators recommend that the evaluation of consumer support materials and presentations be done by consumers. This is being done in Olmsted County and we strongly encourage the other counties to do this as well. We have developed an evaluation protocol for consumer oriented presentations that is designed to be used by self-advocates. This protocol is currently being reviewed by the Olmsted County People First chapter.
6. The DD Community Workgroup recommended that "the state and key constituencies identify essential functions for activities and programs that serve the common interest and/or should be available statewide." Examples that were given include the Minnesota Statewide Direct Services Staff Training Initiative, quarterly state conferences that rotate geographically, workshops on special topics that get families, providers, and consumers to move the system, workshops for agencies to help them redesign their programs, marketing approaches, etc.
7. PBC participants felt that trainers need to validate the efforts staff have already made and tailor the training to where they are in the process. They also preferred to have a variety of trainers rather than the same few over and over.
8. Don't assume because people have been trained once in new ways of providing support that they will make the shift. They will need ongoing reinforcement. Also, provide ongoing training for people new to the system.

B) Individuals and families are supported to assume new roles, e.g., controlling their own resources.

1. Regarding a consumer handbook: One respondent reported that an accountant may be better for this than a labor attorney. S/he said that John

Agosta of HSRI has been commissioned to write a handbook for consumers and the "Cash and Counseling" program may have done one.

2. Does the proposed provider profile manual steer people to looking at existing/current providers, or is real thinking being done to see other ways people could be supported?
3. Try to make a video, or videos, for self-advocates for training on self determination principles, person centered planning, alternative options, and monitoring their supports. This would be more understandable for many of them and would facilitate remembering. If people could have their own copy, they could watch it more than once.
4. Other videos on self-advocacy should be used as well. They would be most effective combined with discussions. To really convince people that the game has changed and to get them to trust the change will take a lot of repetition. Also, videos would be a sustainable resource.
5. One respondent said, "Consumer education and assistance in self determination and person centered planning is essential. Counties cannot and should not be primarily responsible to implement this. Advocacy organizations can and should but are already stretched. There will need to be a commitment of financial resources to bring advocacy organizations to the table so they will dedicate time and resources to this project."
6. One respondent said, "There will be more return with people new to the system. A lot of emphasis should be given there. Look at self determination as a life journey and start training and support at a young age."
7. One respondent said, "An important area to give extra attention to is the question of how you can safeguard the rights of people who can't express for themselves and have no one to do it for them."
8. One respondent said, "It is important to be flexible about how planning is done. For some people, going through a formal person-centered planning process is neither desirable nor necessary. Planning for a person's dreams might take place in a 15 minute conversation."
9. Although all of the projects mention having a number of person-centered planning facilitators, none mention quality control of the planning or additional mentoring and training to improve the quality of the planning. For instance, while the SD presenter at a conference talked a lot about using person centered planning for people to say what they want, no one focused on person-centered planning as a process of "organizing and guiding

community change," which is O'Brien and Lovett's very definition of this kind of planning.

10. Tom Nerney's way of doing person-centered planning is "okay, let's take all systems responses out (to start with) - now what will we do?" The sense is missing that it's about designing a life, not just having money to purchase services. ("If designing a life is there, it might be; it just doesn't come out in these goals and activities.")
11. The DD Community Workgroup stated that both guardianship and representative payee arrangements were overused in Minnesota and as a consequence many Minnesotans with developmental disabilities are denied the basic elements of self determination and freedom. They recommended that these practices be reviewed.
12. Underlying issues of "Who's in control?" and "Who is responsible?" need to be openly and assertively dealt with, particularly regarding service planning. Service providers and case managers are confused about when guardians/conservators have the right to make decisions for the consumers. Old habits and expectations for who runs the meeting, who decides on the goals/outcomes, etc. die hard.
13. Families and consumers need lots of training and meticulous consistency and follow through to overcome their skepticism that this project represents real change and that the change will last. Trust has been broken in the past and we need to be sure that it isn't again.

C) Local entities are supported to fulfill new roles.

1. A recommendation from PBC participants would probably be to close all ICFs-MR. Many comments were made in the recent PBC survey to the effect that "people are held hostage in ICFs-MR" and that "federal ICF-MR has so many restrictions that, without a waiver, it is almost impossible to live a 'normal' life in an ICF-MR."
2. Appoint a project-wide workgroup to look at case management. Transitioning to private support coordinators seems to have a lot of barriers. Analyze them together and call in outside sources (other counties, DHS, Legal Advocacy) to assist. Do some trials and evaluate.
3. Implementing a Single Plan demands lots of technical assistance for computer issues and should have a formative evaluation at least to begin with.

