

**Minnesota Self-Determination Project**  
**Formative Evaluation**

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The Minnesota Self-Determination Project was funded by a three year, \$400,000 grant from the Robert Wood Johnson Foundation. In its Request for Proposals, the Robert Wood Johnson Foundation stated the purpose of self-determination grants as being "to assist states in promoting collaboration among individuals and families, provider agencies, government agencies, advocates and other community members." Through this collaboration, project states were to "reshape community support systems, to facilitate self-determination, and with the experimentation and shared learning required to do so efficiently and effectively." In offering grants to states to support the self-determination of persons with developmental disabilities, the foundation was especially interested in stimulating changes to allow individuals and families greater control of how the available public funds were spent to support them.

Minnesota submitted a proposal to the foundation and was one of only nine states to receive full funding. In the proposal, Minnesota stated its intention to meld comprehensive programs of self-determination with managed care principles to guide system re-design. Minnesota's proposal integrated and expanded several initiatives that were already being developed in the state to support the self-determination of persons with developmental disabilities. These initiatives included person-centered planning, consumer controlled housing, outcome-based quality assurance and quality improvement assistance. By bringing these ideas together and experimenting with changes to the developmental disabilities service system, the Minnesota Self-Determination Project intended to:

1. Improve the management and administration of services.
2. Improve service financing and design.
3. Improve access to service.
4. Improve quality assurance and monitoring.
5. Redesign roles to assure that a viable, accountable, and effective infrastructure is created to support and sustain the services and supports that are created.

The Minnesota Self-Determination Project was administered by the Community Supports for Minnesotans with Disabilities Division of the Minnesota Department of Human Services (DHS). Three counties, Dakota, Olmsted, and Blue Earth, were demonstration sites for the project. Each of the counties was different in terms of size, the number of persons with developmental disabilities served by the county social services, the types of services available, and involvement or past experience in other

system change efforts. In addition, one county was located near an urban center, one included a small city, and the third was largely rural. Each county was given a portion of project funds to hire a local coordinator for project activities. Following is a description of the three counties that served as demonstration sites for the project.

Dakota County. Dakota is a large county in the south metro area of Minneapolis/St. Paul that includes both suburban and rural areas. The county's Developmental Disabilities Division consists of 28 Social Workers plus case aides who serve over 1200 consumers. There are 30 licensed vocational and residential providers in the county and numerous family foster care providers.

Although Dakota County was not involved in a managed care demonstration project as were the other two counties, Dakota was recruited to participate in the project because of their experience with individually controlled budgets. Their Account Management Program started in 1990 with administrative support through a state grant and county support funds. It has grown from six to about 450 people. For this program, families submit an expenditure plan and receive a cash grant on a quarterly basis. They are expected to have receipts available for a possible review. Although there is a policy that specifies how the money can be spent, there are very few boundaries. According to Dakota County officials, this program has cut costs substantially and people are happy with it. The success of this program encouraged Dakota County officials to expand the opportunity into other funding streams.

The goals that Dakota had for their participation in the project were:

- To demonstrate a positive shift in people's 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).

**Olmsted County.** Olmsted County is located in the middle of a rural area in southeastern Minnesota. Its county seat, Rochester, is a medium size city that 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 major residential provider agencies, numerous family foster care providers, the public schools, and a variety of other providers.

Olmsted County began system change planning in 1995 and involved all stakeholder groups in developing these plans. In addition to the Self-Determination Project, Olmsted County was involved in the state managed care demonstration and an alternative quality assurance demonstration, the Region X Quality Assurance Initiative. There was a great deal of overlap between the three projects, and Olmsted viewed them all as a single initiative with multiple funding sources.

Olmsted's goal was 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 expected to learn what the barriers are in the system and what needs to change one person at a time and then try to generalize to make broader changes where appropriate.

**Blue Earth County.** Blue Earth County is located in a rural area of southern Minnesota. The county seat, Mankato, is a medium sized 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 was also planning to participate in the state managed care demonstration project in partnership with two neighboring counties. The local project, Project Assure, had been in planning for several years. Blue Earth County saw both the managed care and the self-determination project as working together to increase the control persons with developmental disabilities have over their services.

The mission of the Managed Care Demonstration, and thus the Self-Determination Project as well, was to make certain that eligible participants had:

- **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.

### **The Evaluation**

**This formative evaluation of the project consisted of four separate components: 1) The development and critique of a program logic model (included as Appendix A), 2) Interviews with 23 project consumers, their families or guardians, and, when needed, their case managers and service providers (case studies are included as Appendix B), 3) Facilitation of the evaluation of consumer education products by self-advocates (included as Appendix C), and 4) a Project Participants Feedback Questionnaire (Appendix D). This report focuses on the strategies that the counties used to facilitate self-determination and how those strategies affected the lives of the consumers whom we interviewed. Because of the small sample and because of the unique experiences of the members of that sample, evaluation "findings" are reported as issues that arose for one or more individuals as they utilized the new strategies. They should not be viewed as generalizable conclusions that will effect all people in similar circumstances, but as issues and experiences to consider as self-determination strategies evolve. In addition, we have included recommendations that the data suggests should be considered.**

### **Strategies to Facilitate Self-Determination**

**To achieve the project goals, the Minnesota Self-Determination Project focused on several strategies to allow greater consumer and family control over their services. Each of the three participating counties was given latitude to choose which strategies they would emphasize and how they would implement them. The major strategies were: 1) Changing procedures related to support planning and coordination, 2) Breaking out service dollars into individual budgets, 3) Providing consumer education and support for self-determination, 4) Experimenting with new methods of monitoring and assuring quality, and 5) Changing provider and community roles. Although all counties had varying degrees of involvement with each of these strategies, their emphasis varied.**

**Because the project planners in Blue Earth County initially thought of the Self-Determination project as part of a larger managed care demonstration project, they did not spend a lot of time on individual budgets. As the Self-Determination Project was**

concluding, the managed care demonstration still not begun, however, and they started to move ahead by developing a tool to facilitate decisions about the allocation of resources for individual budgets. At the beginning of the project, Blue Earth had little capacity for person-centered planning, few trained facilitators, and less experience than the other two counties with moving to person-centered approaches. Their initial focus, therefore, was on building capacity and networks. The project coordinator developed a People First group and revitalized the local Arc chapter. She did presentations and facilitated meetings and discussions with consumers, families, case managers, and providers. An advantage of this approach was that "everyone came to be more on the same page." At the conclusion of the Self-Determination Project, this county felt they had built a solid foundation for future system change efforts.

Dakota County was involved in many strategies as a part of the Self-Determination Project but placed a heavy focus on individual budgets with dispersal of funds through county-owned, consumer-controlled checking accounts. They developed tools and methodologies to accommodate this and software for tracking funds. As the project concluded, their goal was that everyone who wants an individual checkbook will be able to have one within three years. Within five years, they plan for all consumers to have individual budgets and to be able to determine the level of control they desire. Options will range from control over all support and funding through an individual checkbook to having support and services arranged and paid for through the traditional method. Dakota County developed a tool to allocate resources for individual budgets that they used for people who are new to the waiver program, but they based individual budgets on historical costs (for people already in the system).

Olmsted invested much time during the project on developing a methodology to offer consumers individual budgets in addition to implementing other strategies. They also developed an allocation tool for individual budgets that they used for people who are new to the waiver program. People already in the system were gradually transitioned to a budget more closely in line with the allocation tool. They informed people of their historical costs and worked to educate consumers individually about creative options. They also began using checkbooks as an option in the third year of the project. Their philosophy was to work with people "one person at a time" and learn what needs to change as they went along. Their future plans are to integrate the methods that they have developed into their usual way of doing business. Their goal is to get everyone who

receives services under the Home and Community Based Services (HCBS) waiver on an individual budget.

## **Support Planning and Coordination**

### **Support Planning**

In the Minnesota Self-Determination Project, there was an increased emphasis on planning and arranging supports based on the personal goals and dreams of the individual rather than on his or her skill deficits. Participants in the project were offered opportunities to utilize formal person-centered planning methodologies as a way to select the supports they wanted or needed based on their personal dreams for the future. They were also offered an option to plan their supports more informally, such as meeting with their county case manager to develop a support plan over a cup of coffee. Both of these approaches were a significant change from the traditional service planning processes in which an interdisciplinary team plans supports that are largely designed to satisfy the needs of the service system.

**Dakota County.** Dakota County came into the project with a large cadre of person-centered planning facilitators. They also had two organizations that had been playing a role to coordinate and support facilitators. The Dakota County Providers' Network distributes information and provides facilitators and technical assistance to facilitators. The local Arc also provides facilitation at no charge. To supplement this core, another training session for facilitators was held during the project.

For the consumers who participated in the project, Dakota County presented information at orientation meetings about the different forms of person-centered planning. They also distributed a sheet called "Planning Considerations," which was a list of the 30 outcomes developed by the Accreditation Council. They were offered an array of options for planning support under the self-determination system. Consumers who wished to take advantage of a full person-centered planning process were connected with a facilitator. Most of the consumers in the project, however, chose informal planning "over coffee." Most of these people already knew what changes they wanted to make when they enrolled in the project, and some of them had participated in person-centered planning in the past.

Dakota also developed a three-page "Personal Support Plan" to guide the development and use of individual budgets. The questionnaire asks respondents the following questions: 1) What does the client want to do or accomplish? 2) How and where

will the client be supported? 3) Who will find and coordinate the support? 4) What goods and services will the client use and why? (This is followed by nine categories.) 5) How is there reasonable risk of freedom from abuse, neglect, exploitation and danger to self/others? 6) How will support be paid? (all, part, or none with a checking account) 6) If a checking account is used, who will be the signer(s) on the account?

Olmsted County. Olmsted County trained over 60 person-centered planning facilitators during the project. Project staff provided technical assistance and mentoring to facilitators, and this was also available through other trained facilitators in the community. They, too, presented person-centered planning as an option to consumers in the project if they wanted to take advantage of it. They described their view of person-centered planning as not a "thing," but a way to find out what people want and need and to plan how to get it. They felt they placed more emphasis on implementation of plans than planning processes.

During pre-planning phase, project participants were educated that they would be heard and that they do have choices. The facilitator of this process (project coordinator or case manager) also helped them decide whom they can trust and who is their "community." Other parties who were to be involved in the consumer's planning process were also trained about the new procedures and expectations. They were told that there was an expectation that the entire system would react with not whether, but "how" can we do it.

Blue Earth County. Blue Earth County also offered person-centered planning as an option for consumers. During the Self-Determination Project they trained over 50 people to be person-centered planning facilitators. All of the county case managers have been trained as have representatives from all the local provider agencies. Facilitator training sessions were held regarding Personal Futures Planning, Planning Alternative Tomorrows with Hope (PATH), and Essential Lifestyle Planning (ELP). According to the project coordinator, "ELP is taking hold more than others, and is primarily agency-driven with input from case managers."

Blue Earth County reported two results from this training. They have found that only about five (10%) of the trainees are comfortable with the role and are actually facilitating meetings. However, they have seen a heightened awareness of person-centeredness in general. For example, the single plan that was developed by the county includes a section addressing the person's hopes and dreams.

### Support Coordination

All the project counties were involved in defining the difference between case management and service coordination. Minnesota Rules 9525.0004-9525.0190, also known as Rule 185, governs the provision of case management services to persons with mental retardation or related conditions. The rule differentiates between case management administration and case management service practice standards. Case management administration consists of intake, arranging for comprehensive diagnostic evaluations to determine eligibility for case management, arranging for tests of intellectual functioning and assessments of adaptive behavior, making diagnostic conclusions and recommendations, conducting periodic reviews of diagnostic assessments, convening a screening team to evaluate level of care needed by the person, authorizing services, review eligibility annually, and arranging for conciliation conferences. Case management service practice standards include assessing or arranging for an assessment of the person's functional skills and needs and services and supports that meet those needs and preferences. Other service practice standards are reviewing the person's needs for services and supports, developing an individual service plan, identifying service options and providers, assisting the person to access services, coordinating service delivery, and monitoring and evaluating the person's services.

Case management administration represents activities that may be best accomplished by county representatives. Case management service functions, on the other hand, involve planning, arranging for services and supports, assisting the person to access services and supports, and monitoring the services and supports that are provided. These are functions that may be done by an independent support coordinator as determined by the consumer instead of the county case manager. None of the counties went so far as to encourage external support coordination. However, all of the counties provided extensive training, mentoring and support to assist case managers to facilitate self-determination by consumers and families. In addition, they each had unique approaches and experiences.

Dakota County. Dakota County acknowledged that a county social worker may need to continue completing certain administrative and eligibility tasks and monitor health and safety. This role does not need to include finding resources and coordinating services, however. Recognizing that the county continued to need to provide the basic case management function, they did not include resources for case management in the individual budget amount. People could, however, use their individual grant to pay for a

private "support coordinator." For example, a mother of a young adult could choose to pay herself for this function. The county retained the role of determining eligibility, determining individual budgets, and approving and evaluating support plans.

Only one of the people whom we interviewed from Dakota County, Linda, used some of the funds in her individual budget for service coordination. Because the arrangements to revamp Linda's supports have taken a great deal of extra time, her conservator budgeted \$1120 per year to compensate him for some of his time. This is in fact the only consumer we interviewed across all three project counties for whom funds in an individual budget were being used to purchase alternative service coordination. This was not a replacement for traditional county case management however.

Dakota County supported a shift for their social workers from being "givers" and "controllers" to "helpers." They were looking at strengthening the case management facilitation role and saw case managers becoming a resource tool over the course of the project. They held two education sessions for case managers emphasizing facilitation and support roles. In addition, the Self-Determination Project Coordinator provided ongoing support to the regular social workers, particularly with consumers who were trying new things in the project.

Olmsted County. Olmsted saw itself as transitioning county case management to a role of relationship-based service coordination. Their goal was that people would have a choice to do service coordination themselves or hire someone to do it, but the county was not yet offering this choice as the project concluded. The project's Service Delivery Work Group recommended early in the project to not have County Case Managers other than for the provision of financial eligibility and administrative functions. However, the county is still considering to what extent to move in this direction. At the conclusion of the project, Olmsted planned to deal with the issues around service coordinator choice one person at a time as they come up. They did have one consumer using a contracted case manager; but this happened before the project.

There are two primary financial barriers to providing funds for individuals to purchase private case management: 1) The HCBS waiver is the only funding program that provides reimbursement for case management services. Therefore, people who don't receive waived services may not be able to fund outside case management. 2) State dollars for non-waiver case management are directed to the county and are used to fund the required administrative activities and service functions. People who do not receive

waivered services may be able to fund independent service coordination from their budget allocations, but this money may be needed for other supports.

Olmsted established a Service Coordinator position to support individuals and families during the project and to mentor county case managers. In addition, training was provided for case managers, and a group of them developed a job description for "support coordinator."

Blue Earth County. Blue Earth also had plans to split the traditional county case management role into two separate functions, service coordination and support plan facilitation. While the Service Coordinator role would be filled by a county staff member, consumers and families would be able to chose anyone, including themselves to act in the role of Support Plan Facilitator. Plans were delayed as the managed care project was delayed. In the meantime, the project coordinator mentored and supported case managers to incorporate SD principles into their work. Training was also provided for Blue Earth County social workers in the expected role shift. In addition, the case managers from Blue Earth and two neighboring counties (about 10) went on a retreat and discussed the issues involved with service coordination, (e.g., changing roles, contracting out).

### Single Plans

Two of the counties, Olmsted and Blue Earth, developed a Single Support Plan as part of their project activities. These Plans were developed collaboratively in each county by case managers and service providers (The Single Support Plan has combined the plans residential providers, day habilitation service providers, and case managers are required to complete into one document.) The Olmsted project coordinator reported, "The single plan is being implemented with all adults in Olmsted County who have case management through the county. There have been a few minor hitches with people getting used to the process, but the overall consensus is that the Single Plan works very well." The Blue Earth coordinator said, "The Single Plan seems to have finally reached a doable point for everyone. It continues to expand gradually and appears to be going well."

Emerging issues and recommendations related to support planning and coordination in a system based on self-determination are as follows:

- *People and their families need be offered greater control in the person-centered planning process, including who will facilitate and who will attend the meetings.*

Although the counties intended that individuals and/or their families decide who will participate in the planning meeting, some families either do not feel comfortable excluding service providers from person-centered planning meetings or have not considered the option. Neither do they know how to access or have funds to pay for independent person-centered planning facilitators. Troy had two person-centered planning meetings while he was in the project. The first meeting was facilitated by the residential provider, which his mother saw as a major conflict of interest. Moreover, she was concerned that the presence of Troy's DT and H provider at the meeting hampered discussions about developing an alternative to the current DT and H provider. An out-of town provider facilitated a second meeting. Troy's DT and H provider did not attend the second meeting, and Troy's mother viewed this meeting as much more productive.

- *Person-centered planning should not be considered a single event. Support team members need to continue to listen to the consumer for new ideas, and formal plans need to be followed through.*

For many of the people whom we interviewed, person-centered planning happened as a single event. There was no follow-up or evaluation built into the initial plan, and, in many instances, the plan had not been revisited two years later. Another way that person-centered planning could be seen as an event was when things that had not been formally identified as a "dream" in a planning meeting were casually dismissed as unfeasible. For example, when we visited with Dick and his direct support staff, they said that Dick would love to go to a Vikings game and wanted to fly to Texas to visit his niece, but that these things were too expensive for him. We were told, however, that Dick had a lot more spending money as a result of his new job. Apparently, Dick's direct support staff did not place enough importance on helping Dick to realize dreams that were not part of his formal plan. Similarly, Ruth's team was amazed that it took a person centered planning meeting to identify the relatively simple and easily provided things that she wanted to improve the quality of her life.

- *When person-centered plans are followed up diligently, it seems to be because there is a strong advocate involved.*

Although many plans were a single event, two plans in particular did have good follow-through. Both had an enthusiastic and assertive advocate who was committed to ensuring that follow-through occurred. Support teams for both people started out with monthly meetings. One dropped back to quarterly meetings when changes were underway. For the follow-up meetings, the consumers and their support teams found that it was often most effective to have only the advocate and the parties who were making changes attend.

- *There should be a coordinating entity to facilitate the utilization, support, and coordination of funding for trained person-centered planning facilitators.*

Scores of people received person-centered planning facilitator training through the project, but it wasn't always apparent that they were being used to facilitate planning. As mentioned above, families sometimes felt that providers should not facilitate for a person to whom they provided support because of a potential conflict of interest. Without a coordinating entity and funding sources to pay for independent providers of person-centered planning, people may be forced to rely on their current providers of day or residential support for person-centered planning.

- *Some use of person-centered planning elements will probably stimulate the planning team to think more creatively.*

Counties offered project participants an array of options for support planning. Some chose informal planning "over coffee." This often happened when people said they already knew what changes they wanted to make when they enrolled in the project. However, when we interviewed some of these consumers and families, they complained about their lack of ideas and the lack of facilitation for creative ideas about how to use their individual budget. It might be that more time spent on planning and more use of some of the person-centered planning elements that help people to dream would have helped people come up with more creative ways to use the money that they now could control.

- *A workgroup should be formed to investigate ways to transition from traditional case management to service coordination.*

Transitioning from case management to support coordination has been a particularly challenging area for the counties. There is a number of challenging issues that counties, and even other states, have in common. It would be beneficial to work together on this challenge and devote some resources to investigating what has been done elsewhere.

- *A study should be done of "Single (Support) Plans " in the counties that have developed them to determine their success and what are the benefits and challenges.*

Blue Earth and Olmsted Counties report success with a "Single Plan." Dakota has not developed one, but one Dakota County conservator complained of five different plans that exist for her focus person.

### Individual Budgets

Breaking out individual budgets and giving consumers and/or their representative control over how the money is spent was a major strategy of the project and drove much of the system change. Counties struggled with issues such as funding stream differences, access and equitability issues, and notifying all consumers of the cost of their services. Allocating resources, whether by using historical costs or an "allocation tool" was a challenge. Mechanisms for dispersal of funds, such as cash grants or checking accounts, needed to be developed and issues of setting parameters on the spending needed to be dealt with. "Unbundling of services," which refers to separating out the costs of individual services and allowing consumers to purchase only the services that they want or need, was another challenge. Finally, because consumers were starting to use non-traditional supports, counties needed to consider options to handle the administrative and tax accounting responsibilities. Employers of record providers were developed to assist in these functions.

### Breaking out Individual Budgets

One of the first tasks the counties undertook, and one which all of them did to some extent, was to determine the cost of the services that an individual received. They

found that this task involved considerations of funding stream differences, "unbundling" services, and notifying consumers of the cost of their services.

Funding stream differences. There are a number of different funding streams that provide funding for services for people with developmental disabilities. Some of them, such as the Medicaid ICF/MR program, provide funding for services within a facility, and individuals who receive service in that facility cannot access those funds if they leave. Because of this, the ICF/MR program has not been amenable to individual budgets. Many people in Minnesota who receive services through the HCBS waiver for persons with mental retardation or related conditions (i.e., the MR/RC waiver) live in provider-owned or family-owned licensed foster homes in which no more than four people receive waived services. Although the waiver is intended to provide individualized funding according to each person's support needs, in practice, providers often receive the same waived service rate for everyone who lives in the home. Room and board costs for people receiving waived services who live in licensed foster homes are paid for through the Group Residential Housing (GRH) program. If an individual leaves a particular home, he or she can take his waiver "slot" to access services elsewhere, but the amount allocated for support may change to reflect the cost of the services from the new provider. Likewise, the amount of money for his or her room and board costs may change based on the GRH rate of the new home. In spite of these limitations, the MR/RC waiver program has considerable flexibility and was the primary funding source used by individuals who controlled individual budgets in the project.

In-home supports are usually funded by either the MR/RC waiver or the Medicaid Personal Care Assistance (PCA) program. Again, the MR/RC waiver is the most amenable to consumer-directed supports. The Medicaid PCA program, at this time, has flexibility only with the portion of the cost of support that is funded with state money (47%). Minnesota's Consumer Support Grant (CSG) program has allowed consumers to control their budget with the state portion of these funds, and all three of the project counties began participating in the CSG program midway through the Self-Determination Project. This enabled them to offer families using this funding source the opportunity to hire their own in-home support help and potentially to use part of the money for tangible supports. Many of the families who took advantage of this option were willing to accept only 47% of their allocation because, due to staff shortages, they were not able to get more than half of their allocated hours through their PCA agencies anyway. The CSG program freed them up to create their own support arrangements.

The funding for Day Training and Habilitation (DT&H) programs comes from the MR/RC waiver, ICFs/MR, or county funds depending on individual circumstances. It is "portable," i.e. individuals are able to leave the program and use the money for another program. However, the cost of the DT&H program is averaged across the individuals using the program. Therefore, the challenge in creating individual budgets from this funding stream arose for individuals for whom the actual cost of their support falls above the average. They might be unable to create an alternative support arrangement with the funds that they can take with them.

Other funding streams were more amenable to breaking out individual budgets and allowing consumers to control their use. Respite care is often funded with county money and usually a family is allowed a certain number of days per year or a certain dollar amount. The individual budget is thus easily calculated and each county has control over the guidelines that affect it.

