SELF-DETERMINATION FOR MINNESOTANS WITH DEVELOPMENTAL DISABILITIES

A PROPOSAL TO

THE ROBERT WOOD JOHNSON FOUNDATION'S
NATIONAL PROGRAM:

SELF-DETERMINATION FOR PERSONS WITH
DEVELOPMENTAL DISABILITIES

MINNESOTA DEPARTMENT OF HUMAN SERVICES

July 31,1996

MINNESOTA'S SELF DETERMINATION PROJECT PROPOSAL

PROJECT SUMMARY

Minnesota has made significant progress in enhancing opportunities for Minnesotans with developmental disabilities to enjoy full citizenship. Minnesota has committed itself to goals in the area of self-determination that will further the opportunity of Minnesotans with developmental disabilities to enjoy the pride, power, and satisfaction that comes from self-determined lifestyles.

But even as Minnesota commits to taking on existing challenges in meeting its goals, it faces the specter of a "reformed" Medicaid system that appears likely to operate nationally with 55 to 85 billion dollars less in the next seven years than would be spent under the present system. While this prospect raises great concern, the flexibility associated with these reforms is viewed as an opportunity to redesign Minnesota's service system to enhance consumer options, increase effectiveness of providers, and allow for efficiencies in the use of public monies. To that end, members of Minnesota's developmental disabilities community met over a seven-month period to develop a comprehensive blueprint for the future of services for Minnesotans with developmental disabilities as that system undergoes change; and the Minnesota Department of Human Services (DHS) established a stakeholder group to develop principles to guide county-based demonstrations of managed care approaches to delivery of services for persons with developmental disabilities. The resulting plan for establishing Developmental Disabilities Pilot Projects was authorized by the Minnesota Legislature in 1995.

Minnesota, like other states, is using managed care models to address the problem of financial deficits or reductions at the state and federal level and to control increases in health care expenditures. Minnesota has expanded its use of managed care for the acute care needs of persons eligible for Medicaid because they are AFDC recipients, but has little experience with managed care for the acute and continuing care needs of persons with disabilities. This issue is especially important because approximately 42% of Minnesota's total Medicaid budget of $3.1 million is spent on persons with disabilities, and Minnesota spends $600 million annually in providing medical, social, and long-term care services and supports for over 21,000 persons with developmental

disabilities. Since almost 80% of those dollars go towards long-term services and supports, restructuring how these services and supports are provided will need to be part of any solution to the current state and federal budget problems. The question becomes how Minnesota can extend managed care models to long-term care service and supports without significantly restricting *access* to services, limiting individual choice, or reducing quality of service. Minnesota believes that self-determination approaches to long-term care services and supports will help increase service access, consumer choice and control, and the quality of services and supports while helping us to control the rising costs of those services and supports.

The Minnesota Self-Determination Project described in this proposal melds the values, vision, and goals of the Developmental Disabilities Community Plan and the managed care principles of the authorized Developmental Disabilities Pilot Projects. A primary goal of the Self-Determination Project is to demonstrate the implementation of comprehensive programs of self-determination at three carefully selected sites. By comprehensive, it is meant that programs 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. 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. Just as important, within these demonstration sites there will be goals and expectations in the areas of improving management and administration of services, improving service financing and design, improving access to services, improving quality assurance and monitoring, and redesigning roles to assure that a viable, accountable, and effective infrastructure is created to support and sustain the services and supports created.

Success in the Self-Determination Project is extremely important to the future of services in Minnesota and careful attention has been given to the sites that have high potential for success.

commitment to principles of self-determination; experience and/or commitment to developing individually-controlled budgets; willingness to manage resources for both social and health care services; willingness to integrate other disabled populations in long-range implementation; demonstrated local service system reform; commitment of families, providers, and other local groups to the project; and effective local agencies, resources, and experiences in self-determination.

Three Minnesota counties have been selected as Self-Determination Project sites: Blue Earth, Olmsted, and Dakota. Others may join the demonstration once initiated, but the primary focus of time, attention, support, resources, and evaluation will be on these three sites.