D) Service providers are supported to fulfill new roles.

1. The vocational side often gets neglected in systems change efforts. People receiving supports in PBC provider agencies identified choosing where they would work as being second in importance as an area they would like improved. (Having the opportunity to develop friendships was ranked by consumers as most important to them). The SD project needs to include DT&Hs in meetings and training and remember the need to accommodate their schedule. They are usually not available during the day unless they have advance notice and can schedule a day off for consumers.
2. Your plan to provide peer support for service providers in transitioning to self determination is an excellent idea. Perhaps coordinate these efforts with the group working on a Quality Institute. The (Accreditation) Council's Quality Consortium could also be a model. The providers will, however, need a lot of training and technical assistance in addition to peer support.
3. The Monadnock NH project made a commitment to service providers to not let them fail as long as they maintained consistency with the guiding principles. They felt that providers who were experiencing the volatility of change, who were willing to give up control and reevaluate their role, needed and deserved to be supported through the transition. The Minnesota project should look at what they are doing to support providers so they can afford to support consumer decision making.
4. One respondent thought that project activities didn't seem to be oriented to acknowledging that current service providers may not be able to provide what people need, that new forms of support may be needed. For instance, in the five-state federal grant project for consumers to hire their own job coaches (Michael Callahan's), no existing day program was able to shift their billing, reimbursement, and scheduling structures to match project goals and incentives so a whole bunch of new companies had to start up (mainly from non-DD employment service entrepreneurs). Existing providers are often too heavily invested in their buildings to change within the time frame of this project.
5. A strong incentive for providers to improve their services would be to have their change efforts described in the Consumer Report Guide or Provider Profile Manual.
6. Service providers need a lot of technical assistance in promoting self determination for non-verbal consumers.

VI. Quality assurance reflects local community and consumer control.

A) Quality assurance systems, designed within federal and state guidelines, are locally based and provide for consumer and family input.

1. Some respondents were surprised that each local site will be developing its own quality assurance system. They commented on the amount of work this involved, but they also mentioned the loss of comparability with each other or with other localities.
2. Several respondents suggested having a broad range of stakeholders, including direct support staff, families, and consumers involved in developing and implementing quality assurance methodologies.
3. Similarly, respondents also recommended having a broad spectrum of stakeholders involved in any activities developing changes in regulations so that unintended consequences are prevented.
4. A recommendation was made that other quality assurance systems besides The Council's, used in the PBC project, be explored.
5. The DD Community Workgroup recommended that "the state, working with key constituencies, should develop a statement of the specific values, goals, and expected outcomes" to be used in "defining quality, establishing quality outcome measures, developing procedures for reviewing quality and supporting improvement." They suggested that some of these values and goals are probably suggested by the statements of DHS and the Governor's office, but "more representative and inclusive participation in establishing a state foundation to quality is warranted." Quality definitions and review processes that are developed at the local level should then be consistent with these goals and values.
6. Further, this group recommended that the state also "establish with key constituencies all universal rules and expectations including licensing, program reviews, and individual participation [sic]." The group felt that it was "critical that the process include public participation involving the constituencies that will be directly affected." They also suggested a permanent, statewide commission to resolve issues and complaints.
7. The DD Workgroup made some recommendations for the development of local quality assurance programs.

a) They suggested that any new quality assurance systems which have no record of field-testing of reliability and validity should include references to planned efforts to develop such a record.

b) They felt that the number of quality indicators should be reduced to the "critical few" and that there should be distinctions between program types only when necessary.

c) They recommended that "as counties and county cooperatives plan for their quality assurance systems, they should have access to a minimum set of standards related to adequate sampling. Such standards might include alternative sampling procedures which include a mix of direct interviews and telephone interviews with individuals and/or family members. They might specify the length of time that any individual might go without being directly visited in quality reviews (e.g., 2 years). They might specify related procedures that are expected to supplement visits, such as questionnaires sent to all individuals, family members or case managers of persons who are not directly visited.

d) They recommended a shift away from "quality being reviewed by paid inspectors to a broad range of individuals who care about and are able to help with improving the quality of life of persons with developmental disabilities." Further, these review teams should be adequately trained and compensated and should be "capable of providing or providing access to training and technical assistance to improve services."