There are some funding programs that were already cash grants that consumers could use flexibly. The state-funded Family Support Grant provides a monthly stipend to those families of children with developmental disabilities who have been selected to receive it. Dakota County's Account Management program, a cash grant program that has been in effect for several years, is funded with county money. Olmsted county has a program that gives cash grants to families to pay for respite care.

The flexibility in the MR/RC waiver program was increased by the Consumer Directed Supports waiver amendments. These amendments to Minnesota's waiver plan were requested by the state early in the project. They enabled MR/RC waiver funds to be used for more individual options and also paved the way for consumers to pay directly for their support.

Unbundling services. "Unbundling" services refers to service providers separating out the costs of individual services that they provide and allowing consumers to purchase only those services that they want and need. For example, a provider may offer oversight by a registered nurse as a service provided under their per diem rate. If a consumer does not use this service, the provider would separate out this cost and deduct it from the rate the consumer pays. One of the hopes for the Self-Determination Project was that consumers would not have to buy an entire "program" that was offered by traditional service providers but could purchase only the parts of those programs that they wanted or needed. The counties' intention was to address this issue on an individual basis as it came up. Only one of the people whom we interviewed had given much thought to this issue.

Jean's sister was frustrated with the residential provider's inability or unwillingness to "unbundle" services to make Jean's supports more responsive to her individual needs. When plans were made to allow Jean to stay home two days per week, she found that the residential provider had to provide the staff because they would not allow the day provider to have staff working in their facility. She also wondered why she was billed for staff shifts that were not filled. She was particularly irritated about having to purchase nursing services along with residential support even though this was not required by her Waiver funding. She found out that many of the nursing visits took place when Jean was not even home. She also stated that even though they were paying for this unwanted nursing service, the nurse was unwilling or unable to clip Jean's toe nails and the family had to pay out of their own pocket for a podiatrist to do this.

Notifying consumers. Notifying consumers of the cost of their services was a priority for each of the counties whether or not people planned to make changes. Olmsted provided information about historical costs to the individual or family prior to each consumer's annual meeting. This information was used to determine a new, perhaps more appropriate, plan and to consider alternative ways to allocate the funds.

Many family members and consumers were shocked at the amount that was being paid for the support of the person about whom they were concerned. Many felt that it was empowering to have this information. Karen's mother was surprised to find out that the DT&H program was getting the same amount of money when Karen was "sitting around the workshop" as when she was spending her day in community employment and receiving more support.

Respondents to the Feedback Questionnaire (see Appendix D) overwhelmingly thought that notifying people of the cost of their current services was a valuable practice. Sixty-seven percent said it was very valuable, and another 21% said it was somewhat valuable. They felt that it would keep costs down, empower consumers to demand better services, and help consumers to choose from a menu of services. Two people thought it was not at all valuable. One said that providing the "cost of services without an explanation of how the cost is determined is of no benefit." The other commented that "it rarely fosters constructive discussion."

### Allocating Resources

When consumers decide to make changes to their support arrangement to take advantage of the possibilities for self-determination, it becomes necessary to determine a

dollar amount that they can spend in the future. This determination involves two basic choices. Support budgets can be based on the individual cost of services the consumer has used in the past or they can be calculated using a tool to determine an appropriate resource allocation.

The original Self-Determination Project in New Hampshire placed a high priority on cost savings and chose to base individual budgets on 75% of the consumer's historical costs. Olmsted County started out basing budgets on 90% of historical costs. They found the concept of using a percentage of historical costs to be restrictive and inflexible. They found some people were already stretched with their historical allocation and couldn't realistically be expected to cut back 10%. This was especially true of people in more formal, traditional service settings, such as ICFs/MR, private or corporate foster homes where waived services are provided, and DT&H programs. On the other hand, the county found that some people had been allocated more historically than a current analysis indicated that they needed. In these cases, the county felt that more than a 10% reduction seemed appropriate.

Respondents to the Feedback Questionnaire were also unenthusiastic about offering a percentage of historical costs. Their comments indicated that they wanted to reduce the inequity in funding allocations and that they wanted people to have the amount of money that they need—not more, not less.

Olmsted transitioned to using an allocation tool that produced a budget based on need. They used that along with consideration of historical costs for consumers who were creating new support arrangements. This often resulted in less than their historical costs, but it could also amount to more. People who were new to the waiver program had their support budgets computed by the allocation tool.

Dakota County developed an allocation tool early in the project but chose to use that only for consumers who were new to the system and those whose needs changed considerably. For everyone else, they used 100% of historical costs.

Blue Earth County only offered individually-controlled budgets to families who were using county respite care funds. However, they recently developed an allocation tool which they will use with new people in the Medicaid Waiver program. Blue Earth and Olmsted compared the dollar amount that was arrived at using the allocation tool with historical costs and found that the allocation tool figure was sometimes more than historical costs and sometimes less but seemed to approximately average out the same.

Developing an allocation tool proved to be a very challenging task. A state grant paid for the development of an allocation tool before the project began, but the final product only determined need level and was not something that the counties wanted to use. Each county struggled with developing their own tool while taking advice from each other's experiences. All three of the project counties currently have an allocation tool that they are using, but these products are still evolving.

### Disbursing the Funds

Another challenge in using individual budgets is deciding how to disburse the funds to pay for the consumer's support. The options include: 1) having the county pay providers directly or through the state billing system but still allowing the consumer to choose how the money is spent, 2) using a voucher or a cash grant, and 3) having counties supply checkbooks to consumers to pay directly for their own support costs.

Voucher payments have not been used either in the Self-Determination Project or in the funding streams that pay for the services that people with developmental disabilities use in Minnesota. But, as mentioned above, three of the funding programs that were used for individual budgets were already cash grants, i.e. the Family Support Grant, Dakota County's Accounts Management Program, and Olmsted County's CHOICES respite program. In addition, cash grants were used by Blue Earth during the project to allow consumers to access the money that they had been allocated for respite care. This enabled families to purchase the types of respite that they desired rather than being limited to using approved vendors who have traditionally billed the county directly.

Traditionally, counties have paid service providers directly for the cost of a consumer's support services. This arrangement was continued for some people in the project even for consumers who created an entire new individualized support arrangement. For example, Scott's residential program was created entirely for him by his sister helping him decide on the criteria and select the provider. Scott and his sister contracted with a provider who was already providing traditional services, and the state paid the provider directly. Scott's sister prefers not to make the payments herself and is not sure it would make a difference since they had control over how the money is allocated and she is consulted about major purchases.

Another option was one of the more innovative practices in the project. Dakota County, and later Olmsted County, offered consumers who were participating in the project the option of paying for their supports directly using a consumer-controlled,

county-owned checkbook. Dakota County had 55 consumer checking accounts operational. Their goal is that anyone who wants to pay for their own supports through a consumer checking account will be able to do so within three to four years. Olmsted had two to three families using a checking account at the close of the period. They modeled much of their process after Dakota's. Respondents to the Feedback Questionnaire overwhelmingly supported the value of consumer-controlled checkbooks.

In Dakota County, the county put a portion of the annual budget in the account in the beginning and then replenished the money that was spent on a monthly basis up to the original deposit. Either the consumer or his or her representative was designated as a signatory on the account along with a designated county employee. Both the signatory and the county received monthly statements. In addition, the county monitored the expenditures to ensure that they were in concordance with the expenditure plan and

- issued monthly reports to consumers about the status of their account.

One of the more challenging aspects of using the individual checking accounts was tracking the funds and billing the appropriate funding stream. Dakota made deposits into the checking accounts with county funds and then sought reimbursement from the relevant funding program. Dakota County officials were committed to ensuring that the funds appeared seamless to the consumer so that they didn't have to be concerned about whether the money came from the federal MR/RC program, from the state, or from the county. To the consumers, it appeared simply as money available for their support. Dakota tracked funds manually while software was developed and had to limit the number of consumers who could have a checking account because of the magnitude of this task. The software development was delayed but is expected to be completed soon.

#### Setting Parameters on Spending

Allowing consumers to control the dollars allocated for their support requires counties to make decisions about how those dollars can be spent. Olmsted County used their Waiver Management Team to approve individual budgets. The team gradually began specifying guidelines about expenditures as individual situations provoked decisions and as they gained experience with what was working. The criteria Olmsted used are 1) Is it within the person's budget? 2) Does it meet minimum health and safety needs? and 3) Is it a reasonable use of funds, and does it address the person's needs? Blue Earth had not yet specified guidelines at the close of the project, but is taking a "wait until mere's a problem" approach.

Dakota's expenditure plans were approved by a team consisting of the social worker, the supervisor, and the Self-Determination Project coordinator. Dakota took a principle-based approach. They looked at two criteria to determine if an expenditure should be approved. The first criterion was whether the proposed expenditure supports the consumer's health, safety, and general well being and whether it involves no more than a reasonable amount of risk. Reasonable risk is determined by looking at the "ability and willingness of the client and/or their support system to be responsible for the consequences." The second criterion was whether the expenditure represents a "defensible use of public funds." One of the approaches to this determination is to look at the context, or "What about this situation allows us to approve it?" For example, they approved a weekend in a motel for a family because "It's cheaper than respite" and it allowed the family to have a break together rather than to send the child with a disability away while the rest of the family has a break.

There are undoubtedly many controversial issues that might arise around the decisions of approving expenditures. Three that emerged from our interviews were: 1) changing plans after they were approved, 2) paying family members, and 3) deciding how much is appropriate to approve for recreation and leisure expenses.

One complaint that Jennifer's mother had with the way her county is implementing individually controlled budgets was that she felt she needed to be able to predict her needs 15 months ahead of time. When she found that she wanted to spend money on something that was not on her expenditure plan, she needed to get approval of the county's "Waiver Team," which took two to three weeks. She saw the solution as having categories in the expenditure plan that are more flexible, but, so far, neither she nor the county has been able to come up with something that works. One problem mat she described was the purchase of name and date stamps that she and the school decided Jennifer should have rather than to continue trying to teach her to write these items. The cost was \$25, and the request had to go through the process to be approved. Another request that came up unexpectedly was transportation to an adaptive program that was planned for the school holiday break. Jennifer's mom could take her there, but she needed transportation to take Jennifer to her sitter's house afterward. When we last talked to her, she was waiting for approval for this request, but she was afraid that the program had probably filled in the meantime.

Another issue is whether family members should be paid to provide support. One county had no specific limitations on paying family members. Another county had a

policy that no family members can be paid. This was a relevant issue for three of the people who we interviewed. Jennifer's mother was interested in cutting back on her hours at work-in order to stay home with Jennifer, but she said her county has been clear that they are not willing to allow parents to pay themselves for childcare. Tracey's family allocated money for one six-hour shift per week to spend "quality time with relatives." Much of this has been used to pay Tracey's brother and her aunt to take her on an activity. The aunt at first resisted being paid to spend time with Tracey saying she would often be with her anyway. At first, she tore up the checks, but Tracey's mother explained that she couldn't do that. Tracey's mother said she felt better paying her, saying "then it's a commitment." Tracey's brother is 18, just two years younger than Tracey and probably wouldn't take her on activities if he were not being paid. Their mother felt the need to monitor these activities to be sure that they were Tracey's choice and not his. (He suggested that Tracey would just love Vikings season tickets, but Mom said no.)

The third family who was concerned about the ability to use support funds to pay a relative was one who has elected to have the mother quit her job and provide care for her daughter rather than send her to a day program. This young woman needs total care and has severe uncontrolled seizures. Frequently, in the past, when she had seizures, the mother had to take off work to bring her home to rest. In addition, the day program was a stressful environment for the daughter and did not provide her with activities that she enjoyed. Now she and her mother can go shopping and do other fun activities when she is feeling well, and she can stay home and rest when she is not.

The third issue that we saw involved deciding on the appropriate amount of money that should be approved for leisure and recreational activities. Much of what people with developmental disabilities do to learn and become included in their communities could be seen as recreation. However, the potential for backlash exists if friends and neighbors become aware that someone is receiving hundreds or thousands of dollars of public money, some of which is paying for recreational activities. Moreover, there are people in similar situations with similar needs receiving no public money. Dakota County decided on a guideline of approving a maximum of \$1200 per year for a consumer who is 16 years old or older and \$600 per year for a consumer who is 15 years old or younger. There is potential overlap, however, with the Education/Training budget category, which may also include funds "associated with developing and/or maintaining the client's skills in the home, school, neighborhood and community." The overlap may result in more than the maximum being spent on leisure and recreational activities.

### Using Non-Traditional Supports

When consumers and families take control of their support money, they often want to hire their own staff rather than using a provider agency. They may chose to do so in order to pay their existing staff more money, or they may want to hire a friend or a relative to provide support. We have found few people who wanted to advertise and hire staff whom they did not already know, but the project provided information about how to do that in the manual, Finding the Support You Need.

Becoming employers involves a lot of administrative work and legal requirements that most people are not prepared to deal with. Some of the challenges are tax and Social Security withholding, Workman's Compensation insurance, and Liability insurance. Increasingly, people are turning to an Employer of Record or a Fiscal Intermediary to take care of these tasks for them. Olmsted decided to require that people who hire their own support staff use an Employer of Record. The cost of this was about 22% of payroll, but that included the taxes that were withheld, as well as Worker's Compensation and Liability insurance coverage.

Several families, especially those with smaller budgets, avoided using an employer of record by trying to keep the amount they spent on the their helpers under the dollar amounts that require tax withholding. They also considered any overnight help to be respite, which does not require withholding.

Tracey's mother decided against using an employer of record. She wanted all of the money available for Tracey's support. She did handle tax withholding on the "informal support" hours but much of the support time was classified as "respite" and she believed she did not have to take deductions from these funds. Although she said handling the paper work took a lot of time, she was not comfortable paying herself to do it.

Jennifer's mother objected to her county's requirement that she use an employer of record for all the helpers that she employed regardless of how much she used them. She also was required by the county to provide specific training for her helpers in such things as blood-born pathogens. Besides being a burden for her, this has meant that some of the people that she wanted to hire as informal support providers were not willing to do it.

On the other hand, Billy's mother felt that the Employer of Record was well worth the cost. Although they charged 25% (including withholding amounts), the PCA agency that she formerly used was keeping 50% of what Medicaid paid them. In her case, she found and trained her own staff for the PCA agency just as she did under the Self-Determination Project. She said that just the general liability insurance they provide is

worth a great deal. She underwrites commercial insurance and said that no company would write a policy for the kind of work that her helpers do.

Emerging issues and recommendations related to individual budgets are as follows:

- *Minnesota should continue to streamline funding rules where they present barriers to self-determination.*

Ninety-eight percent of the Feedback Questionnaire respondents felt that funding rules impede self-determination. Fifty-seven percent of these felt that funding rules impede self-determination to a great extent. The programs most commonly mentioned were the ICF/MR program and DT&H funding.

- *It may be the case that some individuals with developmental disabilities in the project do not have more control over their lives but that their parents or guardians do.*

While in many cases it was necessary for parents and guardians to assume greater control, it seems important to distinguish the control they assumed from the control the individuals who actually used the services assumed. For most of the consumers that we interviewed, the funds were actually managed by a family member with varying degrees of involvement from the consumer. There was probably a continuum of control that people with developmental disabilities actually exercised. One person managed a small amount of her support money while receiving help with the checkbook from her direct support staff. Tracey's and Karen's families talked to them about their checkbook—their money, and the choices that were involved in using it. Some families admitted that there were expenditures in the plan that would not be chosen by the consumer but that the family felt was in their best interest. Many of the consumers, even some who had sufficient cognitive ability, knew nothing about the project or their individual budget.

- *Basing individual budgets only on historical costs freezes the inequities in past allocations.*

The discrepancy in resources that are allocated to different individuals becomes more obvious when the resources are described by a given dollar amount that they can use for their support rather than a patchwork of programs to which individuals may or may not have access. We interviewed the families of four young adults in one county who had a range of \$1200 to \$18,000 per year available for their support in spite what appeared to us to be similar needs and family resources. These differences came about because of

funding programs that they may or may not have been able to access in the past. John's family, for example, had only \$1200 per year in money for his supports beyond his work support program. His mother reported that they made a choice to forgo respite in order for John to take part in a social program. She regretted not having respite available however. Tracey, on the other hand, had \$18,000 per year and had money for hourly staff, respite, and three weeks and five weekends of camps or vacations. In addition to these differences, we know that many more families in Minnesota and across the nation have no government-funded support at all. Using an allocation tool rather than, or in combination with, historical costs presents an opportunity to distribute resources more equitably, which was a project goal. Olmsted County reported that they were able to support two more persons in the Waiver program with the savings from using the allocation tool to re-align costs.

- *Paying for individual support rather than for programs creates some new issues that may be of concern to community members as taxpayers*

Some of the families with young adults who are living at home told of a small business that offered support for recreational activities for people who do not have facility-based services. This service charged \$18/hour per consumer. Taking six to eight individuals out at the same time results in what would seem to be extraordinarily high total compensation for the provider of this service. Depending on the support needs of each person purchasing the service, it could also result in some of the people in the group not receiving adequate support or supervision, especially if only one service provider accompanied the group. On a smaller scale, parents of one person reported that one of the staff who was employed directly by them took several people who were in the project out together and then billed separately for each. This potentially gave the staff person an income of \$30 to \$50 per hour or more. This mother was not unhappy with this arrangement. She felt that it enabled the staff to do things that were more creative and that it was beneficial for her daughter to be with other people. Although this mother does not see this as objectionable, other community members may see this as an inappropriate use of public money.

- *A controversial issue is which tangible goods are an appropriate use of public funds.*

Dakota and Olmsted used "the defensible use of public funds" as a criterion for budget expenditures. This may be highly subjective and differences of opinion may have potential for public backlash. Examples of some of the expenditures we saw that may spark controversy were computers, software, craft supplies, books, videos, a bicycle, professional sports events, concerts, plays, Y memberships, camps, and vacations. Some of these were purchased with funds from the Medicaid waiver; others were purchased with county funds.

- *Another controversial issue is paying relatives for support.*

One family was able to pay \$7.00 to \$8.00 per hour for relatives to engage in a recreational activity with a young adult who does not need physical care. Another family was able to pay the mother the money that was allocated for the DT&H program so she could quit her job and care for her daughter. In another county, a family lamented that the mother does not have the option to use her child care money to quit her job and pay herself to take care of her child. Some of the situations such as these seem to make good sense, others are questionable. It will be a challenge for the state and counties to sort out which are an appropriate use of public money and which may create undesired public controversy.

#### Consumer and Family Education and Support for Self-Determination

The designers and implemented of the Self-Determination Project placed a high priority on providing information and support for consumers and families so they would be able to exercise control over their supports. Project implementers conducted a range of activities and produced several products to inform and educate consumers and families about the project and the kinds of options it afforded. Many of these products were developed jointly with input from project staff of the Minnesota Department of Human Services and staff from the three participating counties. Other materials were developed and training events were held at the county level in each of the three participating counties. The purpose of these materials and activities was to ensure that consumers and families had sufficient skills and information to: 1) articulate their desires and expectations in arranging supports, 2) select providers and arrange supports according to their preferences, and 3) define quality for themselves and evaluate their own supports.

There were four primary methods used to assist persons with disabilities and their families to learn how to use the project as a way to gain greater control over their supports and their lives. Activities included orientation meetings, networking events, and individualized supports. In addition, several educational products were produced. Each of the consumer education products was evaluated by groups of consumers facilitated by the project evaluators.

### Orientation Meetings

In each of the three counties, orientation meetings were held for consumers and families to explain the project and what it would mean to become a participant. Each county worked closely with local advocacy organizations for persons with developmental disabilities, including Arc and People First, to publicize and host meetings. Two counties gave a portion of their project funds to Arc and People First to make them partners in this activity. The third county used the Self-Determination Project as a means to assist the community in revitalizing its inactive Arc chapter and to initiate a People First self-advocacy organization with the local project coordinator acting as a co-advisor. Later United Way funds were secured to support an advisor. Most of the people with whom we talked had been to an orientation meeting. All felt that they had been helpful in providing an overview of the project.

### Networking Events

Two of the three counties held periodic meetings for consumers and families in the project to meet together, share stories of their successes and struggles, and possibly assist one another in problem solving or forming support networks. One county did not have such an event until the third year of the project. Prior to that, many of the people that we interviewed talked about the need for such an event. They wanted an opportunity to learn from other people about what might be done to individualize supports. In the counties where the meetings were held from the start, people appreciated having them available whether or not they had found them personally helpful. A conservator noted that there was good interaction between the self-advocates who attended. At least one person thought it would be more helpful if separate meetings were held for those who planned supports for a child as opposed to an adult.

### **Individualized Support**

A great deal of training occurred in individual meetings between consumers and/or family members and either the local project coordinator or their county case manager. Many consumers and family members reported these individual and informal meetings were their most frequent means of receiving information and support. This was a preferred support method for many project participants since information could be presented in the context of their goals and current situation. As the result of such support, some families reported that they felt that their county had not only supported them, but also had been a partner with them in designing alternative supports.

### **Education Products**

Several education products were produced by the project participants. They included:

**Video: Person-Centered Thinking: Supporting Self-Determination.** This video introduced the concept of self-determination as it relates to persons with developmental disabilities. It used short vignettes that demonstrated consumers and families exercising self-determination in several ways, such as participating in person-centering planning meetings, using an individual budget to select and purchase supports, and participating in self-advocacy events.

**Fact Sheets on Self-Determination Topics.** Blue Earth County created five one-page fact sheets that described particular aspects of using the service system for persons with developmental disabilities. Each fact sheet described a single topic. The topics included: "Money and Budgets," "Your Case Manager," "Your Team," "Person-Centered Planning," and "Be Informed."

**It's My Life! A Handbook for People with Developmental Disabilities and Their Families.** Blue Earth County produced this fourteen-page booklet that is intended to assist persons to think about the kind of life they want. Clip-art images are used to demonstrate several living options, employment options, leisure options, and support options. The final part of this booklet introduces ideas about how individuals and families can use social services and other support systems to arrange the kind of life they desire.

**Person-Centered Thinking: Supporting Cultural Competence.** This two-page interview guide created by Minnesota DHS staff seems to be intended to assist support

people to learn about an individual's cultural beliefs in a respectful manner. It was still in a developmental stage as the evaluation of support materials was concluding.

**Metro Provider Guide.** This book is intended to describe the many types of support that are available to persons with disabilities. It also provides "yellow pages" of agencies and individuals that provide each type of support in the seven county metro area surrounding Minneapolis-St. Paul, Minnesota. At the time the evaluation was concluding, the initial section describing support options had been completed, but the "yellow pages" were not yet available.

**Housing Guide.** This is a 16-page guide that describes many options persons with developmental disabilities may consider in deciding where to live. These included options such as whether to purchase a home or rent, whether or not to have housemates, etc. The guide includes ideas about pursuing these options, such as initial ideas about obtaining a mortgage.

**Finding the Support You Need.** This is a detailed manual mostly targeted to individuals and families who were interested in arranging supports outside of a traditional provider agency. It contains information about issues such as hiring people, and payroll and tax withholding practices that come into play when consumers and families choose to become employers. It is designed to be used in conjunction with the support of a case manager or service coordinator to facilitate understanding of the information. In order to prevent people from feeling overwhelmed, the manual is designed to allow only those sections that of interest to the person or family to be shared.