Minnesota has developed a wide range of initiatives and activities that directly relate to the Self-Determination Project. The grant will concentrate and sustain these efforts within the comprehensive programs of the Project sites. As part of this concentration, a "tool kit" and technical support will be developed and made available to the sites in the areas of assisting people to define and plan lifestyles they want; assisting people to know what they can have in life; assisting service providers to reassess their mission and practices; managing performance by consumer-desired outcomes; establishing individual budgets; and managing individual budgets. The "tool kit" and technical support in these areas will be developed from existing curricula and experienced personnel who are able to provide agency staff, parents, consumers, advocates, and providers the knowledge, skills, and support to begin to implement self-determination on an individual basis.

The Minnesota Department of Human Services is requesting *$400,000* from *the* Robert Wood Johnson Foundation over a three-year period for implementation of the Self-Determination Project, including consumer and provider support and assistance, allocation model development, local - development and implementation grants, project coordination and communications, and formative evaluation. With federal match a total of $895,000 will be made available. In addition/professional and administrative staff support from the Minnesota Department of Human Services will provide in-kind contribution to the Foundation's financial support in the amount of approximately $ 1 million.

PROJECT DESCRIPTION

In its 1996 report to the Legislature, the Minnesota Department of Human Services (DHS) outlined its principles and goals for services to persons with developmental disabilities (DD[1]). About the same time, the Governor's Office issued its principles and goals to guide Minnesota's response to Medicaid and human services reform. The components of these two sets of principles and goals are described below with notes on progress and remaining challenges.

Age-appropriateness

Minnesota has made major commitments to children and youth, particularly to their right to grow up in families. In the 10 years between 1980 and 1990 the number of children and youth in all types of out-of-home placement was reduced by more than one-half through Medicaid financed programs such as the Children's Home Care Option, Minnesota's TEFRA program, with almost 3,000 participants; Home and Community-Based Services (HCBS), serving over 1,000 children and youth; and state and locally-financed Family Support Grants provided to more than 750 families.

Cultural appropriateness

Minnesota struggles to support people with DD in ways that reflect natal culture. Too many persons with DD have lifestyles that reflect little beyond the "DD services system culture." Minnesota acknowledges the need to focus commitment, creativity, and resources to reflect the cultural ways of social support in different communities. Programs to enhance person-centered planning, to provide direct allocation of resources to individuals, and to support minority community agencies and individuals have been initiated (described subsequently) and will be enhanced in this Project.

Least restrictiveness

Minnesota has made steady progress towards more personally-controlled service settings for persons with DD. Two-thirds of residential service recipients in Minnesota live in settings with six

'Because of space limitations, the abbreviation "DD" is used throughout for developmental disabilities throughout this proposal.

or fewer residents, about 40% in places with three or fewer residents (Prouty & Lakin, 1996). However, because of Minnesota's practice of aggregating resource pools to fund small group homes. less than ten percent of these Minnesotans live in homes where they are the owner or leaseholder. Major efforts (described subsequently) to change this history have been initiated,

Inclusion in the home community

As Minnesotans with DD have moved into community settings, they have benefited from greater levels of participation in community life. However, DHS-funded evaluation studies have shown that social involvements with persons other than fellow program participants and staff are still infrequent. Until recently, state and local government's priorities have focused on physical rather than social integration. Recently, with new emphasis on service outcomes, state sponsored efforts to enhance social inclusion (described subsequently) have been initiated.

Appropriate access

Minnesota has approximately 800 persons awaiting community residential services. Minnesota's residential service system would need to be expanded by about 7% to meet the identified need (as compared with 18% nationally). Minnesota has responded to concerns about access with two initiatives. The first links resource allocation for new HCBS recipients to assessment of need, rather than operating from a single average across all recipients. This has removed disincentives for providing HCBS to persons with more significant needs. The second initiative, which is foundational to this proposal, is the DD Pilot Projects which moves away from "slot driven" access to access based on eligibility and catchment area residence.