9. A suggested framework for designing a quality assurance system:
- Who should design the new quality assurance program? (lawmakers, DHS, stakeholders)
 - What is the purpose of the program? (judgment, improvement)
 - What is to be measured? (inputs, process, outcomes [personal outcomes, functional outcomes, clinical outcomes], reactions of participants, organizational effectiveness, impact on society)
 - How should it be measured? (document review, interviews, observation, standardized instruments, surveys, focus groups)

- Who should be the evaluator? (external professional monitor, community monitoring team, the consumer's support network, the case manager/service coordinator, program staff)
- Who should be the respondent? (the service provider/s, the consumer, the consumer's family or guardian)
- How is the evaluative decision made? (How are the parts rated? How is the whole rated? What are the criteria? What are the possible ratings?)
- How should the information be used? (licensing/accreditation, improving the individual's services, improving generally the agency's services, a Consumer Information System, performance contracting)

10. PBC participants recommended:

- a) Monitoring, either entirely or mostly, by support networks was preferred two to one over monitoring entirely or mostly by an external professionals.
- b) An opportunity for consumers to determine the relative importance of different outcomes for themselves.
- c) Outcome reviews should seek input from families, residential and work support providers, as well as the individuals themselves and should often include observation of the individual in different sites. This is particularly important when consumers can not evaluate their services themselves or can't communicate their evaluation.
- d) Many of the PBC participants would like to see all of the paid supports (case management, DT&H, as well as residential providers) held accountable for consumer outcomes.

B) The quality assurance systems' definition of quality includes choice and control.

1. One respondent hopes that at least some level of quality assurance will be individualized. This could mean monitoring by consumers themselves and their support networks, evaluation criteria set by their own priorities and goals, and/or gathering information in a manner preferred by the consumer. One respondent said, "A common perversion of self determination is to latch on to 'choice' and to loose the concept of really leading a self determined life. An example of this perversion is a support provider who

shared the story of a consumer who identified as his 'dream' to go bowling twice a week. Truly leading a self determined life is much more than this."

3. One respondent wants the definition of quality to include provisions for poor consumer choice. S/he suggests some considerations: Will some consumer choices be reviewed or not permitted? What would be a process for this? How will consumers be protected from poor choices? How is liability shared within the system?
4. One respondent said, "Remember the (SD) principles and whether the person is closer to leading a self determined life. Also measure happiness, power, and a sense of control."
5. One respondent suggested that for quality assurance in a participant-driven managed support system, the consumer and his/her support network should be responsible, not only for planning, but for evaluating the quality of services received. QA should be tied to service planning and should be just as individualized (i.e., person-centered quality assurance). The support plan should indicate not only the desired outcomes and an action plan to reach them but also how the attainment of the outcomes will be evaluated, by whom, when, and to whom it will be reported.
6. Individuals with disabilities who are trained in self-advocacy are often keenly aware of the presence or lack of opportunities for true choice and control in service environments. These may be important individuals for inclusion in local monitoring teams.
7. One respondent suggested remembering that "quality" includes many things beyond "choice" and "control." In New Hampshire emphasis was on "a real life" (not just a chosen option). It would be good to have lots of training about the complexity of choice~for example, Michael Smull has written about the abuse and perversion of this word. John and Connie O'Brien have distinguished that one of the "Escape Hatches from Hard Questions" is "It's the person's choice." This person said, "A quality life includes interdependence-shared decision making, lots of information, mutual thinking~as opposed to an individual, independent, isolated voice. No one makes major life decisions by themselves."
8. Consider including in your quality assurance plan a provision for assessing the degree of support and control that is exercised by the individual's guardian or conservator.
9. One respondent suggested that perhaps governmental service providers should look at quality simply as a) protecting health, b) guaranteeing safety,

and c) granting freedom. This could be looked at as an alternative conceptualization to seeing quality services as providing a high quality of life.

C) Quality assurance is linked with quality improvement support systems.

1. The DD Workgroup recommended that quality review findings be integrated into a statewide plan for training and technical assistance.
2. This group also felt that quality review findings should be publicly available in order for consumers and their families to obtain information on the performance of counties and individual provider organizations.