These educational materials were evaluated by self-advocates and family members, and the evaluation reports for each product are included as Appendix C to this report. The three major criteria used in evaluating the consumer education material were:

- 1) the degree to which the material was respectful to all people, including both men and women, persons of all cultural backgrounds, and persons with a range of disabilities including both type and level of severity,
- 2) the degree to which the material could be expected to be understandable for its intended audience, and
- 3) the degree to which the material would be useful to people in gaining increased self-determination.

Most of the consumer education materials were evaluated by three review panels that consisted of four to six members each. Two of the panels consisted completely of people who had developmental disabilities, and the third panel additionally included one parent

and one direct support staff. Evaluation participants were given a small honorarium for their contribution.

Emerging issues and recommendations related to consumer and family education and support for self-determination are as follows:

- *Families who participated in the project were eager to have self-determination awareness expand.*

All of the families that we talked to were enthusiastic about the possibilities in a support system based on self-determination and were eager for other families to have this knowledge. An advocate that we talked to didn't think that people (providers, case managers, families) were getting information about the new opportunities and expectations as fast as she would like. She wanted to see greater efforts to increase awareness of families about self-determination, particularly families who are new to the system and young families.

- *Greater effort should be expended on training and technical assistance aimed at changing the attitudes and practices of case managers and service providers.*

Many of the people whom we talked to were disappointed by what they perceived to be a small degree of change in the attitudes and practices of service providers and case managers. They felt that this was the county's responsibility, and many people felt that not enough had been done. Jean's mother, for example, had been unsuccessful at trying to get the residential provider to make some changes. She asked her county to advocate on Jean's behalf because she felt the county had greater power. She was disappointed that her county seemed to feel that this was the family's role under a system based on self-determination. (The county coordinator felt that they had offered to arrange a meeting for her, the provider, and the county to help resolve the issue.) Many individuals and families who have been accustomed to traditional services may need considerable transitional support from their counties before they can be instrumental at changing provider's attitudes and practices.

- *Most consumers and families prefer to get their information on an individual, informal, and "as needed" basis.*

Although there were exceptions, few of the people whom we interviewed were enthusiastic about the comprehensive manual, Finding the Support You Need.

Information and networking meetings were ranked higher, but many people found them to be of limited help. What they were enthusiastic about was the individual, informal help they were able to obtain when they needed it. Most often, this help came from a project coordinator, but sometimes it was also available from a case manager. An advantage of this approach is that families are less apt to be overwhelmed by the amount of challenging information that they think they need to master and become discouraged from making changes. In addition, individual learning preferences and styles can be accommodated with an individual approach.

Although many persons with developmental disabilities find group information and training events, such as self-advocacy group meetings, to be helpful sources of information, Michelle preferred to receive information about her options in other ways. While Michelle's case manager told the evaluators that Michelle had attended a People First self-advocacy group meeting, Michelle did not remember it. When we showed Michelle the Fact Sheets on Self-Determination created by her county however, she said they looked very helpful and asked if she could keep them. Although Michelle was planning on attending an upcoming training event on self-advocacy, she seemed much more interested in receiving the information through one to one meetings with her case manager, or through printed material she could read and hold on to. This was verified by Michelle's mother who said Michelle had never enjoyed group activities and preferred individual activities.

- *There should be an information substitute for the project coordinators after the project funding is gone.*

Because consumers and families made extensive use of the local project coordinators for their information, losing them at the conclusion of the project will leave a large void that may threaten the future of self-determination. Perhaps Arc chapters could use the products that were produced by the project and be an official source of information for consumers and families who want to try alternative arrangements to increase self-determination. Some of the information will need to come from the counties, however, so efforts should continue to enable case managers to provide this assistance.

- *Support activities and products that are designed to increase self-determination should include information about advocacy.*

Whether or not families are creating alternative support arrangements, they wanted more information and training about advocacy. They wanted to know how to advocate with traditional support providers, and they wanted to know when and how to use professional advocacy services.

- *Materials for self-advocates should present both the benefits and the challenges of support options.*

Many of the self-advocates who reviewed the materials produced in the project for consumer education said that they felt they were being "sold." They would like information presented objectively so they, with whatever support people they choose, can make their own decisions.

- *Materials for self-advocates should be available in alternative formats.*

Several of the consumer product reviewers had suggestions about alternative formats in which they would like to see the materials available. Audio tape recordings would be relatively easy to produce and make widely available. One person creatively suggested a video tape version be produced of the Provider Guide.

- *Self-advocates should be used for future evaluations of educational materials for which they are the primary audience.*

As can be seen from the individual product evaluations in Appendix C to this report, the self-advocates who reviewed these products had many creative and insightful recommendations about how they could be improved. Self-advocates seemed to appreciate being asked to participate in these evaluations, and they were very willing to contribute even when it meant coming back for a second meeting. Every evaluator contributed ideas about how the products could be improved.

- *Group evaluations that start with an open-ended discussion and then move on to individual criteria seemed to work best.*

Lessons were learned about using self-advocates to review educational products over consecutive sessions. It seemed to work well to begin with an open-ended discussion in which people could say whatever they wanted about the product and then move on to a discussion of more specific criteria. Using a group process produced a valuable synergy

that seemed to stimulate more creative ideas. However, it was important for the facilitator to seek out individual perspectives and to encourage people with divergent opinions not to acquiesce to the group.

### Monitoring and Assuring Quality

One of the tasks specified for this evaluation was to "evaluate local project sites' quality assurance plans and their quality assurance plan implementation to determine the degree to which consumer-based outcomes were achieved." We found that, over the course of the project, participants' thinking evolved from an intention to develop alternatives to standard quality assurance methodologies to a quite different conceptualization of what government's role in assuring quality should be.

Early in the project, each of the three participating counties had plans to develop a formal outcome-based quality assurance methodology which would be designed to ensure that the expectations of a support system based on self-determination were being met. Dakota County planned to model their methodology after an interview protocol used by their Interagency Early Intervention Committee (IEIC), which reviewed a sample of consumers for the presence of selected outcomes. Blue Earth County assigned a workgroup to develop their quality assurance methodology and requested variances to Minnesota's new consolidated licensing rule to allow greater flexibility in this plan. Olmsted County already had a major quality assurance redesign underway in the Region X Quality Assurance Initiative, which had secured funding and legislative authorization to substitute this methodology for existing licensing processes. (At the conclusion of the Self-Determination Project, the Region X quality assurance methodology has begun implementation, but none of the consumers enrolled in the Self-Determination Project have been focus people for these reviews.)

Another early effort was a draft of a general quality assurance framework that a project-wide group developed to guide local quality assurance development. In this document, quality was defined as a multidimensional construct that included a) assurance of basic health and safety, b) definition and achievement of personal outcomes, c) self-evaluation and self-correction by support systems, and d) compliance with regulations.

As the Self-Determination Project progressed, however, participants began to redefine what they thought quality meant and began to conceive of "quality assurance" as something quite different than originally envisioned. A group of project participants,

consisting of the project coordinators, a parent, and a self-advocate, was brought together to discuss what they had learned about quality and quality assurance in a support system based on self-determination. This group felt that what is quality varies from person to person and from day to day, that it is not an outcome but the process of living one's life in a way that is individually determined and personally satisfying. As such, quality can not be globally defined; it cannot be measured, except in relation to the person's definition of quality; and it cannot be assured.

Given this concept of quality, the group saw the function of government as not to assure quality, but to carry out these three responsibilities: 1) to safeguard basic health and safety of vulnerable people who are receiving government-funded support, 2) to ensure that tax dollars are used defensibly, and 3) to provide sufficient information to consumers so that they can articulate their desires and expectations, select appropriate providers, and evaluate their own services. In this conceptualization, consumers and those that support them are responsible for assuring the quality of their own services by specifying what they want from their provider and changing providers, or threatening to, if the service does not meet their expectations.

The expectations for a service provider in this system are thus twofold: to meet minimum standards established and monitored by government entities and to satisfy individual consumers' expectations. This group explained that these expectations for service providers could be thought of as an upside down triangle. The tip at the foundation represents the minimal standards established by the government funder and the vast majority of the triangle represents the individual consumer's expectations. (See figure 1.)

~ consumer expectations

~ minimum government standards

Figure 1. Expectations of a paid support provider

In this system based on self-determination, government entities fulfill their three responsibilities in a variety of ways, some of which are already established and some of

which are new to a self-determination system. Existing methods of ensuring basic health and safety on the individual level include the individual support plan and the risk management plan. Assuring minimum health and safety standards across the system is done through licensing and contracting procedures, although these project participants would eliminate some of the licensing standards that are beyond what they would consider "minimal." Other system-wide methods are the Vulnerable Adult Rule and the rule governing aversive and deprivation behavior management procedures. The second responsibility of government, using tax money in a defensible manner, has traditionally not been a major issue beyond flagrant misuse of funds, and government has not been held to a high level of accountability in this area. As funds become controlled by consumers to use in individually determined ways, however, the potential for backlash increases and this becomes a major consideration. The third responsibility, to provide sufficient information to consumers so that they can articulate their desires and expectations, select appropriate providers, and evaluate their own services, also becomes more salient in a self-determination-based system. As consumers hire and fire their own providers, it becomes necessary for them to be able to obtain information beyond their own experience.

As the project counties have developed self-determination systems, they have not only identified these responsibilities but have begun to develop responses to them. To fulfill their responsibility to ensure basic health and safety and yet support self-determination, one county has responded to individual plans that involve risk with the stipulation that any possible consequence must be something that the person and his or her support network can live with. This is meant to take the responsibility and authority away from the county and allow consumers and their support networks to assume them. Although this stipulation is vague, it does encourage discussion of the possible consequences and how they might be handled.

To fulfill the responsibility to assure defensible use of tax money, all three of the counties are developing methods to decide what expenditures should be approved in the individually controlled budgets and how these expectations should be monitored. There has been considerable tension inherent in these decisions and these procedures have evolved considerably over the life of the project. They are discussed in more depth in the section on individual budgets.

The third responsibility, to provide sufficient information to consumers so that they can articulate their desires and expectations, select appropriate providers, and

evaluate their own services, has been a major activity as the system shifts to accommodate self-determination. Project counties have held information meetings and information sharing gatherings. They have organized People First groups and provided self-advocacy training. They have contracted with local Arc chapters to provide information meetings and individualized support, and they have produced consumer education products such as a video, resource guides, and county specific brochures. Many of these resources have been evaluated and are described in Appendix C of this report.

Emerging issues and recommendations related to monitoring and assuring quality in a system based on self-determination are as follows:

- *The primary evaluator of support quality should be the individual consumer and his or her support network.*

The individual who uses a service is the best judge of whether or not that service is of acceptable quality. However, in order to have that information acted upon, most people who use services need an external monitor or an advocate to mediate for them. Support network members who know the person well and are in frequent contact with the person may be in a significantly better position to evaluate quality than external monitors are. They often know from a historical and intimate perspective how to read their behaviors and interpret their verbal reports.

- *If support network members are empowered to monitor the quality of the service their focus person receives, they need to be promptly informed of all available relevant information.*

Support network members can play an important role in monitoring services, but their effectiveness is limited by the information they have available. Linda's guardian was notified of some serious medical administration errors involving Linda only after the provider received an official citation. Several months after the fact, he still had not been officially notified of a discrepancy in Linda's funds that was discovered in a licensing review. He visits her, attends her planning meetings, and receives copies of all incident reports in an attempt to monitor the quality of her services. It is important to him to know when a concern with the agency's services has been discovered.

- *If a consumer does not have support network members that can adequately monitor their services, a substitute should be provided.*

In the current system, consumers who do not have non-paid support people who are active in their lives must depend on a case manager to advocate for their needs if the service providers fail them. Jean's sister, who has observed Jean's housemates for 30 years, expressed concern about the quality of case management as it affects the quality of services that consumers receive. Many of the women that Jean has lived with are in their 30's and 40's and have no family involvement. For these people, the case manager is often the only person outside of paid providers who can advocate on their behalf. When the case manager is not active or assertive, the individual is left with no one. She hopes that changes in the system as self-determination becomes the norm will provide acceptable alternatives so that all consumers have an advocate monitoring the quality of their support.

- *People's assessment of the quality of a service is sometimes based on "on the best that can be hoped for in this environment. "*

Ruth's conservator said, "If Ruth is happy, that's the best I can hope for." Since Ruth has a naturally happy disposition, that is not a difficult level of quality to attain. However, the conservator also felt that Ruth lives in a very inappropriate facility and was even concerned about her safety there. There is a need to continue to raise the expectations of consumers and their support people about the level of quality that they have a right to expect. There is also a need for a prompt system response when these expectations are not met.

- *Creative thinking can support increased self-determination without compromising health and safety.*

Dick's employer gave him free pizza for his lunch everyday and Dick began to gain weight. His team had serious concerns about this because of his family medical history but realized that Dick had no interest in turning down free pizza. Support network members decided to try to offset the effects of the free pizza by encouraging Dick to walk to work and offering choices of lighter meals at home.

- *Hiring individual, informal support providers shifts the responsibility for assuring quality from a provider agency to the individual's support network*

Although a support provider is known to and trusted by the family, providing support that meets the family's definition of quality may not be their priority. Troy's former PCA had been very close to Troy and had been very involved and supportive in the person-centered planning process. Troy and his mother wanted him to have community employment, and the former PCA, who was starting her own business, agreed to provide vocational service to him one day per week in her office. This was later increased to two days a week. The mother and the case manager became concerned after dropping in only to find Troy unoccupied when they expected him to be working. They asked the provider to give them a description of what Troy would be doing at her office, which she never produced. Shortly after, she told the case manager that she could no longer provide service to Troy because she was having back trouble. She did not return calls from Troy's mother and has had no further involvement. If this direct support provider had been working through an agency, there would have been more oversight and an administrator to serve as a mediator.

- *Assertiveness increases when people are listened to.*

As people have success stating their wishes, they will be encouraged to increase their self-advocacy. Because Dick asked for his dream job and got it, his case manager felt that he learned that it can make a difference if he speaks up about the things he wants. Previously, she said, the team members monitored the quality of Dick's services and "sort of guessed at what he wanted and what worked well for him." Now, Dick regularly brings up concerns and the case manager felt that people genuinely listen. The case manager said that the team is "pretty diligent about passing on and acting on the things Dick is saying." There is still work to do, however, as the evaluator observed Dick's staff dismissing some of his stated desires as "too expensive for him."

- *Quality services equates to a large extent to quality staff.*

Most of the discussions that we had with people about quality involved talk about direct support staff. Quality services means having staff who have the skills needed to appropriately support the consumer, who are attentive to the person's physical and emotional needs, and who are responsible. It also means having adequate numbers of support staff and that staff will show up when they are scheduled to work. The Metro

Provider Guide recognizes this and provides information about staffing to consumers who are shopping for services. This recognition should be expanded to other future quality assurance endeavors.

- *Assessing consumer satisfaction should involve ongoing solicitation of complaints.*

Michelle said her primary means of telling people if she was not satisfied with her services was to wait for her next team meeting. She was aware that she could call a special meeting if she wanted to but said in most cases she would just wait for the next one. She saw this as the only way to change something at her residence but felt she had more options for registering complaints at work. She said she would rarely do so, however, because there was so much "red tape" involved. If providers are to get the feedback they need from people like Michelle, they must find ways to solicit it regularly, not waiting for people to complain. By her next planning meeting, Michelle may have forgotten the source of her dissatisfaction.

- *Consider the prevention of abuse and neglect the basic governmental responsibility rather than maintaining health and safety.*

The consensus of the focus group on quality was that ensuring health and safety should be the primary responsibility of government to vulnerable people for whom it purchases support. The government's responsibility should be to ensure service providers do not place the consumer at risk of abuse or neglect. This includes requiring service providers to ensure that health and safety is not compromised in the delivery of services. Providers in turn, must ensure that consumers are not abused by staff members and that they are not neglected by poor health care or unsafe living conditions. If consumers choose to engage in behaviors that jeopardize their health and safety, providers have a responsibility to support consumers to understand the consequences of their behaviors as well as ensure that consumers have the knowledge they need to make informed choices. Thinking of health and safety as processes allows consumers who are capable of making informed choices to decide for themselves how they are going to live their lives. It also frees providers from the notion that they are responsible for all of a person's life, which leads to over-protection and control.

- *Planning is a necessary precursor to quality outcomes.*

A service cannot meet an individualized definition of quality unless the expectations are specified up front, the service is planned around that definition, and monitoring to ensure that service outcomes are achieved occurs. Therefore, it is imperative that service planning and service evaluation be linked for each individual consumer.

- *Developing new methods of quality assurance for a service system based on self-determination must involve regulatory reform.*

Questionnaire respondents were asked to what extent they think that current licensing standards and procedures impact the principles of self-determination. Thirty-five percent thought that licensing standards and monitoring procedures impede self-determination to a great extent and another 53% to some extent. The programs that they mentioned most frequently were ICF/MR and DT&H. Some also felt that interpretations of rules may sometimes be more limiting than necessary.

#### Changing Roles: Providers and Community

Another strategy was to support persons both inside and outside of the traditional service system to begin rethinking their roles to allow consumers and families to exercise greater control over their supports. The role of government began changing, as described above, to provide individual budgets rather than programs and to support consumers to specify what they wanted from their service provider and evaluate quality for themselves. In addition, the role of service providers began changing to that of a supporter and facilitator rather than a director and decision-maker. Service providers were expected to start thinking about "unbundling" their programs and individualizing supports. One more role change was addressed in the project. Project designers and implementers hoped that the community would take a stronger role in including and supporting people with developmental disabilities. To this end, they conducted training for support providers, consumers, and families on facilitating this change. In addition, project activities included efforts to facilitate culturally competent supports, to support consumer-controlled housing, and to find natural support substitutes for state guardianship.

For all of the parties involved, changing to a service system based on self-determination requires major role changes. Preparing for these changes is a process of

increasing understanding and awareness of what services cost, of where the control lies, and of the possibilities of change. It was described by some project participants as a "gradual cultural change." The role changes that county case managers must make are described in the section on support planning and coordination. The section on individual budgets describes role changes for counties and consumers and talks about the support that they needed from the state DHS in order to make these changes. This section completes the discussion of the role changes that are needed by stakeholders in the service delivery system for people with developmental disabilities by focusing on service providers and the community.

### Changing Roles: Community

In all of the project counties, the primary efforts to increase options for community involvement and inclusion were individually focused. In addition all of the counties provided training for formal support providers on methods to facilitate inclusion for the consumers whom they support.

Dakota County collaborated with the Dakota County Providers Training Group to do a joint workshop on "Building Inclusive Communities." Everyone who worked with the service system was invited - families, consumers, providers, county, and advocacy. They had a chili supper a few months later to follow up on people's progress in implementing the training, and they had follow-up gatherings about every four months. The trainees invited their friends to the supper.

Blue Earth sponsored several training activities designed to increase the system's capacity to help people with developmental disabilities become more included in their communities. Although there have been no concrete results, there have been attitude changes. These sessions did not include an action plan or a formal commitment to proceed with learning.

For most of the people whom we interviewed, there was no evidence of activity or concern for increased community inclusion. Dave and Kathy's program goals and activities seemed to continue in traditional ways. Preferred activities listed for both of them included going for walks and Dave's program included an objective to "access the community one day per week."

Dick became more involved in the community through his job at the Pizza Hut stand at the local college. Now, he goes to the college to shoot pool as well. Because of his presence there, he has enjoyed many acquaintanceships with the students. According

to his direct support staff, however, there were no attempts to help develop these relationships into lasting friendships. His case manager remained unconcerned about increasing Dick's connections to people in the community since he had many relationships with "people like his staff and housemates."

Several people became more involved in the community after they developed an individualized day program. Linda and Dorothy both freed up some of their time and enjoyed individualized activities in the community for much of their day. They were also able to use some of the monetary savings to finance their activities.

"Original project intentions were to change community roles through three structured activities as well as through training and individual supports. These activities were to support culturally competent supports, to facilitate consumer controlled housing and to move people from state guardianship to private guardianship or conservatorship.

Culturally competent supports. The counties did not do anything specific under the auspices of the project to enable more culturally competent supports. It was decided early in the project, that the state would contract for assistance in this area, but a request for proposals process failed to yield any satisfactory proposals. Eventually, DHS developed a Cultural Competence Guide, which is described and evaluated in Appendix C.

Housing. One method that project developers saw as facilitating the community integration of people with developmental disabilities was to find alternatives to facility-based support and find ways for consumers to control their own housing. A Housing Guide was developed under the auspices of the project. This is a 16-page booklet that outlines the housing options for people with developmental disabilities who need support. The guide presents information on several options including purchasing a home, renting a home, or renting an apartment using publicly subsidized or market rate options. This is also described and evaluated in Appendix C.

Guardianship. One way that consumers become more a part of their communities is to eliminate their public guardianship status and have a private person who cares about them become their guardian or conservator. Blue Earth had two information meetings to provide information about public guardianship and the limitations that it places on decision making by consumers and families. Olmsted also held three training sessions to familiarize people with guardianship and conservatorship in Minnesota. That training was presented by a DHS staff, Arc, a lawyer, a private conservator, and county staff to

over 100 family members, individuals with disabilities, providers, case managers, and others. It was reported to be highly successful.

All of the counties focused their primary efforts to eliminate state guardianship on individual consumers for whom it was applicable. The first step was to look for a family member or a friend to assume this function. Frequently, a former direct support staff who had maintained contact with a consumer was willing to become a conservator. When efforts to find informal support persons to become conservators were exhausted, counties turned to paid conservators. Olmsted and Dakota have been doing this, and Blue Earth recently received nine proposals in response to their proposal for paid conservators. Olmsted reported that their efforts to eliminate public guardianship resulted in 20-30 persons who changed to a private conservator. Blue Earth reported that their efforts have yielded 13 persons finding private conservator options.

#### Changing Roles: Providers

Dakota County. Dakota County worked with existing providers to help them change their role to facilitate self-determination. They had a separate orientation for service providers at the beginning of the project. 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.

In Dakota County, service providers serve on the steering committee to provide guidance for the Self-Determination Project. In addition, the county developed a collaboration with the Dakota County Providers Training Group, which consists of providers and county representatives, to decide how to spend the project training budget.

A primary strategy for facilitating role changes for providers, however, was for the project coordinator or other county staff to work with them individually to facilitate flexibility for particular individuals, e.g., adjusting to having people attend the DT&H part-time. In this process, they were able to encourage the provider to view their role as support and facilitation rather than as of director and decision maker. They also found a need to clarify licensing expectations and clear up misunderstandings.

Olmsted County. Olmsted County provided training and support to providers to aid them in transitioning to a role of supporting people rather than operating programs. They also partnered with specific agencies who volunteered to be involved in project

activities and have worked with them on a one-to-one basis around individual consumers' needs.

Informational sessions for providers were held during which project staff reviewed the various system change efforts with which the county was involved. In addition, project coordinators spoke at providers' meetings. They brought in a trainer to provide formal training on self-determination and to discuss how the role of support staff changes when self-determination principles are applied. A total of 120 people (not just providers) were trained.