Promoting personal independence and wellness

The most important contribution policy can make towards promoting independence is to offer lifestyles that are typical for one's culture and that are desired by the individual. Minnesota continues to make progress in this regard by increasing person-centered planning and outcome-based quality assurance. Major efforts to develop, implement, and test new approaches to service planning and quality assurance are now underway (described subsequently). People's right to control basic choices in their lives also depends on knowing their options. Efforts to raise the level of knowledge

and improve the ability to use that knowledge are also described below.

Efficiency **and** value

Minnesota is relatively efficient in per-person Medicaid long-term care (ICF-MR and HCBS) expenditures (i.e., below the national average), but has a high utilization rate. As a result, Minnesota has relatively high overall DD expenditures and must continue to improve its efficiency. For example, Minnesota must continue to reduce the number of persons with mild/moderate mental retardation in small ICF-MR group homes in favor of less costly, more personalized HCBS services. Under existing law, counties, which authorize ICF-MR use, have no liability for costs because the state establishes and manages ICF-MR costs. A major benefit of the Self-Determination Project will be *to create an* environment in which "value" drives purchasing and incentives for economy prevail.

Accountability and responsibility

Minnesota has established a system with substantial division and misplacement of accountability and responsibility. Quality assurance has focused on facility compliance rather than quality in the eyes of service recipients. Recently, there have been a number of efforts (described subsequently) to improve accountability and responsibility through person-centered, performance-based definition and assessment of quality. These efforts have created joint activities of state and county agencies, service providers, advocates, consumers, and families to build and sustain capacities that are fundamental to the goals of the proposed Self-Determination Project.

Minnesota's Goals & **Challenges and the Significance of the Self-Determination Project**

In addition to the existing challenges within the state, Minnesota faces the specter of Medicaid system reform. The prospect of a lower rate of Medicaid growth raises concern, but the associated freedom and flexibility is viewed as an opportunity to redesign Minnesota's service system in ways that reflect the principles and goals described above. As noted **in** the **Project Summary,** key constituencies from government, service provider, service user, family, advocacy, and academic communities have been preparing for such an opportunity for three years. They have developed "blueprints" for the future, proposed and passed guidelines and legislation for DD Pilot Projects,

created and funded demonstrations of key components of self-determined lifestyles, and made and sustained commitments to continue to work together to keep the needs and desires of people with DD at the forefront.

Minnesota's Self-Determination Project proposal melds the values, vision, goals, and legislative endorsement of these products and commitments into an initiative to respond to the fiscal challenges ahead while allowing people with developmental disabilities to continue their movement toward freedom, citizenship, self-determination, and control of their own lives and the resources made available to support them.

Project Goals

The Self-Determination Project has goals in five related areas described below:

Improve Management and Administration of Services

- Provide local entities responsibility for local resources and implications for their use of those resources.
- Develop service approaches that meet the needs of the geographic area being served.
- Increase incentives for people to remain in local communities.
- Support local communities to analyze and expand capacity to meet the needs of local citizens.
- Increase competition among and choice of service providers.

Improve Service Financing and Design

- Provide for and support individual resource allocations and choice.
- Support individuals and families who are controlling their own resources and/or services.
- Develop and implement a rational means of resource allocation to local entities.
- Integrate all expenditures into single budgets for flexibility and efficiency.
- Develop methods and support to transition from obsolete services.
- Define a basic package of services for all persons with DD.
- Support greater innovation and benefit in work and other day programs.

Improve Access to Services

- Increase equity in access and resources for persons with similar needs.
- Increase access to, and resources for, culturally appropriate services.
- Provide for local experimentation with expanded eligibility.
- Establish an ethical basis for access decisions-

Improve Quality Assurance and Monitoring

- Design locally-based systems of quality assurance with consumer and family input, within guidelines established by federal *and state* governments.
- Make choice and control an integral part of the definition of quality.
- Link quality assurance systems with quality improvement support services.

Redesign Roles

- Renegotiate and redesign traditional roles of governmental administrative employees as necessary to achieve project goals.
- Establish appropriate support systems to assist local entities, consumers, families, and service providers to fulfill new roles.
- Evaluate project implementation and outcomes to refine project as needed.