Other recommendations:

VII. The overall project work plan:

1. Several respondents commented that the overall project plan seems very complete and well thought out.
2. Those that answered the questions directly said yes, the proposed activities do have high potential to achieve the projected outcomes and promote self determination principles. They also said yes, the state activities do promote system redesign, regulation reduction and support for increasing local capacity.
- 3 On respondent noted, "Renegotiating and redesigning traditional roles of government administrative employees is a major activity that likely involves negotiations with labor unions. It may be difficult to achieve by project end date, but it is very essential to success and replication of the project. Are all participating counties committed to this?" It might be worthwhile to do a study of the ways this change might need to occur, the incentives and the barriers, e.g., civil service, union agreements, etc. and how they might be managed.
4. Be sure to address what happens at the end of the demonstration project. This needs to be worked out up front to be sure county, providers, and the state are on the same playing field. Consider what will happen with regulatory variances, job positions that are funded with project funds, and how project components, e.g., individual budgets and support for them, will be continued or transitioned.

VIII. The project structure

1. The recommendation was often made to use principles to guide every action. In addition to the four self determination principles that underlie the project, it would be good to consider the DHS set of guiding principles as well as the Medicaid/Human Services Reform Goals that were set forth by the Governor's office. Another set of values and indicators was developed in 1995 by the Minnesota Developmental Disabilities Community Workgroup in their Values and Indicators for Managed Care and System Change. It would be valuable, in itself, to synthesize these and let stakeholders know they are being used, but it would also set the project up as the direction Minnesota is going and not just another project that will come and go when the funding is gone.
2. One respondent said that the concept of "local control" calls for a strong group facilitator (e.g., one from an outside entity) to manage intergroup relationships and to control the length of time needed to resolve issues.
3. One respondent said that organizations which have gone through serious and major systems change (such as some of the New Hampshire agencies in the original RWJF Self Determination Project) often had outside "experts" regularly come in and visit so they could question. "Are we on the right track?" "What else do you see?" This person felt such an approach was in sharp contrast to many Minnesota local workgroups who insularly are bound to 'we know best for our people.'
4. One respondent observed that there is "an overwhelming emphasis in all the plans here on people's control of money and their services, rather than helping people have the life they want."
5. One respondent said, "The only change I see that might be beneficial would be to have more focus on specific life areas. Specifically, it's great that there's a housing workgroup. How about the rest of life? Like a jobs workgroup and a friends workgroup? Also, shifting the current day program culture/system is going to take at least as much, if not more effort than consumer-owned housing." Moving people into more productive employment is also a major emphasis of the Robert Wood Johnson Foundation at the national level.
6. One respondent said, "The four principles of self-determination are really solid, but, in day to day work, people need more detail. The nine operating principles (from Ellen Cummings, attached) work well for this. Missing

from the four principles are developing relationships and contribution (which may mean a job)."

7. One respondent said, "In order to ascertain whether what you are doing will lead to system redesign and local and consumer control, weigh everything against the four principles: Freedom, Support, Authority, and Responsibility."
8. One respondent said, "Be careful of too many committees. Keep a clear focus and try to keep it simple."
9. There were several compliments on the well thought-out and comprehensive planning that has gone into this project.
10. PBC participants identified the following contributors to effective workgroups:
 - strong leadership.
 - consistent attendance.
 - a consistent location.
 - supporting and learning from each other.
 - a purpose. Don't just meet to meet.
 - involvement of all stakeholders: DHS, case management, consumers and families, advocacy, DT&H and residential providers.
 - support from DHS to assist in making changes.
 - a lot of time and commitment. It might be good to assess each individual's capacity for this upfront.
11. The local project committees seem to be heavily weighted with county personnel. Although it is admittedly difficult to obtain, there should be increased emphasis on broader stakeholder involvement. Perhaps some kind of incentives could be tried.
12. One person recommended that all consumers, whether they are in the project or not, be offered at least person-centered planning for some level of involvement immediately
13. New Hampshire's Self Determination Project placed a high emphasis on community citizenship. The qualitative evaluation of that project stated, "In actuality, the Self Determination Project is about community development as much as it is about empowerment and control by people with disabilities." Another comment from that evaluation is, "One of our objectives was to help the wider community define itself better, as a richer and diverse place." Some of our respondents felt that emphasis was missing from the Minnesota project. One comment was, "While there's a strong emphasis in all the counties and state about more consumer choice and control, there's a

sense missing of the kind of planning and change which the New Hampshire people present - that of assisting people to 'get a real life', freeing people from disability - and systems-based thinking about how to live their life."

14. Two key concepts in the literature on Total Quality Management and Continuous Quality Improvement are system alignment and cyclical organizational learning. Alignment is accomplished by making sure all the entities in the system are working toward the same goals and operating on the same principles. It also involves making sure the stages of service delivery hang together. Service evaluation (quality assurance) should follow from service planning. Organizational learning involves setting up a cycle of planning, implementing, evaluation, and revising subsequent implementation.