Olmsted County partnered with Arc to restart a provider group that stopped meeting a few years ago. This group is a means to share information on how systems are changing and allows providers to support each other in adapting to the changes. It is lead by an Arc advocate, rather than by the county, which keeps the focus neutral.

The county also partnered with service providers regarding training to enhance the change to self-determination and individual budgets and dealing with these changes. Early in the project, they sent a letter to providers requesting volunteers and four responded. At the end of the project, the county coordinator felt that all providers were actively partnering with the county to make self-determination the norm. In addition, service providers serve on the Advisory Committee to provide guidance for the Self-Determination project.

Another primary strategy was to work with providers on a one-to-one basis to develop individualized supports for someone they serve. This proved to be quite successful not only in changing that individual's support, but also in stimulating providers to "think outside the box."

Olmsted chose not put a great deal of effort into recruiting new formal provider organizations. Instead they focused on helping current organizations rethink how they do business.

Although Olmsted does not have a formal plan to close ICFs/MR, they actively supported providers to close two ICFs in the past year—one for 20 people, the other for six. Olmsted initiated an effort to downsize one of their 15 bed ICFs, but it has not progressed largely because the provider is not completely behind the idea. Another provider also initiated discussions and plans to downsize their current 40 bed ICF. The county is very supportive of this effort and will be working closely with the provider to assure that the individual needs of current residents are met.

Blue Earth County. Blue Earth facilitated role change for service providers in several ways. Service provider agency staff are included as part of the local project advisory council. The project coordinator met individually with service providers and school district staff to educate them about the demonstration and to encourage them to pass information on to consumers and families. She also held regular roundtable discussions to provide education and support to direct service staff. In addition, service provider agency staff received training in using person-centered approaches to service planning with consumers and families.

A primary need for Blue Earth was to develop an alternative to the only DT&H program in town so that consumer could have a choice of provider. Two very recent efforts are promising. A group of parents and teachers have developed a Saturday leisure program for people with developmental disabilities to try different types of art activities. The long-term goal of this group is to market their products either through a storefront or on a consignment basis with local boutiques. They are also hoping that it will eventually become a center for artists with and without disabilities. The other effort is working with a metro-area provider to develop an alternative work support program. This is expected to culminate in a contract to develop a "DT&H without walls." The County also is working with the local vocational provider around individualizing rates.

Blue Earth still has a 44-bed ICF/MR and two 15-bed ICFs/MR. Downsizing has not become an administrative priority in large part because of a generalized labor shortage in the area and concerns about being able to adequately staff smaller homes.

Emerging issues and recommendations related to changing provider and community roles to support a system based on self-determination are as follows:

- *Working individually with providers to make changes requested by individual consumers has worked well.*

One of the principles in the "Framework for Provider Support" was to provide education and training on an individual basis as it relates to the individualized needs of the consumer. This seems to have worked well. Many providers who served the consumers that we talked to had made changes (e.g., staff schedule changes, allowance for part-time employment) to accommodate their requests.

- *DHS and counties should work with provider organizations (e.g. ARRM, MnDACA.MnHab) to facilitate developing their own methods to transition to a service system based on self-determination.*

Original project plans to facilitate peer support for service providers were lauded by the respondents to the logic models cited in Report 1 (Appendix A). These respondents also stressed that providers will need a lot of training and technical assistance in their transition to accommodate consumer self-determination. Project counties have had some information and training sessions for providers, but much more needs to be done in this area.

- *Existing traditional service providers are needed and should be supported to make the transition to self-determination.*

Several family members expressed the view that there were not many feasible alternatives to traditional providers, particularly with facility-based supports. They wanted help to change the support their loved one was receiving with these providers. The notion that providers who do not provide responsive, consumer-directed supports will go out of business is probably not realistic, at least in the near future. Until they do, many consumers will be receiving support from them and have a right to take advantage of some of the benefits of self-determination principles. The original Self-Determination Project in New Hampshire made a commitment to not let existing service providers 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. This suggestion applies to all providers, but may be particularly helpful to ensure that large ICFs/MR, are downsized and that the consumers who live there receive support that is appropriate to their needs.

- *Consider providing, at the state or county level, assistance, flexibility, and start-up support to establish new, innovative programs.*

Original intentions for the project were to develop and utilize alternative support arrangements. Dakota County holds monthly sessions for individuals interested in developing innovative supports. More needs to be done in this area as families perceive that they have little choice without taking on the daunting task of developing and managing their own programs. The DD Community Workgroup, which was cited in

Report 1, recommended that government entities play a role in supporting this development.

- *Offer support and technical assistance to providers to work within current regulations to find ways to promote self-determination.*

Some respondents to the Feedback Questionnaire pointed out that service providers (and others) often have a perception of regulations that is more limiting than it needs to be. These misperceptions are the result of common assumptions that have existed for years and have become "truth" in many people's minds. There needs to be a concerted effort to assist providers and others to reexamine these regulations and to work within them until they can be changed (if they should be). Part of this effort should be to provide a "user-friendly" process to request variances when they are appropriate.

- *Counties should ensure that there is at least some choice of providers.*

While the Self-Determination Project afforded consumers and families to create new support options, it remains important that counties assist in making options available. There was consumer dissatisfaction in one county because there was only one DT & H provider. Two families were unhappy with this provider's lack of commitment to developing community jobs, and they were frustrated by the lack of alternatives. One person was particularly unhappy when she requested an evaluation from the Department of Rehabilitation Services, and was told that this same provider, with whom she was dissatisfied, was the only agency with whom the county could contract for an evaluation. (This county expects to finalize a contract soon with another provider who will provide an alternative.)

- *PCA and in-home support agencies may be of more use to families if they were freed of some of their regulatory restrictions.*

Many of the functions of agencies that provide in-home support staff are still needed. One of the stated needs of families who were hiring their own in-home support staff was a list of people who might be interested in working for them. They would also like for these people to be pre-screened. Most of these families are also using an agency as an employer-of-record. The state should investigate whether most of the other functions that in-home support agencies perform, which are not needed or wanted by families, are provided because of unnecessary regulations. It's possible that with

regulatory reform, these agencies could flexibly provide what families need without costing much more than an employer-of-record.

- *Developing community capacity to include and support people with developmental disabilities should be a focus in the future.*

The New Hampshire Self-Determination Project placed a heavy emphasis on "helping the community to define itself better, as a richer and diverse place." Many of the respondents quoted in Report 1 felt that activities to encourage natural supports were missing from the project plans. This should be a priority in future efforts to promote self-determination.

## **Appendix A**

### **Minnesota Self-Determination Project Evaluation**

#### **Report 1:**

#### **Project Logic Models and Expert Feedback**

**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  
Janet Bast, John Smith, and K. Charlie Lakin  
The Center on Residential Services and Community Living  
Institute on Community Integration  
University of Minnesota**

**August, 1998**

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

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.

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### \*\*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.

#### Additional Local Activities

##### The Counties will:

- Provide education for all involved to facilitate role changes with emphasis on supporting consumer choice.
- Form stakeholder groups and meet to develop transition strategies and grass roots efforts to promote the use of self determination principles.
- Develop education and community outreach methodologies that have a high potential to be self sustaining over time.

### 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:

- 0 **FREEDOM** to plan and live a life of their choosing,
- 0 **AUTHORITY** to control available resources necessary to live that life,
- 0 **RESPONSIBILITY** to accept the benefits and risks of those decisions,
- 0 **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 (heir 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 (his model will help them to drive change at the state level as well.

### Blue Earth

## Overview of Participating Counties

### Dakota

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

**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.")

**"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.

**Transition principle:** We believe it is important that the current system not be seriously destabilized. We are engaging in an evolutionary process of change.

**Equity principle:** We believe people with similar needs should have similar financial resources with which to obtain their support.

**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

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### Dakota

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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.

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### Olmsted

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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.

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### Blue Earth

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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

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- 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

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- 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

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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 consumers 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.

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#### Dakota

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

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#### Olmsted

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

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#### 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.

<u>Dakota</u>	<u>Olmsted</u>	<u>Blue Earth</u>
<ul style="list-style-type: none"><li>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.</li></ul>	<ul style="list-style-type: none"><li>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.</li></ul>	<ul style="list-style-type: none"><li>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.</li></ul>

**Intermediate Outcome:**

B) Individuals have access to culturally appropriate services.

<u>Dakota</u>	<u>Olmsted</u>	<u>Blue Earth</u>
<ul style="list-style-type: none"><li>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.</li><li>All counties should benefit from the project-wide contract for technical assistance for cultural considerations.</li></ul>		

## 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.

<u>Dakota</u>	<u>Olmsted</u>	<u>Blue Earth</u>
<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 and safety needs?</p>	<ul style="list-style-type: none"><li>• 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.</li><li>• Individual SD budgets are set at 100% of historical costs.</li><li>• 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.</li><li>• 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.</li><li>• 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 implemented.</li></ul>

## 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.

<u>Dakota</u>	<u>Olmsted</u>	<u>Blue Earth</u>
<b>Person-centered Planning</b> <ul style="list-style-type: none"><li>• 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.</li><li>• Dakota has numerous person centered planning facilitators available. They have tentative plans to do more facilitator training.</li><li>• PCP is offered at consumer information meetings. Connection to planning facilitators is made if desired.</li><li>• 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? pay for)?</li></ul>	<b>Person-centered Planning</b> <ul style="list-style-type: none"><li>• They have trained about 50-60 people to be facilitators during 1997 and early '98.</li><li>• 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."</li><li>• 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."</li><li>• Pre-planning activities also focus on training all of the parties that will be involved in the new procedures and expectations.</li><li>• There is an expectation that the system will react with not whether, but "how can we do it?"</li></ul>	<b>Person-centered Planning</b> <ul style="list-style-type: none"><li>• Consumers and family members have participated in training regarding person-centered approaches to service planning.</li><li>• 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.</li></ul> <b>Education</b> <ul style="list-style-type: none"><li>• A Family Forum was held with the local Arc to provide information about the project.</li><li>• Two mailings have been sent to all consumers and families explaining the concept of self determination and the changes available through the project.</li><li>• A bi-monthly newsletter is sent out from the managed care project.</li><li>• A contract is being developed with the local Independent Living Center to develop a self-advocacy curriculum and to provide training.</li></ul>

### 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.

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**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.

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**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.

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**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.

<b>Dakota</b>	<b>Olmsted</b>	<b>Blue Earth</b>
<p>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.</p> <p>&gt; 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.</p>	<p>Olmsted County is part of the Region X Quality Assurance Initiative in which:</p> <ul style="list-style-type: none"><li>• Legislation was enacted to authorize and fund a pilot project for an alternative quality assurance system.</li><li>• 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.</li><li>• 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.</li><li>• 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.</li></ul>	<ul style="list-style-type: none"><li>• An alternative quality assurance program is being developed by a workgroup.</li><li>• 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.</li></ul>

# 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."

. 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.

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.
2. 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 unsystematized, 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.

## **Appendix B**

### **Minnesota Self-Determination Project Evaluation**

#### **Changes Consumers Made**

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For the 23 consumers about whom we compiled case studies, we found a wide continuum of change in their lives and services. Some people made no apparent change at all, and some made major structural changes in their supports and consequently in their lives. Many of these changes were made because consumers or their support people took control of the money that was spent on their supports. Within that category, some made major changes, and some made smaller changes that still made a significant difference in their lives. Some of the people who took control of the money did not make any structural changes and may or may not have felt empowered by the control.

Other people did not take control of their support budget, but changes were made because they were finally listened to or because the project caused attitudes to change. There were also people who joined the project to accomplish one specific thing and then did not go any further

It should be kept in mind that the people we talked to do not necessarily constitute a representative sample of all the consumers that participated in the project. Our sample was selected from those who enrolled in the project in the first few months and this meant that county systems and policies were not yet fully developed. We also attempted to get a representation of consumers with differing ability to directly communicate their desires, who were under state or private guardianship or who were their own guardian, and who received services in facility-based or home-based programs. Because of the way the counties selected or recruited individuals to participate in the project, some groups were not represented by all of the counties. For example, only one county included people who were living in ICFs/MR, a circumstance that makes significant change more difficult. Another county enrolled primarily individuals, whether children or adults, who were living in their family home.

People who took control of their support budget **and** made major changes:

Tracey. Tracey is a 20-year-old woman who lives with her family and receives transition services through the public school system. Her family receives in-home support through the MR/RC waiver, and control Tracey's resources through a consumer-controlled, county-owned checkbook. In addition, they have an allotment from their county that previously was allocated for respite care. Tracey's family had several complaints with the agency they used for in-home support prior to their joining the self-determination project. The agency insisted on a permanent schedule, and allowed no flexibility even with agreement of the staff person. They had a six-month period when the agency was not able to send any staff at all, and they often were not satisfied with the staff they did send.

When the self-determination project began, the staff person, who they were currently using and with whom they were satisfied, changed from being an agency employee to being employed directly by the family. She was motivated to leave the agency to be paid more money and to not have to take part in mandated training. Her pay went from \$7.95 per hour with the agency to \$10 and then \$10.50 working directly for the family. Tracey's mother feels that the project enabled them to keep this staff person because she would have quit the agency soon anyway. By saving the money that was paid to the agency for administrative expenses, the family was able to purchase equipment for Tracey's educational and recreational use, to pay for camps and vacations for her, and to pay family and friends to participate in community activities with her.

Tracey's mother says that she would not claim that the budget is planned by Tracey because Tracey resists new ideas. Instead, her family plans things that they think Tracey would enjoy. For example, Tracey says she does not want to go to camp, but her budget allows for two weeks and four weekends at camp. Tracey is gradually learning that this is her checkbook and that her staff person is paid through this checkbook.

Sarah and Abbey. Sarah and Abbey are 8 and 15 year-old sisters who have severe autistic-like behaviors. They live with their parents and brother in a home which, thanks to the project and a the family's ability to creatively use the waiver funding available for each of them, has been modified to address each girl's unique needs. Prior to the project, the family received a \$3000 annual grant from the county for each girl that the family could use at their discretion. The first year, a substantial portion of the money the family controlled was used on home modifications. One such modification was adding a door for the dining room, making it a private area for planning and consultation meetings. Another major improvement, which the mother describes as "awesome" is a "therapy room" in the basement. This is a place for the girls to go with their staff in order to give their parents and their brother some normal, private family time. Mother explained that "It is kind of invasive to have somebody in your home all the time." A significant part of the second year's budget will go toward stocking this room with things that will entice the girls to want to go there. Another first year expense has been to repair some of the property damage that the girls have done. The case manager, family, and the behaviorist agreed that using some of the money for household help was appropriate to alleviate the parents' burden and free them up to work with the girls. They hired an organizer to help get the house organized. Mother said things had gotten so out of control that "you couldn't even see the carpet in the living room." Once they get the house organized, they will be able to make use of a housecleaner. The family has been working with an in-home behaviorist who has brought in a staff person who is able to spend more time implementing programs with the girls.

Abbey and Sarah's mother says they feel "way more" in control over their lives—"there's no describing it. Because of their ability to use the funds authorized for the girls more creatively, they have been able to substitute highly trained people for the PC A help that they were never able to get. Because the mother's "life is filled with meetings," having household help has enabled her to spend time with the kids as well as to keep herself in a better state of mind.

Billy. Billy is a six-year-old boy with autism who lives with his parents and older brother. Billy had received services through the MR/RC waiver for a year and a half prior to when the family began participating in the Self-Determination Project. For the past three years, his parents have been implementing the intensive Lovaas Model of behavior modification. The first year, they were able to do this with a little help from the Medicaid PCA program and a lot of mounting personal debt. Using the PCA program meant finding and training their own staff and yet watching half of what Medicaid paid go to administrative overhead. Buying the curriculum and extensive amount of toys and equipment needed for this program resulted in a mounting debt load that the family could no longer sustain. Billy's mother claims they would have had to discontinue the Lovaas program if the Self-Determination Project hadn't come along. Because of the additional flexibility, the family could pay higher wages to their highly qualified staff, and they could use some of the money for equipment and supplies. Billy's family has been managing his program through the Self-Determination Project for the past two years.

The intensive Lovaas program has been very successful for Billy. He will start kindergarten next year and is reading and comprehending at the third grade level. His mother no longer believes he has mental retardation in addition to his diagnosis of autism. There are still some behavioral and self-stimulation issues that continue to be addressed, but his parents feel that because of the possibilities of the Self-Determination project, "We have a kid out of the deal—a whole different kid."

Billy's mother said the project has enabled them to have "way, way, way more control." She said what they are providing is a different kind of service than they would be able to get through an agency—"No one else would work this hard for him."

Linda. Linda is a 34 year-old woman with limited verbal communication skills. Her past services have been in programs set up specifically for people with challenging behaviors, and they were usually offered in chaotic environments in which she found it difficult to cope. Linda has little family involvement. Her

conservator met her when he was her direct support staff. He enrolled her in the project because he wanted to help her access supports that better met her individual needs. One of the early changes was to help her buy her own car with the money that was spent on transportation to her day program. This, combined with the residential program's willingness to shift staff schedules to accommodate taking her to work, was designed to eliminate the long, chaotic ride to work with other people with high-needs. It also eliminated the need to hurry to be ready for the van when it came. A more recent change is a new individual day program. Now the direct support staff person comes to Linda's home in the morning, and the two of them take Linda's car to access a short work shift and community activities. There are plans to have another consumer join Linda in this program eventually.

Linda's conservator feels a lot more empowered in his attempts to arrange individualized services for her. Because he has control over the money that is spent on her services, he can go directly to the provider to arrange services rather than work through the case manager. In addition, the provider has to work with him on how services are priced. He feels that Linda has more control over her life although it is not direct. Because of her limited communication skills, she must rely on him and other support people to identify what works best for her and arrange for it to happen. He feels her quality of life is better because she has more freedom and less of the things that formerly distressed her. The case manager also feels the direct control lies with the conservator. He believes that what the conservator does is based on what Linda seems to want.

Scott. Scott is a 37 year-old man who, before the project, lived in a licensed foster home where he received services through the MR/RC waiver. Scott lived with three other men who had much higher needs; and, consequently, Scott was left to fend for himself much of the time. He used to lock himself in the laundry room when one of his housemates was exhibiting challenging behaviors. His sister, who works in the field of service provision to people with developmental disabilities, is his conservator. When she heard about the project, she immediately signed him up. She saw it as a

chance for him to have a say about where he lived and who his housemates are and to live a "more normal life." She was also dissatisfied with the amount of staff turnover and the system-centered rules, such as the fact that the agency providing services required Scott's friend/volunteer to sign him in and out when he took Scott out of the home.

Scott's team started out by reviewing his budget and decided to arrange for a new home for him. They looked for an appropriate roommate and invited seven or eight providers to a "Bidders' Conference." Scott made a presentation using an overhead projector explaining what he needed and wanted from a support provider. He received five proposals and Scott had no doubt who he wanted to be his provider. According to his sister, the winning proposal had "more of a personal touch." Scott's sister, mom and the county social worker found the house and the roommate subject to Scott's final approval. Scott and his housemate selected their own furniture. His sister commented, "after all those years of paying (for residential services), he came out with nothing." The new provider screened potential staff and then Scott and his sister interviewed them and made the final selection. She said that they have had no problems finding staff because they are "fun guys."

Scott's sister says this arrangement is "wonderful." Scott is happier, more self-confident, and more outgoing. He takes a lot of pride in his home, and he advocates better for himself. Not only does he have control over his residential environment, but he has a lot more control over his daily life as well. He has a lot more freedom to be independent and to have guests in, and he is more challenged to assume more responsibility.

She says that developing a new residential program for him "took a lot of time, but there was a lot of support from the family." Also if she "ran into roadblocks, the county would help out."

**People who took control of their support budget and made smaller changes that made a significant difference in their lives:**

Dorothy. Dorothy is a woman in her mid-60's who lives with three other women in a licensed foster home where she receives services through the MR/RC waiver. She is able to get around the community independently and has been a member of a People First group for several years. She joined the project in order to manage her work support resources more flexibly to begin a phased retirement. She has freed up some money by reducing her attendance at the DT&H program to four days per week, and she is using it for community outings, transportation, and vacations. Other expenditures in her individual budget are a new mattress, some adaptive equipment for safety, and adapted clothing due to recent surgery.

Dorothy expresses satisfaction with the amount of control she has over her life. Her staff agrees and says that Dorothy has always been free to voice her opinions. Her case manager said that her team thought Dorothy would increase the amount of time that she has away from the structured work program, but she has been clear that she wants to continue working four days per week for now.

Angela. Angela is a thirty-year-old woman who lives with her parents. She spent two years in a group home about five years ago, but her parents brought her back home because they were not happy with the quality of service. They were dissatisfied particularly with a lack of communication with the agency and frequent staff turnover. Since returning home, Angela has received in-home services through an agency under the Medicaid waiver program. The supports that the staff provide are in the areas of recreation, cooking, doing laundry, cleaning her room and occupational therapy exercises. The quality and consistency of staff continued to be a problem. Prior to becoming involved in the self-determination project a new staff person took Angela out in her car and decided to teach her to drive. Angela crashed the car and had to be treated for injuries in an emergency room. Angela's mother was also frustrated with what she viewed as a wasteful administrative expenditures with

the provider agency. She said they called planning meetings every three months, which was "ridiculous for a program where (staff) people don't even show up."

Angela's mother enrolled in the Self-Determination Project so she could select the staff herself and pay them more. They were able to retain the primary staff person whom they used through the agency. They still use the agency for some of Angela's support. Assuming control over the budget has freed up money to pay higher wages to the staff person and to pay for recreational and educational activities and supplies.

Angela's mother does not feel Angela has more control over her life than she did before the project, but she thinks they do as a family. Now they can feel secure with the staff Angela goes out with because they can control that, and they only use staff they know and trust. They also appreciate that they now have more flexibility in when they have staff and how they are used.

Tim. Tim is a 24 year-old man who lives with the family that adopted him when he was eight years old. The family has adopted or is doing foster care for several children with disabilities. They are not planning to have Tim move out as long as they have children in the home. In addition to an adoption subsidy, the family has received Medicaid PCA services and the county's Accounts Management Grant. Now, the Accounts Management Grant and the money that had been spent on Tim's work support program have been placed in a checkbook over which the family has control. They continue to use PCA services through the agency. The only significant change that was made to Tim's supports during the project was to take him out of the DT&H program two days per week and to pay his PCA to support him individually. His family feels this is beneficial because Tim likes quieter, more laid back activities and because the PCA has been a consistent person in his life. The DT&H program, by contrast, is a busy and noisy environment and has constant staff turnover.

Tim's mother feels she is more in control of her life since the project. The times that she has arranged for Tim to receive support out of the home are now more convenient for her. Tim does not seem to have the cognitive ability to understand

self-determination, but she feels his support is more relevant to his individual needs and desires now.

Jennifer. Jennifer is a 12-year-old girl with high support needs who lives with her single, working mother in an apartment. They had been receiving in-home support under the Medicaid Waiver program, and their involvement in the Self-Determination Project has been primarily to take control over those funds. Jennifer's mom thinks that the help that she receives now is somewhat more relevant to her needs, but she is not sure it has been worth the effort. The first year she was frustrated because, although she said the county had sold the project with a promise that "the sky's the limit," very few of her innovative support requests were approved. The second year the county approved most of her original requests, however, she is finding the restrictions and record keeping to be a frustrating and overwhelming burden. She has seriously considered forfeiting the individual budget and going back to her former service with the in-home support provider.

Jennifer's mom feels she has more control over the money that is spent on Jennifer's services but not necessarily over her life. She feels the restrictions and nuisances that the county has imposed have increased her frustration level, and the amount of work involved in managing and paying her own supports has at least partially negated the value.

Tom. Tom is a five-year-old boy with autism who lives with his parents and two siblings. The family receives periodic respite care and several hours of PCA services each week. The Self-Determination Project has given them an opportunity to directly control the use of respite dollars. Because of the resultant freedom from existing rules, they are able to use more of their respite allotment, hire a neighbor girl who also baby-sits for their other children, and use respite for shorter and more spontaneous outings.

Tom's family feels "a little" more in control of their lives now that they have more control over the use of respite funds. They are still frustrated, however, by the lack of control they have over the PCA funding. Currently, after a history of much

staff turnover, they have had the same PCA for about a year. Unfortunately, however, she is not interested in taking the full allotment of Tom's hours because she has a PCA job with a different agency in another county where she is paid \$9.95/hour. This other agency does not have a contract with the county in which Tom's family lives. The PCA agency that is being used by the family receives \$12/hour to provide PCA services, but only pay their staff \$7.00/hour. The family also finds it frustrating that the agency pays a nurse to oversee Tom's PCA services, which they see as a complete waste of money. Another agency policy that frustrates the family is that a PCA cannot transport Tom in her car. Tom's mother would like the PCA to take Tom to some of his therapies so that the PCA can learn how to do them and, at the same time, free up the mother to do other things. Some of her friends circumvented this rule by arranging for Medical Assistance paid transportation to take both the child and the PCA, but Tom's mother has not yet been able to arrange for this. She also feels this would be a great waste of resources.

**People who took control of their support budget but did not make significant changes:**

Karen. Karen is a 26-year old woman who lived with her mother until recently. Karen's mother saw the project as an opportunity to "be on the cutting edge." At the time of enrollment, she was considering reducing Karen's time at the work support provider to three days per week. She also thought that taking control of Karen's support money might give her an opportunity to develop a non-traditional residential placement for Karen. Karen has been on a waiting list for a Medicaid waiver allocation, which was intended to facilitate her moving out of her mother's home. Recently, however, a woman they know who has been a direct support staff in a group home expressed interest in doing adult foster care. Karen and her mother saw this as a positive opportunity and Karen moved to this home.

Karen's mother has been paying for all of Karen's services with a consumer-controlled, county-owned checkbook. Although she did not change the way Karen's

support money was allocated, she feels that controlling the money was empowering. She feels that the work support provider has responded to her control with more responsive services. Karen's mother feels that Karen would not say that she had more control over her life than she did before the project, but her mother feels that she does have. She has been introducing Karen to the concept of the money that is available for her support and the fact that there are now some options about what to do with it. She feels she now has a "better understanding of the role of money in her supports and in her future."

Karen's mother feels that the project afforded a "gradual process of understanding the costs and benefits of services and of shifting the control." This was true for herself, for Karen, and for the DT&H provider.

Jean. Jean is a 40 year-old woman who needs basic care and is not able to hear or use verbal communication. Her mother and sister, Joan, share guardianship and had begun making changes to improve and individualize her support even before the Self-Determination Project started. Joan enrolled Jean in the project because she wanted to have more control and influence on Jean's support providers. She had been dissatisfied with Jean's services and had found it difficult to "get anyone to listen." She hoped the project would help make their "loved one the valued client rather than the county." She did not wish to make major structural changes in Jean's services, but simply make the providers more responsive to her individual needs on a daily basis.

Joan has paid for Jean's services with a county-owned, consumer-controlled checkbook. She pays the residential and DT&H providers directly. She has also written a check for an occupational therapy video and for staff training. She does not feel that paying providers has given her more influence and feels the county may as well take it back. She states that only managers, not the direct support staff, are aware that she writes the check. She scoffs at the county's suggestion that their ultimate power is to "fire" the provider. The family does not feel able to take over Jean's care on a full-time basis. Even if they did, she states that one needs to remember that if

you take someone out of the system and you need to get them back in, you would have to wait until there was an appropriate opening.

One of Jean's provider agencies has actively participated in the project and made significant attitudinal changes. The other, Joan feels, has not changed much. She feels greater changes will happen when the county takes more responsibility for orienting providers to the need to listen to consumers and their families. As a member of Dakota County's steering committee on the self-determination project she reports a struggle with county staff over this. Management staff in the county's Developmental Disabilities Division are saying that families need to deal with the providers directly if they are not satisfied. Joan, however, feels the control still lies with the county because there are not really satisfactory and available alternatives to current providers.

Joan feels that Jean definitely has better quality services than she did before the project. She feels the primary benefit of the project has been the learning process that has occurred for Jean's family members. They are now much more willing to fight for more individualized services for Jean.

John. John is a 25 year-old man who lives with his parents. His mother is paying for his supports directly with a county-owned, consumer-controlled checkbook. His individual budget was based on the cost of his services at the start of the project. These costs were only \$1200 per year in addition to the cost of his work support program. His mother was interested in the opportunity of the Self-Determination Project because she thought the flexibility might be useful in the future. At one point, she did consider setting up individual work support services, but the existing program was able to develop a job that met John' needs. Because of some bookkeeping problems with one provider, she has relinquished direct payment to a social program from which John receives services. Consequently, the only changes that have taken place are that she writes a check for the cost of John' work support program and the family has about \$200 per year for informal supports.

John's mother feels that she has an increased sense of control because of the project. She feels that, although she hasn't made changes, she has the freedom to do so if needed. She says, "It's nice to be writing the check. " A major difference is that she is more aware and starting to think of possibilities.

John has been active in the local self-advocacy group. Since the project started, he and other members of his group have had opportunities to develop their self-advocacy skills. John went to the Self-Determination Project Conference in Milwaukee and to a statewide self-advocacy conference. John makes the decisions about what events he wants to attend with the recreational support provider. His mother doesn't feel he understands the broader issues of self-determination.

John was on a waiting list for an apartment program that was being planned. When the time came to make a final commitment, however, his father made the decision that John should stay at home a while longer. His mother reports that John does want to move to an apartment, but she thinks he is comfortable with his father's decision. John does seem to have a good life with his parents. He has a friend who lives nearby, a dog, lots of space and spending money from his SSI, much of which he would lose to higher rent if he moves out. Unfortunately, however, it seems the decision of whether or not to move out of the family home at age 25 was made by John's father rather than by John.

**People who did not take control of their budget, but for whom changes happened because they were finally listened to:**

Ruth. Ruth is a quiet, pleasant woman in her early 60's who has lived in the same ICF/MR with 14 other people since leaving the institution ten years ago. Her conservator feels that the Self-Determination Project has opened doors for Ruth by bringing awareness of an individualized approach to services. A person-centered planning meeting revealed that there were some simple, inexpensive things that Ruth wanted. Some of these things were a deck of cards, a calendar, a Bible, a new bedspread, a TV in her room, and going to church and to the cemetery. According to

her team, these things were provided quickly and have made a significant difference in Ruth's life.

Another significant change was that arrangements have finally been for Ruth to leave her DT&H program to return home to her residence and rest in the afternoon. Ruth has been having an increased number and severity of seizures and a full day's activity makes her very tired. The DT&H was willing to arrange transportation for Ruth to go home early. A major hurdle was staffing at the residence, but eventually the residence and the team agreed that she could be there with the cook and the program manager during the afternoon until the other staff came in. Ruth seems to enjoy this opportunity to rest in the afternoon.

Although these were significant changes, Ruth's conservator and DT&H staff hoped for another major change in the project, which did not happen. They feel that Ruth's residence, a 15-person ICF/MR with a two to 15 staff ratio is not able to meet her needs, particularly as she gets older. They feel that Ruth does not receive enough staff time to meet her needs adequately and that the chaotic environment, with residents who are aggressive and disruptive, is disturbing for her. They hoped that a smaller home would be an outcome of the project. It hasn't happened, however, because the provider is not interested in downsizing and the county, according to the conservator, has not given it a big enough push. Another factor is that Ruth is a quiet, good-natured person who does not complain. After the first draft of this report was written, we learned that Ruth's ICF/MR has received a one-time rate adjustment and is now able to provide a more adequate staff ratio.

Ruth's conservator does not feel that Ruth has more control over her life than she did before the project. She qualifies this, however, by saying that she will do whatever people want her to do. The conservator feels that she has had a little more control in that she has finally been able to arrange for Ruth to spend her afternoons at home rather than at the DT&H program.

Dick. Dick is a 50-year-old man who has lived with two other men in a licensed foster home for the past nine years. Although neither Dick nor his direct

support staff were aware of the project when we talked to them, his case manager attributes significant change to his participation. Dick's project involvement started with a person-centered planning meeting and he repeated his long-term dream to work at Pizza Hut. This time he was listened to and his support providers stretched beyond their usual modes of service delivery to make it happen. Because of this job, Dick has more involvement in the community, more money to spend on the things he wants, and has shown more responsibility. He recently bought a video game, which he shares with a housemate, and his sisters bought him a larger TV to make it even more fun.

His case manager said, "His demeanor has changed. He has more confidence in his abilities, and more faith that he will be listened to by staff and team members. He has accepted his responsibility to follow work rules to keep his job and he is an enthusiastic worker. Dick used to try hard to please everyone.. .He is much more assertive now."

**People who did not take control of their budget, but for whom changes happened because the project caused attitudes to change:**

Andrea. Andrea is a 30 year-old woman who lived in a large ICF/MR until two years ago. (The "downsizing" was in process before the project began.) Andrea now lives in a licensed foster home with three housemates, which her mother reports has been a very positive move for Andrea. Andrea does not use words to communicate and the idea of the project may be beyond her cognitive ability, but her mother enrolled in the project because she was not satisfied with Andrea's DT&H program. She wanted Andrea's support to be more individualized to her needs and interests. One change was made immediately after Andrea started in the project. Andrea is not a morning person and her 7:00 AM pick-up times were very unpleasant for her. Now she is able to start her workday at 10:00. The DT&H program agreed to pick her up later, and the residence already had staff on duty in the morning. Although her mom was surprised about how easy it was to make these arrangements,

she said it may not have happened without the project. With the project, she said, "We just knew we could ask. Before, we may not have known that."

Andrea's mother feels that Andrea is more in control of her life than she was previously. Now her team is paying more attention to what she wants. She is getting up and going to work later which has made a big difference in her life.

Dave and Kathy. Dave and Kathy are siblings in their early 50's who did not see each other for many years. After a family friend became Kathy's guardian, they were reunited and seemed to enjoy being together. The primary reason for enrolling them in the project was to mobilize their planning teams to make it possible for them to live together. Dave's case manager was able to obtain a waiver allocation for him and the two are now living together in a four-person home. Although this has been positive for both of them, their current housemates tend to dominate staff time, and there are plans being developed for a new home for just the two of them.

When the new foster home was being developed, Kathy's guardian was able to be involved in the selection of the home, the other people who would live there, and which staff would handle Kathy's money. In addition, when the guardian objected to a staff person working there whom she already knew, that staff was transferred to a different site. Although nothing happened for Dave and Kathy that couldn't have happened without the project, their case manager attributes many small changes to the "new mentality."

Because of the project focus, Dave and Kathy were given more choice over the selection of their service providers including doctors, dentist, and hairdresser. Kathy's guardian said they now have a normal life and are sometimes overwhelmed with the many choices they have about what to eat, what to wear, etc. Their case manager, on the other hand, did not feel they necessarily had more control over their lives because of the project, but she did feel that their quality of life was better because they now were living together. Dave currently remains on state guardianship. This is unfortunate since assisting people to move off public guardianship was an intent of the project, and since private persons serving in the role of guardian or

conservator are seen as able to provide more personalized support and assistance to the person. A positive development during the course of the project is that Kathy's guardian has expressed an interest to become Dave's guardian as well.

Wayne. Wayne had a major change take place at the beginning of the project that changed the way his existing services were provided. His friend and former direct care staff was asked to become his private conservator. She was happy to do this because she had been frustrated with being ignored when trying to give input regarding improvements in his services. Since then, she says she's "been signing him up for everything I could," and "now when I say something, they listen." The first need she identified was that, although Wayne was deaf, nothing was being done to help him learn to communicate directly. Now, his direct support staff have been trained to sign, and he is able to sign "yes" as well as the names of some of his staff.

Wayne had a severe case of scoliosis, and although his primary physician said surgery was not necessary, his conservator persisted and took him to an orthopedist. The orthopedist said that without surgery, Wayne would soon not have been able to walk. Wayne has had the surgery and is recovering well. Another medical victory the conservator had was to convince his dentist to try not sedating him before his medical appointment. Afterward, the dentist admitted she could not tell the difference in his reaction to the dental work.

An early goal was for Wayne to have more community involvement. To facilitate that, Wayne now wears clothes that are more stylish, and he has regular haircuts. His "runny nose" problem has been addressed, and he is being taught more manners. He has taken a trip to Disneyworld and has attended church. There are plans for increasing community involvement when he recovers from his surgery.

Although many good things have happened, Wayne still has important unmet needs. He is 38 and physically healthy, but he still lives in a six-person ICF/MR with people who are elderly and medically fragile. His community job was discontinued and now, according to his conservator, "he's just hanging around the workshop." She plans for both of these situations to change when Wayne recovers from his surgery.

**Wayne's future looks much more promising than his past. His conservator refers to the squeaky wheel metaphor and says, "I can be very squeaky!"**

People who joined **the** project to accomplish one **specific thing and then did** not go any **further**:

Bob. Bob had a community job through a DT&H program, but it was a long way from his home in a small town. Although he had requested work in his town, there was no evidence the DT & H provider had conducted a job search there. With the encouragement and support of the project coordinator and his foster provider, he quit his job and interviewed and hired a job coach. He soon found, however, that he did not need a job coach, and he is now working at competitive employment within walking distance from his home.

Troy. Troy's mother has taken him out of the Self Determination Project after two years. In spite of a lot of hard work on her part, she does not believe the project has made a difference in Troy's services. Troy is a 25-year-old man who uses a wheel chair and does not use words to communicate. His mother's primary reason for enrolling him in the project was to find an alternative to the sheltered workshop where he spent his days. Because of his physical support needs, he spends his time in a section of the workshop with people who have high needs due to challenging behaviors. Although the provider has been supportive in providing staff and transportation, most of the work of developing community alternatives has been left to the mother. Several alternatives have been developed, but most ultimately did not work out. The mother feels particularly frustrated because there is only one DT&H provider in town. She does not feel she wants to take the money and develop an individualized program for Troy, but she does feel she should have some choice in providers.

Troy's mother did not feel the project gave them any more control over services. She had found, in spite of much hard work to change things, that she could not appreciably change the way his services were provided. She felt the primary thing that was missing was choice of provider in this area with only one DT&H provider.

Michelle. Michelle is a woman in her twenties who lives with three other women with similar disabilities in a foster home. Michelle is her own guardian. She

said she joined the project because she thought it would give her more freedom at the foster home where she lives. In fact, although she is not dissatisfied, she now feels she has less control in several areas of her life. For Michelle, the self-determination project has heightened her awareness of her responsibilities for making desired changes in her life, and of the rules she needs to follow to obtain the life she wants. Michelle feels she has learned to accept the rules at her foster home because she now sees how they are teaching her to take more responsibility for herself as well as other things that will prepare for her independence. She still hopes to move out on her own some day, but for now is content with the foster home.

Both Michelle and her mother felt that the project had been important in teaching Michelle about her options and the responsibilities associated with each. Although none of the goals identified in her person-centered plan had been realized, she felt that she had more choices about her life and felt more respected by staff. Michelle expressed satisfaction with the limitations in her life because she felt she was learning the skills and responsibilities that would enable her to attain greater independence.

### **Emerging Issues and Recommendations**

- *Small changes that are very important to a person's quality of life can be easily made with an openness to listen.*

Dorothy is easing into retirement and Tim likes to get away from the busy, noisy environment at the DT&H and spend time with his long-time PCA. Because their support teams have begun to really listen and see the possibilities, they have both reduced the number of days they spend at their DT&H programs. Instead, they use the money for community activities that they enjoy. Dorothy, who goes about her activities independently, has money left over for vacations and household adaptive equipment.

Andrea, who is not a morning person, found her 7:00 AM pick-up very unpleasant. Now she is getting up and going to work three hours later, which makes

her whole day go better. Ruth is able to get away from her disruptive housemates now that she has a TV in her room. Dick always wanted to work at Pizza Hut, but nobody really paid attention since it was not a site that the DT&H program worked with. With the Self-Determination Project and an increased interest in listening to people and making things happen, Andrea, Ruth, and Dick have had their most immediate desires met.

- *Self-determination increases not only with consumer control of the money, but by attitude changes by existing providers.*

The changes that the people described in this chapter made, whether or not they involved control of the money, often involved some accommodation on the part of existing service providers. Several DT&H providers arranged to pick someone up later or take someone home earlier. Residential programs in two situations shifted staff schedules to accommodate resident's desires. Both types of providers stretched beyond their usual modes of service delivery to make things happen for people. Several of the parents and guardians attributed this willingness to the "new mentality" or the general awareness of individualized services that has come about because of project activities.

- *Consumers and families generally felt supported by their counties to make innovative changes, but sometimes wanted more support to make services from existing providers more individualized and responsive.*

Most people who tried innovative approaches to support delivery were very satisfied with the support that they had received from the county. Other people, who wanted to use existing providers but have supports delivered in a more individualized and responsive manner, were not as satisfied. Some people were frustrated with the lack of alternatives to ICFs/MR or with the county's inability to force an ICF/MR to be downsized. One mother was frustrated with the lack of DT&H choice in her town. Several people felt that the counties should push providers to change their attitudes, and some felt the counties still needed to take responsibility for satisfactory services.

Jean's sister, for example, feels greater changes will happen when the county takes more responsibility for orienting providers to the need to listen to consumers and their families. As a steering committee member for the self-determination project in her county, she reports a struggle with the county management staff over this. The county is saying that families need to deal with the providers directly if they are not satisfied, but she feels the control still lies with the county because there are not really satisfactory and available alternatives to current providers.

- *Most family members and conservators felt more empowered to ensure quality support for their loved one. Those who were also caretakers felt more in control of their lives.*

Many of the parents who were able to control the supports that were delivered in their home found words inadequate to describe the increase in control they felt. Abbey and Sarah's mother says they feel "way more" in control over their lives—"there's no describing it." Billy's mother said the project has enabled them to have "way, way, way more control." Angela's family says that now they can feel secure with the staff Angela goes out with because they can control that, and they only use staff they know and trust. Tim, Tom and Angela's families appreciate that they now have more flexibility in when they have staff and how they are used.

Family members who support the consumer in another home also felt empowered. John's mother and Karen's mother felt that just controlling the money was empowering. Karen's mother feels that the work support provider has responded to her control with more responsive services. Linda's conservator appreciates that he can go directly to the provider to arrange services rather than work through the case manager. Scott's sister, along with Scott, was able to develop a new home for him. Wayne's new conservator said, "Now they (the team) listen to me."

There were exceptions, however. Tom's family is still frustrated by the lack of control they have over the PCA funding. Jennifer's mother thinks that the help that she receives now is somewhat more relevant to her needs, but she is not sure it has been worth the hassle. Troy's mother did not feel the project gave them any more

control over services. She had found, in spite of much hard work to change things, that she could not appreciably change the way his services were provided.

Jean's sister does not feel that paying providers has given her more influence. She states that only managers, not the direct support staff, are aware that she writes the check. She scoffs at the county's suggestion that their ultimate power is to "fire" the provider. The family does not feel able to take over Jean's care on a full-time basis. Even if they did, she states that one needs to remember that if you take someone out of the system and you need to get them back in, you would have to wait until there was an appropriate opening.

- *Most consumers did not have direct control over their supports or the changes that were made in their lives, but members of their support network claim the changes were made based on what they appear to want.*

Sometimes consumers were not given direct control because they didn't seem to have the "cognitive ability to understand self-determination" and sometimes because although a consumer had good communication skills, the family felt that they knew what she had enjoyed in the past and made decisions accordingly. For example, Tracey's mother says that Tracey resists new ideas so they plan things that they think Tracey would enjoy.

However, everyone felt that the changes that were made reflected what the consumer wanted. Linda's guardian feels Linda's quality of life is better because she has more freedom and less of the things that formerly distressed her. Andrea's mother feels that now Andrea's team is paying more attention to what she wants. Because of the project focus, Dave and Kathy are given more choice about what to eat, what to wear, and over the selection of their service providers including doctors, dentist, and hairdresser.

Scott and Dorothy, on the other hand, had a great deal of direct control over the changes that were made. Scott was very involved in the development of his new home and staff arrangement. He made a presentation at his "Bidders' Conference" using an overhead projector explaining what he needed and wanted from a support

provider. He chose the provider and had final say over the house and the roommate selection. Scott and his sister interviewed staff and made the final selection, and he and his housemate selected their own furniture.

Dorothy made the decision to reduce her attendance at her DT&H program to four days a week, even though her support team members encouraged her to cut her work schedule back more. She chooses, with the support of her case manager, how to spend the savings realized by attending only four days a week, and she writes the checks with the support of her direct support staff. Dorothy says that she is satisfied with the amount of control she has over her life.

- *There are often far reaching effects when consumers have control*

Dick's case manager said, "His demeanor has changed. He has more confidence in his abilities, and more faith that he will be listened to by staff and team members. He has accepted his responsibility to follow work rules to keep his job and he is an enthusiastic worker. Dick used to try hard to please everyone.. He is much more assertive now."

Scott's sister says that Scott is happier, more self-confident, and more outgoing now. He takes a lot of pride in his home, and he advocates better for himself. Not only does he have control over his residential environment, but he has a lot more control over his daily life as well. He has a lot more freedom to be independent and to have guests in, and he is more challenged to assume more responsibility.

- *Some of the major changes that were made by participants in the project came about as a result of the flexibility provided by amendments to the MR/RC waiver that allowed increased self-determination and control of resources.*

Abbey and Dave got Medicaid waiver allocations about the same time they enrolled in the project. The money that Abbey and Sarah's family received for their support that they were able to control effectively increased from \$6,000 to \$40,000. Billy had been receiving waived services for a year and a half prior to participation

in self determination. For his family, participation in the project allowed them to use his waiver allocation in much more creative ways than was possible before. Dave was able to leave his ICF/MR to live with his sister because of the waiver allocation that he received.

*\* Some people remained in residential or DT&H programs that were unable or unwilling to provide the types of services they desired.*

Wayne, who is 38 and physically healthy, still lives in a six-person ICF/MR with people who are elderly and medically fragile. His community job was discontinued and now, according to his conservator, "he's just hanging around the workshop."