Transferability to other disability groups.

1. The consultant from New Hampshire stated, "If you keep the process simple and unsystemetized, you will find it is a universal approach."
2. The DD Community Workgroup report pointed out that "the better the service system is able to respond to the personal needs of people with developmental disabilities, the more attractive and appropriate it becomes to others... We recognize that over time the approach to services that we hope to design will appeal to and be accessed by many people who are not developmentally disabled. Indeed we hope it will be. On the other hand, we believe it is extremely important, until the implications are fully understood, that eligibility be treated with caution and that currently dedicated resources be reserved for those people for whom they were originally allocated."

Recommendations regarding consultations:

1. Minnesota's RWJF grant proposal states that a primary goal of the Self Determination Project is to implement programs that 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, as appropriate, the type and amount of support. The proposal states "Minnesota has important, ongoing activities in all of these areas in various settings across the state; the focus of the Self Determination Project is to concentrate them within

demonstration sites, to allow individuals with developmental disabilities to increase the control that they have over their own lives." We recommend that the intention of concentrating this expertise in the project be continued and that the valuable and available expertise from other innovative efforts be utilized.

2. In addition, as specific information needs arise, project coordinators, assisted as requested by project evaluators, should consider various initiatives and demonstrations that have taken place around the state and determine which individuals that were involved in that activity would be helpful as a consultant. Some examples, in addition to DHS projects, are the Stearns County Citizenship Project, The Person-Centered Agency Design Project, Parents as Case Managers, as well as efforts by individual counties or service providers.
3. Likewise, project coordinators, assisted by project evaluators, should consider various initiatives and demonstrations that have taken place around the country and determine which individuals that were involved in those activities would be helpful as a consultant. Many of these activities, with a brief description and a contact person, will be available in the upcoming edition of Reinventing Quality. There are also current and recent research projects, such as the Core Indicators Project that is being conducted by HRSI and NASDDD, that can be tapped for up-to-date information on cutting-edge ideas.
4. Another valuable source of counsel would be individuals who have worked on successful or promising Self Determination or system change projects. Ellen Cummings, who was project coordinator of the New Hampshire Monadnock Project, is now doing private consulting. Marc Fenton, with the Public Consulting Group, Inc. in Boston, has had considerable experience with system change. Along with his feedback to us, he wrote that he thought he could help with facilitating state wide implementation. Angela Amado, a local person who does consulting nation-wide, has done projects with system change and organization development as well as community development and promoting friendships.
5. Ellen Cummings is now doing training in self determination topics. Overviews of training for the various stakeholders that she does are attached.
6. Train person-centered planning facilitators in all of the major methods and when the various elements might be appropriate.
7. Essential Lifestyle Planning (ELP) from Brainerd RTC was enthusiastically received by PBC participants.
8. Brian Aberly, of the U of MN, has designed training for consumers and direct support staff in self determination.

9. Finally, we would urge project personnel to make full use of the program logic models that have been developed (Sections I and II of this report). A purpose of program logic models is to clarify program intent and uncover the assumptions behind the program plan, and also to facilitate the assessment of bottlenecks, illogical links, and the potential of the activities to achieve the projected outcomes. We suggest that the Minnesota people who have been intimately involved with the development of these projects for the past several years come together to critique these models. The program models that have been developed can provide an objective and holistic look at the project as it has developed thus far and a structure for discussing where it should go. We urge the program coordinators to use the models, along with the suggestions in this report, as a springboard for developing future directions with whatever advisory group seems appropriate.

All in all, Minnesota's Self Determination project is well designed and incredibly well planned. If you changed nothing, you would have accomplished a lot. The efforts of the local sites, too, are ambitious and well thought out. Specifically, we received kudos for these county activities:

- Dakota County's allocation tool.
- Dakota County's goals and principles.
- Dakota's directly contacting all 1200 consumers for the information meetings-encourages participation from the start.
- Dakota County's designing systems that are user friendly and easy for consumers to understand.
- The efforts of Blue Earth and Olmsted Counties to collaborate with other disability groups and other counties.
- Olmsted and Blue Earth for collaborating with the local Arc for consumer and family education.
- Blue Earth's development of a self advocacy group.
- Blue Earth's efforts to revitalize the local Arc.
- Olmsted's use of People First to evaluate consumer training materials.
- Olmsted's Personnel Initiative in which they collaborate with provider agencies and self advocates to address staff recruiting, training, and retention issues.