Troy, who uses a wheelchair, still spends his day in a portion of the workshop with people with challenging behaviors, and his mother questions his safety there. She worked very hard to find a community job for him, but finally gave up. She is not happy with the DT&H provider, but it is the only one in town.

## Appendix C

### Minnesota Self-Determination Project Evaluation

#### Consumer Education Product Evaluations

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**Video: Person-Centered Thinking: Supporting Self-Determination**

The Minnesota Self-Determination Project produced a video that introduced the concept of self-determination as it relates to service delivery to persons with developmental disabilities. The video included short vignettes featuring consumers and families who had been involved in the project as well as some persons who were involved in other person-centered initiatives. In these vignettes, consumers and families described ways their lives and their services had changed through the project. In particular, the video demonstrates: a) the use of individual budgets to design and purchase services, b) the use of person-centered approaches to service planning, c) some ways consumers have used the project as a way to access generic community resources services, and d) the participation of persons with developmental disabilities in a self-advocacy organization. The video depicts the impacts of these activities both by showing scenes of consumers and families actively engaged in a variety of activities and through interviews with consumers and family members who talked about their experiences with the project.

The video was evaluated by two review panels consisting of self-advocates, one parent, and one direct support staff. The evaluation instrument for programs, which was described earlier, was used as a guide.

Respectful. Those reviewing the video thought it did a good job of demonstrating the strengths and potential of the people who were featured. One reviewer particularly liked the way in which the scenes of the self-advocacy group activities showed a sense of teamwork and discussion of significant issues. During discussions, one reviewer commented that "the video really showed what families and consumers could do if given the chance." The video also did an effective job in including both men and women, and one of the persons included was a member of a minority cultural group.

Some reviewers were concerned that the video came off as a marketing piece for self-determination initiatives instead of a training video demonstrating both the benefits and risks to consumers and families in taking greater control in arranging

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their own supports. One reviewer commented the video "made it look easy." He wished the video would have included more information about the challenges individuals and families faced as they began to take greater control of their resources, and especially the ways people addressed particular problems as they emerged. A parent of an adult with significant disabilities stated "You can talk about person-centered all you want, but you have to face reality." She made this statement as she talked about her struggles in attempting to push traditional service providers to change with the project and the failure of the video to capture such struggles.

Some reviewers thought the video had an over-representation of persons whose disabilities seem to be mild. They thought that the video should have included ideas about how self-determination approaches might look for persons whose disabilities are more severe. The parent of a person with more significant disabilities shared the concern that watching the video may leave some viewers with the idea that self-determination is most applicable to persons with mild disabilities. A person with mild disabilities made the comment that for persons with more severe disabilities a small increase in control may be "quite amazing," and may make a very real difference in the persons life.

One group of self-advocates who reviewed the video was very concerned that it did not depict persons with disabilities as "equal people" in the self-determination process. By this they meant that the video placed great emphasis on the increased sense of control gained by parents as part of the project rather than on persons with disabilities being the ones experiencing a greater sense of control. A suggestion was to create two separate sections in the video. One section could clearly demonstrate what it meant for families to gain greater control in arranging services and supports. The other could focus on persons with disabilities taking an increased role in selecting and arranging supports and services for themselves according to their plans and goals.

One person with disabilities thought including the choice one person made to sing Karoke in a bar as part of the video was ill-advised since such a choice may

seem offensive to some. Most others however were happy with this scene since it showed a person with disabilities making a choice common among persons his age.

Understandable. Although the video made most of its points in a somewhat indirect manner, such as using personal stories to illustrate components of service delivery that facilitated self-determination, most people thought the video used words and concepts that worked very well. One suggestion to make the video more understandable was to give a clearer definition of what self-determination means in the beginning. Reviewers also suggested adding a narrator to discuss important ideas at the beginning and end of the video. Another suggestion was to make sure that any words appearing on the screen are also read by a narrator so non-readers do not miss any content.

Useful. Most reviewers of the video commented that it did a very good job in showing methods in which persons with disabilities could experience increased self-determination. Several people commented positively on the display of teamwork and collaboration, which is an important factor in encouraging and facilitating self-determination. Nearly all persons with disabilities were impressed with the portion of the video that demonstrated self-advocacy, particularly the ways in which a self-advocacy group talked and worked together. They especially liked this part of the video because it showed persons with disabilities in a very positive light. Some noted the group in the video was talking about issues that are important to many self-advocates such as finding a good job or getting married. One reviewer commented "the people in the video said what we all are saying, "We want a good job" or "We want to be able to get married." People also especially liked the part of the video that demonstrated a person-centered planning meeting and showed a person with disabilities taking a great deal of control over her planning meeting.

Most reviewers thought the video should contain some practical information for viewers about how self-determination approaches actually work and how they could experience the attractive outcomes shown in the video. One reviewer suggested having a county case manager briefly explain how people could receive their service

dollars in an individual budget, how they could arrange a person-centered planning meeting, or how to locate a self-advocacy group in their area. Another suggestion was to add some discussion points at which the video could be stopped and some questions that people could discuss. This would help them to integrate what they were seeing and share ideas with each other on how to use the information. A similar idea might be to create a discussion guide to accompany the video.

### Fact sheets on Self-Determination topics

One county involved in Minnesota's Self Determination Project created a set of five one-page fact sheets on topics related to using the service system in Minnesota for persons with developmental disabilities. The five topics are "Your Case Manager," "Your Team," "Person-Centered Planning," "Money and Budgets," and "Be Informed." The sheets describe to the reader how each service or support is intended to work and the choices people have in using it. Some sheets also include technical information that may be difficult for some people to understand. Each sheet encourages people with disabilities and family members to take greater control of their services.

These documents use an attractive font, large print, and generous line spacing. The fact sheets are completely text based with no drawings or pictures and few graphics. Each sheet was printed on bright colored paper, with each sheet a different color, making them quite attractive.

Respectful. Since the information was quite general, the evaluators had no concerns regarding respect for different groups, such as men and women or members of minority cultural groups. Some who read the fact sheets commented that they seemed to be "selling ideas," or suggesting ideas about what consumers should want to do, rather than presenting options and choices at face value.

Understandable. Nearly all reviewers thought the worksheets were clear and easy to understand. People had few or no complaints about seeing words that were difficult to understand or ideas that were unclear or overly complicated. Many reviewers liked the idea of separate, one-page fact sheets that broke down information into easy to manage pieces.

Useful. The opinions of reviewers varied in terms of the utility of the information presented in the worksheets. Most reviewers thought they provided information that was practical such as suggestions regarding who consumers and family members could invite to be a part of their team. Nearly all reviewers rated the fact sheets favorably in terms of informing persons of the choices and support options

they had and in encouraging persons with disabilities and family members to take greater control of their services. One reviewer made the comment that the fact sheets described things that "I can go out and try."

Another reviewer pointed out that the information was not consistent with her experience. She didn't feel that she had the choices that were described, for example she said, "I can't have anybody I want on my team." She felt the description of the role of the case manager may set up unrealistic expectations based on current caseload sizes. While these were seen as negative points in the eyes of this self-advocate, they actually may be strengths in raising consumer expectations for support that encourages self-determination. It may be advisable, however, to acknowledge it when suggested options may be inconsistent with past practices.

Other suggestions to improve the worksheets were to include information about both the pros and cons rather than emphasizing only the positive parts of the options explained. Reviewers felt this would make the fact sheets seem more like training materials on making informed choices rather than sheets that unintentionally advocate for particular options. The comment was also made that the fact sheets may assume well-developed self-advocacy skills on the part of the reader in order for the suggestions to be implemented. For some fact sheets, such as those titled "Your Team" and "Person-Centered Planning," it may be worthwhile to highlight who can provide more information or support in making the suggested changes. The information contained in these worksheets would be equally useful in other counties across the state. If adapted for individual counties, specific resource information could be included.

One reviewer suggested an additional Fact Sheet be prepared about the use of professional advocates. This should include information about when accessing this service may be advisable and the possible roles an advocate may take.

## **It's My Life! A Handbook for People with Developmental Disabilities and Their Families**

This handbook is a three part, 14-page booklet whose target audience is people with disabilities and their families. The booklet is divided into three sections: "Part 1: What do I want? What do I need?" "Part 2: Learning about services I need," and "Part 3: Finding the supports I need."

The first section is made up almost entirely of clip art images of options people have or can develop in several areas of life, such as places to live, jobs, transportation, and leisure time. These images are presented as the same lifestyle options of all people, such as "Should I live in a house, or an apartment?" The images are large and represent several options in each area.

The second and third sections continue to use clip art images but also contain much more text. Some of the words and ideas in these sections may be complex for some users. Section two of the guide reviews services available to persons with developmental disabilities and their families that are mostly system-based. They include service coordinator roles and program models such as Adult Foster Care, Intermediate Care Facilities, etc. In addition, financial programs such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medical Assistance are described.

The third section of the guide is only one page long and directs people to think about the preferences they identified in section one and the resources described in section two to obtain the supports they need. This final section reviews the options of buying supports through a provider agency or hiring support people directly.

The handbook was evaluated by one review panel consisting entirely of self-advocates. They used the evaluation instrument for reading material, which is described earlier. In addition, this report includes suggestions from the evaluation team.

Respectful. This booklet makes extensive use of clip art, and most people felt it showed men and women in respectful ways. There were generally equal numbers of males and females shown. Although no reviewers mentioned it and it is a minor criticism, most of the clip art images perpetuate gender stereotypes. In the booklet, male figures are generally shown doing work traditionally associated with males (construction, janitorial) and female figures are shown in roles traditionally associated with women (waitress, cook, nurse, and support provider).

Some reviewers were concerned about the degree to which the guide was respectful of persons of all races and cultural groups. Although much clip art appears to be culturally neutral, the images in this booklet look consistently European-American. Additional attention should be given in future products to clearly represent persons of other cultures and races.

It was impressive that in the section on employment choices the option of choosing to retire was included. This option is often forgotten for persons with developmental disabilities who receive services. In addition, it would be good to demonstrate the choice between working for pay and working as a volunteer.

Understandable. Most reviewers observed that the guide had a clear introductory/cover page that informed people of its purpose. They also noted that the final section tied all the ideas together. These factors enhanced understanding of the purpose and facilitated use of the document.

The booklet also did a great job of using clip art to show ideas and options and to encourage people to think about other ideas. The use of many pictures and images makes the booklet useful for a person with limited or no reading skills if given some assistance by another person. The reviewers suggested adding color to make the guide more attractive and using larger type in sections two and three to make the information easier to read.

If the booklet is for use by persons with developmental disabilities, even with support from another person, it is important to simplify the language and the ideas presented in sections two and three. This may mean organizing the types of supports

described into clear categories such as "Income Supports," "Living Supports," and "Work Supports." In addition, section two should probably have more options for vocational support such as enclaves, supported employment, working as a volunteer, etc. Another idea would be to include a greater number of generic community support along with more traditional support options.

The final section of the booklet is very brief, yet introduces a very complex area. This page introduces users to the choice between working with a provider agency or hiring their own support persons using an individual budget. However, it offers no clear definition of what these options really mean and suggests no considerations in making this choice. It would be helpful to describe the differences between using a provider agency and independently hiring support people much more clearly and succinctly according to a set of criteria. It also may be helpful to present this information using a comparison grid, and including a worksheet or set of questions for users of the booklet to evaluate which option best matches their situation.

This section suggests several ideas for people to investigate in deciding whether to hire their own support or to work through a provider agency. It would be clearer to arrange these ideas under the relevant support options and add a sentence explaining why the idea is relevant.

The second and third sections of the booklet should have a layout similar to that of the first section. The first section includes many graphics and seems to be largely targeted for use by persons who have cognitive disabilities with help from a support person. However, the second and third sections seem much more complex and targeted mostly to support people.

Useful. In the second section, the booklet gave some helpful descriptive information about different types of support options. For example, all descriptions of programs offering residential services give some idea of the physical size of a typical living arrangement and the amount of support provided. A strength of the guide is that the information is not used to depict one option as being more or less desirable

than another, but simply shows how supports are different and lets users make their own judgements.

A way to improve section two may be to describe each option in terms of 3-4 consistent criteria chosen for that type of support and include a comparison chart for each. For example, every residential program might be described in terms of the amount of support and assistance available, the typical number of people who live together, the degree of structure and rules, and the costs, or how the support is paid for. Combining this with a simple worksheet to guide consumers and families in making decisions about what is most important to them in selecting supports would make section two simpler and easier to use.

While the booklet introduces many options, it lacks the format consumers and families need to evaluate ideas and to begin acting on them. Section 1 provides places where people can write notes, but the other sections do not. It may be useful to include additional note sections for users to record personal thoughts or choices for each section.

Several consumers noted that the booklet would be more useful if it contained more information about where people could get more information about the options described. It may also be helpful to give readers some information at the end of section 1 about arranging for a person-centered planning process if they are interested in assistance to generate additional ideas or to develop a group of supporters to assist them in attaining the lifestyle they desire.

### **Person-Centered Thinking: Supporting Cultural Competence**

Staff from the Minnesota Self-Determination Project developed a three-page worksheet to be used as a cultural competence guide. The worksheet begins with an introduction that states that its purpose is to "increase sensitivity to the unique contribution that all people can make if given the chance to appreciate the diversity that is all around us." It then states that this is "a tool that can be used to start a conversation to learn more about what is and isn't important" to the other person. The introduction stresses the need to build trust by asking questions respectfully and honoring the responses provided by the interviewee, and an example is used to illustrate this point. Except for this example, which is labeled as coming from Japanese culture, the worksheet does not mention any particular cultural groups, and the term culture does not appear in any of the questions.

Following the introduction are five sets of questions. There are no labels provided for the individual sets of questions, but they appear to deal with 1) the person's sense of feeling understood in terms of language and background, 2) the types of cultural events that are important to the person, 3) the customs and traditions followed, 4) the rituals and habits followed, and 5) the roles of people to whom the individual listens and from whom he seeks advice. Some of the questions can be answered with a yes/no response, but most questions are "open ended" and ask people to respond in their own words.

This product was evaluated by three Institute on Community Integration staff who have substantial expertise in cultural issues. It should be noted that this product was still in a draft form at the time it was evaluated, and many of the problems noted by the evaluators might have been attended to in further revisions.

Respectful. Both the introduction and the questions are unassuming and seem respectful of all groups including both men and women, persons of any race or culture (including European-American culture), and persons of all ages. Without directly mentioning culture, which may seem patronizing, the questions ask about everyday aspects of a person's life that are likely to generate information about a

person's cultural preferences. Many of the questions seemed based on the ideals of person-centered planning which is a process based on respecting each person's unique dreams and gifts. (The evaluators noted that the questions in the worksheet seem to be based on the "Essential Lifestyles Planning Process" developed by Michael Smull, and this should probably be credited.)

Understandable. A strength of the worksheet is that it presents a set of very simple, non-intrusive questions for use in considering cultural preferences. The section headings include examples or definitions to give context to the questions. In most cases, this is helpful; however, the questions on customs and rituals are abstract and open-ended and may be difficult to answer. These questions should be re-worked to become as concrete and direct as most of the others.

Although there were some weaknesses in the format of the worksheet, criticisms are probably premature since the document that was reviewed was a very early draft. The final worksheet should use a larger, more attractive font, increased space between lines, and some graphics. Responses should be facilitated by providing a clear expectation about how to record yes/no choices and sufficient space to write responses to the open-ended questions.

Useful. It is not apparent who the prospective users of this worksheet are or how it is to be used. The target audience is unclear both in terms of who will use the worksheet to interview people and who will be interviewed. It is apparently directed toward a broad range of users both inside and outside of the human service system. (The introduction suggests using it with "people in your life who are important to you.") However, a more specific designation of who, within the human services system, will use this worksheet would allow for clear instructions and enhance its usefulness.

Neither is the targeted use specified. The worksheet asks about many lifestyle preferences that represent ways in which an individual or family expresses their culture (e.g., language, celebrations, rituals, etc.). However, the worksheet does not

tie this information to use in arranging supports or encouraging the person's or family's self-determination.

When the prospective use and users are specified, it will be possible to write clear directions about how to use the worksheet. An inconsistency in the current version will need to be corrected. In the introduction, the worksheet suggests the questions be used to get better acquainted with a person important to them; but the worksheet ends with the statement "Thank you for taking the time to complete this."

The worksheet may be more clear if it was constructed as a self-assessment instrument for people to consider their own cultural beliefs and how they want to express those beliefs in their daily lives. This self-assessment could be completed by individuals and families—independently or with help from a support person. This information could then be used to plan how supports should be provided. The self-assessment could also be completed by support coordinators or service providers in order to facilitate understanding of their own cultural beliefs and preferences and how they may differ from those of another person.

The usefulness of this worksheet would be enhanced by defining "self-determination" and "culture," and providing a short description of why understanding these concepts is important to feeling self-determined and supporting another person's self-determination. It may also be helpful to attach a list of resources for users to learn more about different cultures and cultural groups.

## **Metro Provider Guide**

The Metro Provider Guide is a guide to service options and service providers in the seven-county metro area surrounding Minneapolis and St. Paul, Minnesota. At the time of the evaluation the main body of this guide, which gives readers a description of the general nature of different types of supports according to traditional service categories (ICF-MR, Waiver, SILS, Day Habilitation Services, etc.), had been completed and was reviewed. In its final form, the Metro Provider Guide will also include a "yellow pages" section listing service providers from throughout the seven county metro area. Service providers will be listed both by the exact type of service(s) they provides and the geographic area they serve. Unfortunately, these yellow pages had not yet been completed at the time of the evaluation, so only the main portion of the guide was evaluated.

The Metro Provider Guide appears to be directed to a large audience including both persons with mild disabilities and members of their families who may assist them in making decisions about the types of services they desire. The guide uses large print with ample spacing between lines, as well as drawings to illustrate particular areas and ideas being explained in each section.

This product was evaluated by two review panels consisting primarily of people with developmental disabilities along with one parent and one direct service staff. The previously described evaluation instrument for reading material was used to guide the discussion.

Respectful. All reviewers thought the metro provider guide was respectful of any audience who might use it. The booklet uses black and white drawings of people with a roughly equal mix of men and women. Reviewers felt these figures could be thought of as belonging to any culture, although some people thought the guide would be improved if some of the figures more clearly represented persons from minority cultures. While the booklet discussed the support needs of persons with a wide range of abilities and disabilities, one reviewer made the comment that she wished the

figures representing persons with physical disabilities demonstrated more active vs. sedentary activities.

Understandable. Reviewers with developmental disabilities who had good reading skills found the metro provider guide to be generally easy to understand. Several people especially appreciated the large type and generous spacing between lines, and most people thought the drawings included in the booklet were very effective in supporting the ideas being described in the text.

While acknowledging that the version of the booklet being evaluated was considered a draft, reviewers made several comments regarding ways to make the booklet easier to read and understand. Many of these comments point to things that probably will be rectified as the guide moves from a draft to a final stage. These include adding a more attractive and eye catching cover page and adding page numbers and a table of content to assist readers in finding the information of interest to them. Several reviewers saw it as important that the final printing of the Metro Provider Guide include some color, and further, that color be used to highlight and organize particular information. For example, one reviewer suggested that all telephone numbers throughout the guide be printed in a consistent color and manner that would be reserved for telephone numbers.

Additionally, the Metro Provider Guide may be easier to understand if it was written exclusively for persons with disabilities rather than having some sections written for persons with disabilities and other parts referring to the reader as someone who will be arranging supports for another person. Reviewers felt including a glossary at the end of the guide was a good idea, but an even better idea would be to include definitions of confusing terms on the same page where the term was being used. This would eliminate the need for people to flip back and forth between the text and the glossary. Reviewers also suggested an audiotape be developed to accompany the final guide, which would make the booklet much easier to read and follow for many people.

Useful. Nearly all reviewers found the Metro Providers Guide to be useful. Many of the reviewers were experienced self-advocates who probably have a greater degree of knowledge about service options than many persons with developmental disabilities. Nevertheless, they reported that the provider guide contained information and ideas that were new to them. Several reviewers especially liked the sample questions that consumers and family members could ask when checking into a service option or with a service provider to determine whether it is right for them. Reviewers also liked the fact that the guide included telephone numbers they could call for further information about obtaining services and information about using the services of an advocate.

Suggestions for improvement included expanding the section that gives people information about agencies that provide advocacy services. Reviewers thought it would be helpful to include some information about when to consult an advocate and what kinds of assistance and support they might expect. In addition, reviewers saw it as important to distinguish "self-advocacy" and explain the differences between agencies or programs that support consumer and family members to advocate for themselves and those that primarily provide more traditional advocacy services.

There were several comments regarding ways in which the guide could become more effective in supporting consumers and families in making choices between different service types. For example, many people noted that the Metro Provider Guide was often more explicit about the benefits and positive parts of various services than about the limits or possible risks. It may be helpful to include a summary for each service type that illustrates very clearly the strong points and cautions associated with that particular service. One review panel suggested that the Provider Guide include information on the responsibilities of consumers and families that are associated with each type of service. This may mean explaining the tasks individuals and families would be expected to take on as part of using a particular type of support or things that a particular type of support wouldn't do for a consumer.

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Information that very clearly showed the pros and cons associated with each type of service, coupled with some basic information or models for making decisions regarding desired supports, may go far in empowering consumers.

It is unfortunate that the Provider Guide does not explain to consumers and families the option of arranging their own services using an individual budget. While it would not be desirable to compromise the simple and straightforward approach of the Metro Provider Guide by trying to include all the possibilities and considerations that are part of deciding to use an individual budget, the omission of this option places limits on consumers' expectations.

## **Housing Guide**

The Minnesota Self-Determination Project created a 16-page guide to housing options for persons with developmental disabilities. The guide presents information about several options including purchasing a home, renting a home, or renting an apartment using publicly subsidized or market-rate options. The guide also includes considerations when deciding whether to have a roommate and who that roommate should be.

The Housing Guide that was evaluated was a draft copy and did not include several appendices that were still to be developed. These appendices will include a resource list, an income worksheet, a chart to use in comparing renting a home with home ownership, information on the adult foster care and group residential housing options, and a house hunter's checklist. The guide was evaluated by two review panels consisting entirely of self-advocates.

Respectful. The reviewers felt the Housing Guide did a good job of being respectful and demonstrating that the housing options being presented belonged to all people including men and women, persons of all races and cultures, and persons of all abilities. The Housing Guide uses black and white clip art images to show people and these are generally neutral in terms of depicting culture. One reviewer suggested finding ways to show people with different types of disabilities instead of always showing a person in a wheelchair to symbolize people with disabilities.

Understandable. All reviewers found the Housing Guide generally easy to read, and many commented that its layout was very attractive. Reviewers thought the type used in the guide was large enough and the spacing between lines was adequate. The guide used page numbers that were "artsy" and the reviewers felt they added to the attractiveness of the guide. The page numbers, however, appear in different positions on each page, and some reviewers had difficulty in reading them and/or in recognizing them as page numbers. They suggested they would be easier to use if they appeared in the same position on each page.

Most, but not all, of the reviewers thought the words and ideas used in the guide were easy to understand. A couple people thought some words were difficult to understand and some sentences were hard to follow.

Reviewers recommended that this guide should be used by most persons with disabilities in cooperation with a misted friend. This recommendation came not so much because the Housing Guide is hard to understand, but because it talks about very important decisions that all people must consider very carefully.

Although it is probably planned, reviewers thought the addition of a cover page and a table of contents would make the Housing Guide more attractive and easy to use. Reviewers also felt that it would be beneficial if the final version of the guide could include some color, both to make it more attractive and to highlight important information such as telephone numbers. While reviewers thought the drawings included in the book were very effective in making the information easier to understand, there could be even more such drawings, or even photographs, to demonstrate options. People thought this would be helpful particularly in the section describing home ownership.

Useful. Nearly all reviewers commented that the Housing Guide included a significant amount of information that was new to them. Several noted that the information and the way it was presented caused them to think about different options they had. One reviewer commented particularly on the very practical ideas used on page six to help readers to think about whether they wanted to have a roommate; and, if so, what type of person they might seek. She thought these ideas may have helped her avoid some negative experiences she had with roommates in the past. Many reviewers especially liked the idea that the Housing Guide described both the positive and negative aspects of many housing options. One suggestion was to organize these into a grid illustrating pros and cons for people to use in comparing options. This seems to be already be planned as an appendix to the guide.

Additional information that reviewers suggested for inclusion were considerations in deciding whether to have a pet, information on assessing the

physical accessibility of housing, a directory of persons or agencies to contact for further information about particular options (including sources on the internet/World Wide Web), and the types of ongoing maintenance responsibilities that come with different housing options. One reviewer who received subsidized rent through Section 8 saw a need for extensive information about the guidelines and responsibilities associated with this option. While review panel members had many ideas for additions to the Housing Guide, these must be balanced with the need to keep the booklet small and easy to use. Perhaps many of the ideas illustrated above may make useful appendices to the Housing Guide or separate booklets that people could be referred to as each applied to their housing plans.

## **Finding the Support You Need**

"Finding The Support You Need" is a guide to arranging supports targeted mostly to family members and support persons, but it may also be useful to some people with developmental disabilities who are aware of the types of supports they need and desire. The manual was designed to be used in conjunction with a support person such as a case manager to facilitate understanding of the information. The first two sections of the book describe the options of purchasing/obtaining supports through an existing service provider agency and of hiring persons to provide support outside of an agency. The remaining six sections describe topics specific to individuals and families who decide to purchase support independent of a service provider agency. These topics include basic information about taxes, insurance, hiring a fiscal agent, hiring an employer-of-record, and about labor laws as they relate to hiring persons to provide in-home and community-based supports.

"Finding The Support You Need" deals extensively with the legal and technical aspects of being an employer, which persons need to be aware as they use individual budgets and hire support staff outside of traditional agencies. In describing this information, the book provides many examples that describe somewhat abstract concepts, such as whether to "bond" employees, and shows how they are relevant in hiring people to provide personal support. At the end of each section are sample forms that have been discussed such as tax forms, worksheets, and checklists to assist people in developing documents like job descriptions and employment contracts. These worksheets and forms generally follow the ideas and information reviewed in the text very closely.

Respectful "Finding The Support You Need" is free from bias towards any group of person based on gender, race, culture, level or type of disability, or any other personal characteristic. The book shows respect for persons with disabilities by addressing the person with disabilities as the reader rather than some other support person. This approach encourages those who are supporting, and perhaps making decisions on behalf of persons with significant cognitive disabilities to consider

decisions from the perspective of the person rather than their own. Such an approach is likely to lead to persons with disabilities having supports that are "person-centered." "Person-centered" supports and decisions are those based on the needs and preferences of the person with disabilities rather than those of others involved.

Understandable: While "Finding the Support You Need" was designed to be used by consumers and families in conjunction with a support person such as a case manager, it was the evaluators experience that many families were using the manual on their own. Therefore it seems pertinent to evaluate its understandability as a product that consumers and family may use with or without support. As stated above, "Finding the Support You Need" is almost entirely text with no graphics so it relies on the user having well developed reading skills. In addition, it describes some very complicated ideas and decisions. This means most persons with cognitive disabilities would probably need a great deal of assistance in reading the text and understanding all of the ideas being presented. At the same time, one review panel member who had a mild cognitive disability reviewed some sections of the book and found it to be of interest to her, and quite easy to read. She benefited from the large text and generous line spacing, and found most words were easy for her to understand. She noted the pages seemed very neat and organized, and appreciated the use of boxes to highlight important information such as agencies to contact, phone numbers, and summary points. This reviewer explained how the use of boxes and other strategies to organize and highlight text would make it easy for her to later refer back to important information. She also appreciated the worksheets that were included at the end of each section because they would help her and other readers to act on the information included in each section. For example, she especially liked worksheets following the section on "Hiring your own support" since they asked very clear questions that forced her to think about and identify those tasks she desired assistance with from others.

Andrea's mother told evaluators she had received a copy of "Finding the Support You Need" and has found it very useful as she attempts to develop a new

vocational program for her daughter. So far, she has directly used the sections on writing a job description and an ad to attract potential support people. Andrea's mother has also used the book in her job as a professional advocate at Arc. As did the review panel member, Andrea's mother thinks the book will be easy to understand for all families.

Although one review panel member with mild disabilities found some parts of the book useful and easy to understand, it is likely that much of the information will be difficult for many persons with cognitive disabilities to understand and relate to.

Based on comments of reviewers across all products, many decisions reviewed in this book are the types of decisions most persons with cognitive disabilities would want and need assistance with, or have someone else they trust make for them. Reviewers however did identify some sections as covering areas about which most persons with developmental disabilities would want and be able to participate in making decisions. For example, many persons with disabilities will probably be interested and able to assist in identifying the particular areas in which they want and need support. Many persons with disabilities are also likely to take great interest in identifying the most important characteristics they desire in a support provider, be it an agency or an individual. Information about making these types of decisions is placed very early in the book, which is a logical location for information most likely to be reviewed by persons with disabilities. A recommendation would be to especially concentrate on making the text easier to understand and modifying worksheets in these initial sections of the book to better accommodate persons with disabilities reviewing them together with a trusted friend or advocate. The placement of more complex information later in the book also is a logical idea since it is likely only to be needed by those users choosing to independently hire persons to provide supports. This group probably represents a small minority of all the people who will use the book, and are likely to be persons with strong reading and cognitive skills such as family members, guardians, or conservators to persons with developmental disabilities.

"Finding the Support You Need" provides users a great deal of information to assist them in making very significant decisions. While the volume of information may be considered a strength of the book, it also may cause "Finding the Support You Need" to be overwhelming for many persons who use it in planning and arranging supports. It is likely that some readers will have difficulty remembering and organizing all the information included as they begin considering how to design their supports. In the initial sections of the book, it may be useful to arrange the most important concepts about the differences between hiring support providers through an agency, or outside an agency into some type of a decision tree. The purpose of a decision tree would be to provide a way for consumers and their advocates to organize and perhaps record personal thoughts and ideas while considering the decisions they will make. A decision tree in this initial section could also be used to direct users to those sections of the book important to review based on the decisions they are considering. In some sections, a decision tree could also remind readers of factors they don't need to be concerned with, and point out those worksheets, forms, or possibly sections of the book they can skip over based on their plans for arranging supports. For example, if a person is considering choosing their own persons to provide support, but using an employer of record to handle most administrative tasks, they would be guided to all information on hiring and supervising people. At the same time, readers making such a decision could be reminded of areas they do not need to review such as the sections on insurance and taxes. This use of a decision tree once introduced could be carried throughout the book to provide a graphical image of the considerations and necessary decisions related to each section (e.g., Do I need to buy additional insurance?, What type(s) do I need or want?, What additional information do I need?).

In addition to making information in certain portions of the book more accessible to persons with cognitive disabilities and adding decision trees, there are several other suggestions regarding ways to make the book more understandable for all readers. One such suggestion is removing or reducing the amount of information

that would seem applicable for only a small number of users of the book. An example of information that might be removed, or at least be shortened and moved to a less prominent location, is that on the Minnesota Human Rights Act. This information is reviewed early in the section on hiring support people, but actually does not apply to "domestic workers." Another example of information that could be presented much more succinctly is that on bonding of support providers which may of concern to only a small number of individuals and families involved in this type of endeavor.

Finally, it seems important that this book receive a very careful proofreading to assure all ideas are presented in the most accurate, clear and succinct manner possible. The evaluators noticed sentences that are very long and complicated, or information that is unclear or leaves "loose ends" such as that on the State Unemployment Tax described on page 7 of the section on taxes. In other cases, information may be misleading to a reader, such as on page 3 of the section on "Hiring Your Own Supports" which states the money in an individual budget "is yours to spend." Such a statement neglects the fact that in most cases money must be spent according to some type of an "approved support plan." Also, the supporting information following the section on taxes includes three tax forms which receive no mention in the text, The Minnesota New Hire Reporting Form, The Application for Business Registration, and the W-4. Finally, one reviewer suggested the book would be easier to follow if sections were lettered (Section A, B, C, etc) and page numbers included the section and the page (such as the third page in "Section C Managing Your Own Support" being labeled page C-3). It is obvious that a vast amount of complex information has been reviewed and the most relevant information has been translated into understandable language. However, the book would benefit from one more iteration of edits and revisions. In making edits, special attention should be given to identifying and reworking those areas of the book that are most difficult to understand.

Usefulness "Finding the Support You Need" provides readers a good overview of the considerations in making the choice between purchasing supports through an existing provider agency or hiring support persons outside of an agency. For persons who decide to purchase supports outside of an agency, the book provides a great deal of information about both the practical, and the legal considerations in hiring and managing support persons. The book is very effective in presenting options and ideas in a very complete and objective manner, and reviewers felt it explained both the positive sides and risks associated with most choices. Reviewers also liked the fact that the book provided several ideas about where to go for more information about each of the areas that were discussed.

Several families who had made the choice to hire their own support staff found the book very useful. Tracey's mother received and used "Finding the Support You Need." She felt it was very helpful. She has used it often for ideas and advice as she began hiring support staff to assist Tracey at home. For example, it was helpful to be told to get a copy of a prospective support workers driver's license. Tracey's mother also showed the book to the new staff to explain how she was doing tax withholding. She feels an improvement would be to add sections to the book about the background of self-determination for persons with disabilities and why this option has been created.

Some participants noted "Finding The Support You Need" does not live up to its title in discussing all the various supports individuals and families involved in a program promoting self-determination for persons with developmental disabilities may benefit from. While the information in "Finding the Support You Need" is very helpful to users in arranging people to provide support to persons with disabilities, it contains no information or acknowledgement of other supports that may increase control of services. Such supports may include sources for finding specialized equipment and toys or suggestions about alternatives to traditional support approaches such as several families developing a support cooperative or using person-centered planning approaches to design supports.

As noted above, "Finding The Support You Need" has a great deal of very technical and legal information only needed by individuals and families who choose to manage significant amounts of money and hire people without support from an agency. Most persons who we interviewed for the project evaluation were not interested in taking on this responsibility, and found most information in the book far beyond what they needed. Angela's mom received an early version of "Finding the Support You Need." She said they "glanced through it" and had their staff person look through it, but did not use it because they haven't had to hire anyone and they are using an agency as employer of record to handle administrative tasks. Tim's family also received "Finding The Support You Need." but they haven't needed to use it because they are trying to keep the amount they spend on support people under the amount that would require tax withholding. They consider most of the support they are paying for to be "respite," which doesn't require withholding. As the use of individual budgets becomes more prevalent and more consumers and families decide to manage larger amounts of money, a book such as "Finding the Support You Need" may be of much greater use.

Some families who received a copy of "Finding the Support You Need" used bits and pieces of the book. Billy's mother received "Finding the Support You Need." and although she is using an employer of record, she does have some "informal" help for whom she is withholding social security. She used the manual to locate the correct form to use in submitting these payments and for directions about how to apply for an employer ID number with the Internal Revenue Service. Billy's mother felt the information in the book was clear and easily understood. She has not had to find new staff yet, but she anticipates it will be helpful for that.

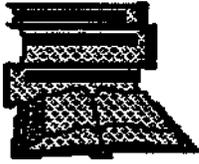
The information in "Finding the Support You Need" seems clearly designed, and heavily weighted towards persons interested in purchasing support outside of a traditional provider agency which limited it's usefulness to many program participants. Jean's mother commented that this and other consumer support materials lacked any information for individuals and families whose interest in

joining the Self-Determination Project was improving the quality of services delivered by traditional provider agencies. She stated that with the self-determination project she now writes a check to the agency that provides residential supports for her daughter, but still is not satisfied with the quality of Jean's services. She was not interested in arranging new supports since that would amount to forcing her daughter to move from the living space she had called "home" for the last several years. Jean's sister echoed her mother's concerns and was concerned about Jean losing her place in the group home if the family tried a different system of supports and they didn't work well. Based on these concerns, it seems important for a book such as this to include much more information about ways for individuals and families to effectively manage relationships with service providers that will lead to better quality services in traditional agencies.

Finally for some participants, this book was too big and contained too much information to be of great use. Like Andrea's mother and many other families, John's mother told evaluators she received a copy of "Finding the Support You Need" but didn't read it because she was not planning to hire staff at the time. She added however, that if she were going to hire staff she would prefer to work individually with someone to learn how to do it rather than reading a manual. The sentiments of John's mother were shared by many other persons involved in the project who preferred receiving information in small pieces and at the time when they needed it. Many persons also appreciated reviewing information with someone individually who could help them apply complex ideas to their particular situation. In this project, individualized information sharing was often provided by project managers and county case managers and was well received by most families.

We are rating:

READING MATERIAL



What was the name of the material?

Who produced it? \_\_\_\_\_

What was the material about? \_\_\_\_\_

How long does it take to read? \_\_\_\_\_

**WAS IT RESPECTFUL?**



1. Was the material respectful of both men and women?



2. Was the material respectful of people from all races and cultural groups?



3. Was the material respectful of people of all abilities?



4. Did the material look neat?



5. Does the material have pictures?



6. Does the material have some color?



7. Was the type big enough for who doesn't see well?



**DID WE UNDERSTAND IT?**



8. Did the material say what it would be about in the beginning?



9. Did the material go over the main ideas at the end?



10. Did the material use words that we could understand?



11. Were the ideas clear and easy to understand?



12. Does the material give clear examples to help us understand?



13. Were there suggestions about the things we could do to to help us remember or try using the we learned?



14. Did the material tell us things we didn't know before?



15. Did the material encourage us to make our own decisions how we want to live?



WAS IT USEFUL?



16. Did the material tell us about different kinds of support we could ask for?



17. Did the material show the good and bad parts of different choices?



18. Did the material talk about new ways to make decisions?



19. Did the material tell us where we can get more information?



**OUR RATING Is...**



**Good program!**



**Some good & Some bad**



**Didn't cut it!**



**Next time, we suggest that you**



We are rating: A PROGRAM

What was the name of the program?.

Who put it on?.

What was the program about? \_

**WAS IT RESPECTFUL?**



1. Was the speaker respectful of both men and women?



2. Was the speaker respectful of people all races and cultural groups?



3. Was the speaker respectful people of all abilities?



4. Was the program held in a place that was easy for us to get to?



5. Was the program held at a time that was easy for us to come?



DID WE UNDERSTAND IT?



8. Did the speaker say what it would be about in the beginning?



9. Did the speaker go over the ideas at the end?



in



10. Did the speaker tell us where we can get more information?



11. Did the speaker use words we could understand?



12. Did the speaker make his or her ideas clear?



13. Did the speaker have us actually do something to help us like role playing discussion?



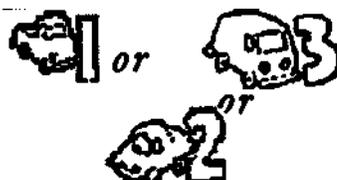
WAS IT USEFUL?



14. Did the speaker encourage to make our own decisions how we want to live?



15. Did the speaker tell us about different kinds of support we could ask for?



16. Did the speaker talk about the good and bad parts of different choices?



17. Did the speaker teach us some new ways to make decisions?



OUR RATING Is...



Good program!



Some good & Some bad



Didn't cut it!



Next time, we suggest that you

Four horizontal lines for writing suggestions.



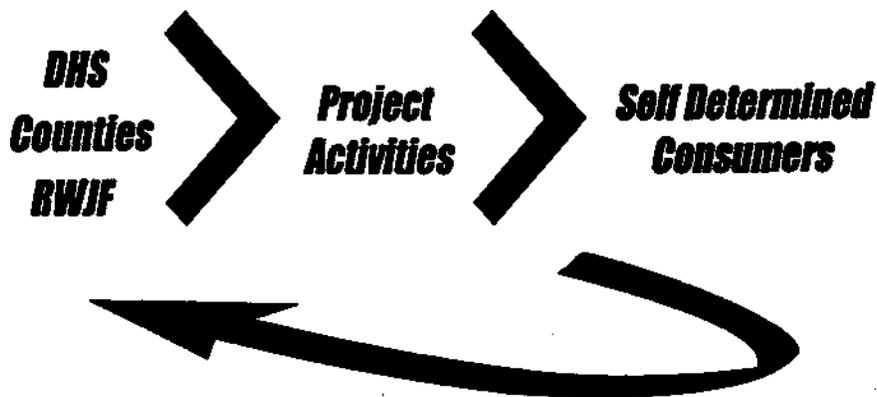
## **Appendix D**

### **Minnesota Self-Determination Project Evaluation Project Participants' Feedback Questionnaire Results**

*Minnesota's RWJF Self Determination Project*

# ***Project Participants' Feedback Questionnaire***

## ***RESULTS***



*What worked? What didn't?*

Before you begin, please tell us a little bit about yourself.

a. Which choice best represents your role in the Self Determination Project? (circle one)

- 22% 1. State employee
- 27% 2. County employee
- 24% 3. Residential support provider
- 7% 4. Work support provider
- 9% 5. Advocacy organization representative
- 11% 6. Consumer or family member
- 7. Other. Please explain \_\_\_\_\_

b. Which statement best represents the extent of your involvement with the Self Determination Project? (circle one)

- 18% 1. Project related activities are part of my job at least once a week.
- 14% 2. Project related activities are part of my job less than once a week but more than once a month.
- 15% 3. Project related activities are part of my job less than once a month.
- 41% 4. My primary involvement with the project is on an advisory committee.
- 11% 5. Other. Please explain \_\_\_\_\_

c. Some of the questions ask for your opinions about county-specific activities. If you are directly involved with one of the three project counties, please circle the appropriate choice below. If you are not, please select the county about which you have the most information and answer the county specific questions with this county in mind, (circle one)

- 36% 1. Blue Earth.
- 27% 2. Dakota.
- 33% 3. Olmsted.

*The following questions are organized around the six projected outcomes for the project. They represent some areas on which DHS would like your opinion There are a number of open-ended questions. We would like you to pause and reflect a moment on these questions, but if nothing comes to mind, feel free to leave that space blank.*

**A. Service approaches meet the needs of the geographic area being served.**

**A 1. One of the project goals was to involve consumers and their families in project steering activities at the State level. From your experience, how would you rate the project's success with this goal? (circle one response)**

- 26% 1) The project was very successful.
  - 65% 2) The project was somewhat successful.
  - 9% 3) The project was not successful.
  - 4) I was not involved in any state level activities.
- COMMENTS:**

a. What strategies have been successful?

- Inclusion of consumers and families in training, workshops, conferences and as part of panels describing self-determination and the impact on them. Video-taping project participation.
- A steering committee was formed with parents and advocates on it Input from People First groups was regularly obtained.
- Appointed/invited people they knew would be interested.
- Direct case manager contact, discussions about project

b. What suggestions do you have for improvement in this area?

- Find a way to continue to get regular feedback from focus groups, clients, guardians, about if the system is meeting the clients goals and wishes.
- The most effective use of consumers and families is at the local level
- More parent meetings
- Actively involve individuals with disabilities through People 1st of individual counties.

- No one with a disability in Olmsted County wanted to participate at state level but they are active locally.
- Be more specific on what is expected of families.
- Financial support for consumers and or family members, i.e. childcare, mileage stipend, etc
- Rely less on case managers and providers, contact parents/clients directly

A2. One of the project's goals was to involve consumers and their families in project steering activities **at the county level**. From your experience, how would you rate the project's success with this goal in the county with which you are most familiar? (circle one response)

- |   |                  |
|---|------------------|
| <p>35% 1) The project was very successful.</p> <p>63% 2) The project was somewhat successful.</p> <p>3% 3) The project was not successful.</p> <p>4) I was not involved in any county level activities.</p> | <p>COMMENTS:</p> |
|---|------------------|

a. What strategies have been successful?

- Using **project facilitation to conduct family meetings, informational and educational.**
- Involvement with People First**
- Self-Advocacy training.**
- Development of written educational materials.**
- Spending time at organizations/meetings already in place rather than creating another group.**
- Meeting time conducive to family members (evenings)**
- Again, it's very important that consumers and family members are listened to.**
- Respectful of parent input and genuine attempts to implement suggestions.**
- Local self-determination "chat" groups have been very popular.**
- Using the Project as an educational tool.**
- Help to look at non-traditional and traditional services.**
- Contracting with People First to review materials.**
- Knowledgeable people steering the project**
- Getting families together informally to share where they are, what still needs to be done, share success.**

b What suggestions do you have for improvement in this area?

- Spread the "ownership" of the project around to more families, case workers and providers instead of just going with a "core group."**
- Consumers/family members need to take an active role in learning and advocating for change.**
- Joint leadership from the start**
- Clearer tasks and expectations.**
- User friendly terms - too many acronyms!**
- Hire consumer reps to coordinate these efforts on the local level.**
- Professionals on the steering committee should actively involve people with disabilities and be more respectful**
- Recruit more and offer needed support**

A3. One of the project's goals was to involve members of non-dominant cultural groups in **project steering** activities at the state level. From your experience, how would you rate the project's **success with this goal?** (circle one response)

- |  |                  |
|--|------------------|
| <p>7% 1) The project was very successful.</p> <p>31% 2) The project was somewhat successful.</p> <p>61% 3) The project was not successful.</p> <p>4) I was not involved in any state level activities.</p> | <p>COMMENTS:</p> |
|--|------------------|

a. What strategies have been successful?

—**Increased participation, but many people in our area do not want to be involved at state level**

b. What suggestions do you have for improvement in this area?

-**Heighten the awareness of regional DHS staff outside the Metro area of the presence of people from minority cultures**

—**Try to secure representation of diverse cultural backgrounds in staff positions**

A4. One of the project's goals was to involve members of non-dominant cultural groups in project steering activities at the county level. From your experience, how would you rate the project's success with this goal **in the** county with which you are most familiar? (circle one response)

- 0% 1) The project was very successful.  
36% 2) The project was somewhat successful.  
64% 3) The project was not successful.  
4) I was not involved in any county level activities.

COMMENTS:

a. What strategies have been successful?

—**Anyone who wanted to be involved in the project was able to be**

b. What suggestions do you **have** for improvement in this area?

—**Very few people, not well organized themselves, no apparent interest**

—**Learn more about the background of cultural groups.**

-**We need to talk to cultural groups more to see if they would like to do it**

—**Continued efforts to secure representation on committees and staff positions.**

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

Following are some individual budget practices that have been used or proposed in **the** project. Because you have been involved with self determination and have had a chance to think about **the** options, we would like your opinion about each practice whether or not you have had direct experience with it. If you have **had** some experience that influences your answer, please explain in the comments section. How would you rate the value of **the following** practices?

**B1. Notifying everyone in the project of the cost of their current services (circle one response)**

67% 1) is a very valuable practice.

- There is no doubt in my mind that it would help keep costs down
- They're demanding better services.
- Of course, how else can I intelligently choose from a menu of services.
- Helped make a power shift work
- Providers became much more accountable
- Educates, provides reality, solidifies teamwork, ownership grows

21% 2) is a somewhat valuable practice.

7% 3) has questionable value.

- Does it involve case manager costs?

5% 4) is not at all valuable.

- Cost of service without an explanation of how cost is determined/calculated is of no benefit
- It usually incites people and rarely fosters constructive discussion.

**B2. Allocating funds on the basis of a reduced percentage of the cost of former services (e.g., 95%) in return for expanded flexibility with and control over these funds (circle one response)**

3% 1) is a very valuable practice.

- I think developing a tool to allocate \$\$ versus a random % makes more sense.

28% 2) is a somewhat valuable practice.

- Let's do away with inequity in \$ allocation.
- I believe funds should be shared by all who qualify, that there should be no waiting lists that all disability groups should have equal-financial opportunity.
- In reality, many costs for services are an average rate that does not reflect the true cost of service for the individual - this reduces the value of practice.

35% 3) has questionable value.

- We need more money to provide services - not less.
- We need to be able to pay staff reasonable salaries
- Doesn't work well if client continues with formal vendors.
- I think this was helpful to assist people in thinking differently, but the major question should be "is this person spending an appropriate amount of \$ for their services?"
- We had people spending much less than was appropriate and people spending much more - our focus shifted to getting them more in line with costs rather than simply reducing.

7% 4) is not at all valuable.

- The self-advocates should get the amount that fits their needs - that they need to stay independent!

**B3. Setting aside funds to create a "risk pool" for individuals' changing support needs (circle one response)**

76% 1) is a very valuable practice. COMMENTS:  
 24% 2) is a somewhat valuable practice.  
 0% 3) has questionable value.  
 0% 4) is not at all valuable.

B4. Providing individuals and families with a consumer-controlled checkbook to pay for their own supports (circle one response)

55% 1) is a very valuable practice. COMMENTS:  
 26% 2) is a somewhat valuable practice.  
 19% 3) has questionable value.  
 4) is not at all valuable.

B5. What recommendations do you have for improving individual budget practices?

- **Parents are overwhelmed by the perceived paperwork and have been reluctant to pursue this option.**
- **Developing methods of equitable allocation rather than historical allocation of resources.**
- **Take case management fees out of the mix. Let families purchase case management only if they choose.**
- **Give people incentives for not using their full budget**
- **Attach budgets and approvals more closely to goals and objectives to be accomplished with the monetary expenditures.**
- **Talk in the level of the self-advocates so he or she can learn as much as they can with their budget.**
- **1. Inform everyone of their costs. 2. Give people responsibility and authority to use funds with a firm set of guidelines, and 3. Make the informing of costs and designing of services an annual practice.**
- **There must be an oversight committee to monitor funds.**
- **Be sure there is flexibility to increase or decrease budget as needs change.**
- **An easier way to move the use of money around as long as it's within the approved area. It seems the best laid plans change and rewriting your projected budget is a pain.**
- **Explore incentives to cost efficiencies without putting people at risk.**
- **Change funding rules to accommodate individual budgets.**

B6. To what extent do you think current funding rules impact the principles of self-determination?

57% 1) Funding rules impede self-determination to a great extent COMMENTS:  
 41% 2) Funding rules impede self-determination to some extent.  
 2.4% 3) Funding rules neither impede nor promote self-determination.  
 4) Funding rules promote self-determination to some extent  
 5) Funding rules promote self-determination to great extent.

B7. If you think funding rules impede self-determination, which programs are **the** worst offenders (e.g., ICF/MR, DT&H, Group Residential Housing, HCBS Waiver)?

- **The worst offender is ICF/MR because funding is tied to beds, not people. It is not "portable."**
- **DT&H funding impedes self-determination because rates are assigned to providers and are "averaged." Though they are portable, they do not accurately reflect individual support needs.**
- **GRH would be much more beneficial if it could be used for unlicensed lining situations. Currently, people must live in situations where they have more support than they need for higher cost because it is the only way they can have a roof over their heads.**
- **The addition of the Consumer Directed Community Support in the HCBS Waiver is one thing that really supports self-determination, as does the Consumer Support Grant**

*C. Individuals and families control their own resources.*

**C1. What do you see as the top three incentives for individuals to control their own resources?**

- able to choose traditional supports or try novel approach to supports/services
- less reliance on government agencies
- It creates a market economy in which people are valued as a customer
- Opportunity to hire staff and use funds to increase wages
- Ability to purchase support from personal network
- Ability to choose combinations of support options, paying only for what is wanted
- Support own beliefs and values
- Assists providers to become more focused on peoples choices and dreams
- Learn what they are paying for/what things the cost
- Ability to have providers be accountable directly to client
- More natural- why would a 3rd party (I.e. social worker, agency, bookkeeper) have the same ability to improve/maintain my daughters quality of life?
- Cost effective- I am motivated to stay in budget and get the best service for my dollars.
- Getting rid of county micro-managing
- Resources will be spent based on their priorities, not others (provider, parent, county case manager)
- Ability to shop for services

**C2. What do you see as the top three disincentives or barriers to individuals controlling their own resources?**

- How to do it?
- What if it (\$) runs out?
- Problems with the tax system when large budgets must be counted as income.
- lack of understanding/responsibility in making decisions
- Taxpayer resentment
- Limited financial management skills
- Administrative burden- accounting, employment practices, etc.
- Some people might feel uneducated on the choices they have
- Some people may feel uncomfortable with this responsibility
- Will require a time commitment
- Not having much available
- Needing creative people to develop resources
- Difficulty understanding the various funding regulations; sometimes it feels like a maze.
- Lack of training/expertise in operating at a small business mode.
- The self-advocates is afraid to lost their services
- Lack of trust by family for county
- Lack of administrative support
- Trying to plan 1 year plus in advance

**C3. What suggestions do you have for how those disincentives or barriers can be addressed?**

- education and training; case manager oversee (help) and a back-up plan.
- The stories told by those who have done it successfully is very important Step by step suggestions/work plan in easy to understand language. A safety net if this becomes too much to handle.
- All rules, regulations and funding streams will be reviewed to determine specific legislative recommendations that contribute to our service system becoming one that is driven by principles rather than prescriptions
- Parents need to have more opportunities to teach each other/professionals need to be respectful of those attempting to control, not just their resources, but their life. Service providers and social workers will need to redefine their roles.
- Identify problems experienced by participants, plan and conduct informational/training seminars for more critical areas.
- have other people that have done it before show others how it works (self-advocate, social worker and families)
- Training, support and mentoring for individuals, families and professionals on an individual basis is important

***D. Redesigned roles support local community and consumer control***

D1. One of the goals of the project was to help consumers and families to think creatively about and develop innovative supports. From your experience, how successful has the project been with this goal? (circle one)

- 26% 1) The project was very successful. COMMENTS:  
70% 2) The project was somewhat successful.  
3% 3) The project was not successful.  
4) I don't have enough experience to answer.

a. What strategies have been successful?

- I needed someone to interpret rules and run defense for me-Karen Courtney did her best to remove barriers-I am not sure that the project helped me think creatively, but it did remove as many barriers to developing supports as possible.**
- Some key people in our community have begun to step out and do this so I feel we are on the verge of much more individualized, creative support packages.**
- Project was very good at empowering the client and his or her family.**
- It worked to make the client somewhat responsible as well.**
- The idea of brainstorming and being creative has been good but often nothing can happen with ideas because there are no "waivered slots" or rules and regulations interfere.**
- Sitting down as a team and dreaming about people's "perfect" work day-then really working with an open mind to meet their desires.**
- Giving families support and information.**
- People need to be at the "right place" before they're ready to think in alternative ways.**
- Need to keep providing information until they're ready -I think it will take longer for certain parts of the state than others.**
- Continue to focus on life with support, not developing services, thinking "outside" the box**
- The seven metro counties have standardized many procedures making the system easier for families and consumers to assess providers.**
- Bringing in more natural supports.**
- Giving control of the dollars to individuals and families**
- Changing work times, staff pattern, team approach**
- Families sharing successes and barriers.**

b. What suggestions do you have for improvement in this area?

- Take field trips to look at what other states or communities are doing.**
- DHS and the Health Dept have to let go of rules and regulations particularly for ICFs/MR.**
- Again, real life success stories-examples of what might be possible.**
- Listen to consumer.**
- Keep expanding the program-ideas grow with time people try new things and then others are more willing to try**
- Change will take time, we need to allow families to move at a pace that they are comfortable with, not at a pace we design for them.**
- Families need help with creative planning and making connections.**
- Review the rules and regulation to enhance quality of life, simplify, and be cost effective.**
- Greater time and emphasis on person centered planning and on thinking of "what would I do if I needed support" rather than what the "system" has to offer**

D2. One of the goals of the project was to help existing service providers change their role to accommodate greater consumer self determination. From your experience, how successful has **the project been with this goal?** (circle one)

- 10% 1) The project was very successful. COMMENTS:  
65% 2) The project was somewhat successful.  
22% 3) The project was not successful.  
4) I don't have enough experience to answer.

a. What strategies have been successful?

- Having meetings to talk about it
- Giving providers "ownership" in the project
- The project helped us increase our focus in this area along with lots of planning with the individual on goal development
- Some of the provider training was helpful but it didn't push us beyond our current knowledge base.
- We have been challenging ourselves to think outside the box.
- We have initiated more variety in people's days based on what they want
- Initially, representatives from several service provider organizations were involved with the steering committee at the county level, a change in meeting times caused the loss of most of these people.
- Individualizing budgets within residential programs.
- Informing people of costs.
- Getting useless middlemen providers out of the way!

b. What suggestions do you have for improvement in this area?

- Include all providers, not just a few.
- They need to hear it from the start, not told about it halfway into it
- As a provider, we can only change our role as far as our rules and regulations allow.
- Continue this project as providers are beginning to realize this is not a fad that will go away
- It will come-providers can discuss changes and some are beginning to respond-but it will only happen when consumers/families demand it
- Resource allocation based on need, not provider
- The county should monitor provider participation in supporting self-determination and tie that to reimbursement
- I am very conscious of telling them when they do a good job.
- Consumer reports of providers, so people can gather information.
- Mentoring from other providers who have begun doing business differently would help hesitant providers take a new look at things.
- Providers must be supported to ensure choice-accommodating provider-viability in this system should be researched and supported

D3. One of the goals of the project was to help county case managers change their role to accommodate greater consumer self determination? From your experience, how successful has the project been at this goal? (circle one)

- 18% 1) The project was very successful.                      COMMENTS:  
68% 2) The project was somewhat successful.  
15% 3) The project was not successful.  
4) don't have enough experience to answer.

a. What strategies have been successful?

- Education, opportunities, for discussion and sharing ideas, concerns, etc.
- Informing people they can choose case managers.
- Use of a coordinator that was respected by county staff.
- Supervisor/directors that verbalized and actualized self-determination

b. What suggestions do you have for improvement in this area?

- Some county case managers seem to be threatened by self-determination and person-centered planning—they need to be made to make the change.
- Families should be brought in to address case managers
- I think strong leadership by counties to assist CM's in changing their roles is important
- Peer reviews-county to county to measure consumer centered approach
- If clients want self determination, it won't happen unless the social worker cooperates.
- The case managers need a lot more training and understanding. They still act like it's their money.
- Include in social work curriculum and develop incentives for individuals to change.

D4. One of the goals of the project was to encourage and support consumers to increase their use of generic community resources. From your experience, how successful has the project been at this goal? (circle one)

- 20% 1) The project was very successful. COMMENTS:  
66% 2) The project was somewhat successful.  
14% 3) The project was not successful.  
4) I don't have enough experience to answer.

a. What strategies have been successful?

- As people gained control of dollars, they quickly tried out generic supports
- People tapping personal networks.
- Family members providing service.
- Using the YMCA
- The checkbook has made it easier to use generic resources
- County designated person to work on project got families together to share

b. What suggestions do you have for improvement in this area?

- The community as a whole still needs to be educated so that discrimination decreases
- Support and information to think generically.
- Case managers and group home staff should assist consumers in buying the proper-in-style clothing and other things so that people are better accepted in the community.
- Get service providers and community to talk to each other-show each the benefits of increased utilization of generic community non-handicapped resources.
- The community needs to be more involved!
- Getting out and talking about the issues and showing it works!
- Review what's worked-what hasn't
- Develop new strategies to avoid repeating mistakes.

D5. One of the goals of the project was to enlist increased support from the community for persons with developmental disabilities. From your experience, how successful has the project been at this goal? (circle one)

- 11% 1) The project was very successful. COMMENTS:  
64% 2) The project was somewhat successful.  
25% 3) The project was not successful.  
4) don't have enough experience to answer.

a. What strategies have been successful?

- Feel some consumers have natural support network through families, friends already in place.
- Situations which occur out of natural circumstances that make sense are successful—can't be forced or contrived
- As an example-I sent my daughter to a YMCA camp for three weeks and she was part of the staff-
- Last week we had our yearly planning meeting and the YMCA was part of it
- Engaging employers to support persons with disabilities on the job and paying them directly through training rather than a contracted agency.
- Individuals invite who they want as part of the team.

b. What suggestions do you have for improvement in this area?

- Needs to be one person at a time—making it a "project" impedes process—needs to happen informally not formally
- Look for and support naturally occurring opportunities
- Hold events in public places such as the library

*E. Quality assurance reflects local community and consumer control*

E1. A goal of the project was to enable consumers to define quality for themselves. From your experience, how successful has the project been at this goal? (circle one)

- 26% 1) The project was very successful. COMMENTS:
- 62% 2) The project was somewhat successful.
- 13% 3) The project was not successful.
- 4) I don't have enough experience to answer.

a. What strategies have been successful?

- We've had training on our county on techniques to use when finding out what people want in their lives—techniques that have been implemented with many people.
- Developing plans based on individual values and priorities
- I believe person-centered planning assists people in defining quality for themselves
- I believe the Region X project has made significant strides toward developing a consumer based system

b. What suggestions do you have for improvement in this area?

- This will be an area of needed focus for the long-term. Providers and case managers must continue to work with people to realize that they truly have a choice and control over what happens and with whom.
- QA is a tough one and something needs to happen in this area. Important, but tough to operationalize
- Let those who receive support be the evaluators of quality
- Offer training for consumers and families regarding studying the quality of service
- A parent/family/advocate review board could be established to help define quality not just from the county or state

E2. To what extent do you think current licensing standards and procedures impact the principles of self-determination?

- 35% 1) Licensing standards and procedures impede self-determination to a great extent. COMMENTS:
- 53% 2) Licensing standards and procedures impede self-determination to some extent.
- 5% 3) Licensing standards and procedures neither impede nor promote self-determination.
- 5% 4) Licensing standards and procedures promote self-determination to a some extent.
- 3% 5) Licensing standards and procedures promote self-determination to great extent.

E3. If you think **current licensing standards and procedures impede self-determination, which programs (e.g., ICF/MT, DT&H, Group Residential Housing, HCBS Waiver) are the worst offenders?**

**ICF/MR mentioned 18 times.**  
**DT&H mentioned 10 times.**  
**Waiver mentioned 7 times.**  
**Consolidated Rule mentioned 4 times.**  
**Rule 185 mentioned 3 times.**  
**GRH mentioned 7 times.**

- I think a number of providers use the excuse of "licensing won't let us" when the actual problem is this means we will have to do things differently
- The Region 10 QA project greatly helps.
- ICF/MR rules have been used as the basis for limiting self determination and especially at meals. Residential providers just don't want to have to deal with the wrath of the state if a resident would

prefer a different food item than the one available-we also have HCBS homes that measure out amounts of food. Weight gain is an original sin and cannot be tolerated-these restrictions are not in place because of medical conditions

—The Consolidated Rule has helped somewhat.

-Individual provider organization often interpret them rigidly, more in the vein of "this is how things have always been done"

-I am not really familiar with most of the licensing standards etc I do know that my daughter's brief stay in ICF was totally unacceptable. The "rules" were a hindrance to normalcy.

—The people implementing the rules impede or promote self-determination

—I think the worst offender is the we/they approach by so many involved including county staff, state staff, consumers and providers. As we design the new system, blaming and scape-goating need to be absent from the dialogue

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

F1. From your experience, how would you rate the collaboration in the project between the state and the participating counties? (circle one response)

31% 1) The project was very successful.

COMMENTS:

66% 2) The project was somewhat successful.

3% 3) The project was not successful.

4) I don't have enough experience to answer.

a. What strategies have been successful?

—The relationship between the counties and the state coordinator has been very positive

-Barb has been very good to work with! I think it has been helpful to have such a competent, organized, politically in-tune staff person

—The non-mandatory approach by DHS

—They allowed each county to "do their own things"

—It helped having a person in county designated to work on self determination

b. What suggestions do you have for improvement in this area?

—I think that the state's shifting jobs is a great deterrent to progress-it seems like an individual is committed to the project, then poof, he's gone

-Musical chairs is being played by DHS - who's the contact this week?

—Need to include the county more in decisions

—Don't force-provide incentives

F2. From your experience, how would you rate the collaboration in the project between your county and the local stakeholders? (circle one response)

36% 1) The project was very successful.

COMMENTS:

59% 2) The project was somewhat successful.

5% 3) The project was not successful.

4) I was not involved in county level activities.

a. What strategies have been successful?

—Focus groups, information sessions, steering committees

—Good people in the organizations helping the project and self-advocates

—Information sharing

—Using people first as advisory board

—Informal connections

—Committees-workgroups

b. What suggestions do you have for improvement in this area?

- More and better communication with the county-include them in decisions more**
- This area just needs work to develop and build trust**
- Consistent leadership**
- More shaping of information with other stakeholders-if it works for someone else, why not share it**
- Education through Arc**
- Keep local workgroups going.**

F3. From your experience, how would you rate the project's success at disseminating self determination information to other counties? (circle one response)

- 48% 1) The project was very successful.                      COMMENTS:  
48% 2) The project was somewhat successful.  
5% 3) The project was not successful.  
4) I don't have enough experience to answer.

a. What strategies have been successful?

- Going to region case manager mtgs.to talk about it**
- Information in local newsletters**
- Meeting with other counties**
- Responding to all requests-developing "tool kit"**
- Getting other counties involved in project meetings-learning about success**
- Have people speaking on the project**
- Mentoring, training**
- Seminars, newsletters, minutes, committee, regional meetings**

b. What suggestions do you have for improvement in this area?

- Have updated information to keep them going**
- State support in getting word out**
- I am not convinced that many other counties are able to look at these changes.**

F4. From your experience, how would you rate the project's success in disseminating self determination information to other disability groups? (circle one response)

- 24% 1) The project was very successful.                      COMMENTS:  
48% 2) The project was somewhat successful.  
29% 3) The project was not successful.  
4) I don't have enough experience to answer.

a. What strategies have been successful?

- Information got out but was not always well received.-Change is inevitable, growth is optional**
- Because we are working with the managed care demonstration project with other populations we have had the opportunity to address this.**

b. What suggestions do you have for improvement in this area?

- It is clear that the advocates for individuals with DD are competitive rather than collaborative with the other disability groups**
- Perhaps a newsletter or articles for newsletter, continued support**
- Make it a part of transition planning**
- Go out and talk to other dept. and show them the model**
- It is difficult for other groups who have limited resources to imagine how to do this. Add the Rehab Option to the MA plan so folks with mental health can get some services**

F5. Given what you know about the changes that have been made at DHS during the project, how likely do you think it is that these changes will be sustained? (circle one response)

- 23% 1) very likely. COMMENTS:  
40% 2) somewhat likely.  
27% 3) somewhat unlikely  
10% 4) very unlikely  
5) I don't have enough information to answer.

a. What would you recommend to increase the likelihood these changes will be sustained?

- What is learned and needed must play a key role in policy-making
- Involve more staff at DHS
- It was difficult for Barb and counties to get buy-in and change high policy making levels.
- The state has been in a constant state of change for too long-settle down and worry about doing the job
- Continue to fund positions that are responsible to implement SD statewide
- DHS tends to enforce and preach rather than support and teach.
- Consistent support from state staff (CSMD)
- I believe all training across the state needs to have a local county representative
- An ongoing SD workgroup like we have now only expanded to include other counties
- Consumers/family members/advocacy org. need to keep this in the forefront of what they do
- Think about self advocates and where they are going and if the project dies they may go back to hell!!
- Changes will be sustained because families and consumers will refuse to go back to the old way

F6. Given what you know about the changes that have been made in the county with which you are most familiar during the project, how likely do you think it is that these changes will be sustained? (circle one response)

- 44% 1) very likely. COMMENTS:  
47% 2) somewhat likely.  
5% 3) somewhat unlikely  
5% 4) very unlikely  
5) I don't have enough information to answer.

a. What would you recommend to increase the likelihood these changes will be sustained?

- Continue to fund coordinator change infrastructure, so SD is regular way of doing business. I fear when the person goes away, so will the concept
- A commitment and clear direction from top leadership
- Help bring relevant providers aboard
- Having brief informational meetings to share successes and challenges between providers would be helpful
- Keep educating consumers and case managers about individual budgets
- Think about where you put the self-advocates
- Organize an ongoing stake holder group SD advisory group to maintain the effort

F7. What do you see as the top three incentives for counties to undertake self **determination** efforts?

- Lower cost
- Better services
- Flexibility
- Expanded support options
- Pride
- Greater consumer/family satisfaction
- Time
- Possibly more fiscal responsibility
- It is good practice (to listen)
- Less reliance on county case manager-they could be fired up to actually practice social work

- Make lives better for persons with disabilities
- The formal system can't provide the service-not enough stuff

**F8. As the vision of self determination for all citizens with disabilities expands across the state, what advice would you give DHS and the new counties about implementing a self determination program?**

- Include everyone from the beginning.
- The project needs to be set up in a manner so the county coordinator is not seen by the consumer/family as having the ability/power to get them what they want while undermining the credibility of the case manager who has to work with the reality of the situation.
- All providers really need to see the vision and work together to move past current models. Having fun and exciting trainers can really help boost people's interest
- Talk with others that have done it Start with a few people. Devote enough resources—including people time.
- Quit thinking of it as a program—It's a way to think and approach an issue.
- There is no one way to "implement self-determination." But there are principles to be adhered to. All decisions, processes, and procedures must be evaluated against these principles which are determined up front
- Look seriously at current regulations and licensing issues. Without that in balance, the programs would not be as successful as they could be.
- Don't wait until you have all the answers. Take a chance and do it Learn from what has been done in other states and counties.
- Keep focus on individual budgets. Educate the social workers about what this means.