Project Sites and Design

A primary goal of the Minnesota Self-Determination Project is to demonstrate the implementation of comprehensive programs of self-determination at three carefully selected sites. By comprehensive, it is meant that programs 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. 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 increase the control that individuals with DD have over their own lives. The ongoing activities and their significance to the goals of the Self-Determination Project are discussed subsequently. First, it is important to briefly describe the three demonstration sites and the capacities, commitments, and accomplishments that led these sites to be

selected.

Pilot Project Sites. The 1995 Legislature authorized the Department of Human Services to develop pilot projects to test managed care reform of DD services through integration of service funding and management at the local level. Local planning groups, consisting of consumers, family members, providers, advocates, and *county staff*, have met regularly to design a system that provides increased flexibility and sensitivity to consumer needs. New approaches and renegotiated state-county-consumer roles in assuring consumer protections will reduce existing regulatory demands so that the local efforts can be flexible and responsive to what consumers want.

Mankato State University will evaluate these pilot projects, attending to the relative benefits and cost-effectiveness of current fee-for-service versus integrated managed care service models for consumers, their families, counties, and other stakeholders. Findings will guide future initiatives to proceed with rule and statute changes, training, and technical assistance and other support to make Minnesota's service system more responsive to the needs of the persons with disabilities. Both outcome and process evaluation will occur to better understand the necessities of successful implementation.

DD Pilot Project and Self-Determination Sites. Criteria for selecting sites included counties' ability to manage resources; county and community commitment to principles of self-determination; willingness to manage resources for both support and health care services; willingness to integrate other disability populations in long-range implementation; demonstrated local service system reform; commitment of families, providers, and other local groups to the project; and effective local agencies, resources, and experiences in self-determination.

Initial Self-Determination/Pilot Project sites are described below[2]:

Blue Earth. For over two years the DD community of Blue Earth County has been meeting to discuss redesign of their service delivery approach. Consumers, parents, advocates, county

[2]Minnesota may request the authority to add a limited number of additional counties meeting selection criteria over the course of the demonstration.

representatives, and service providers continue to meet regularly. The overall goal of this effort, called Project Assure, has been to design fiscally responsible changes to the service system that will promote movement from special facilities and programs to a support model that adapts to, and complements, community, family, and individual resources through provision of the assistance and support necessary to achieve desired lifestyles.

Project Assure's goals include improving the availability and responsiveness of services for persons with DD, increasing efficiency in service delivery, increasing accountability to consumers and taxpayers for outcomes, increasing flexibility through consolidation of financial resources, reducing regulations that impede attention to outcomes for people, and facilitating local management of all aspects of service delivery. To achieve these goals, work groups meet regularly, focusing on behavioral support/crisis services to keep people in the community, vouchers, futures planning strategies, administrative aspects of transition from fee-for-service to managed care, information systems, evaluation, fiscal performance, redefinition of the providers' role, and consumer advocacy. These groups have included representatives of each of the stakeholder groups described above.

One of the characteristics sought in project sites was leadership. Local agents of change, who demonstrate new approaches to benefit people, are critically important to wider adoption of change. In Blue Earth County, the Harry Meyering Center (HMC) fulfills that role. HMC has moved from its traditional interdisciplinary team planning to person-centered planning, in which the individual controls the meeting, who attends, and what will be his/her goals. HMC staff and service coordinators have been completely retrained in facilitating and supporting the plans, dreams, and goals of each individual. As a result, one individual developed and successfully implemented a three-year plan to set aside money for a car and get her license. She is now planning to get married and buy a house, with considerable help from her circle of support. These efforts are supported through a cooperative program with the University of Minnesota's Research and Training Center/Institute on Community Integration (RTC/ICI) that currently involves 25 individuals. This project has also been successful with individuals with more limited cognitive and communication skills and is a good example of the *types* of approaches and outcomes that the Blue Earth site will

adapt in its implementation of the Self-Determination Project.

Olmsted. Olmsted County's pilot project, Project Foresight, began in February 1995 with a DHS grant to examine ways to redesign DD services. Project Foresight has involved all stakeholder groups in this effort. The Advisory Committee and issue related working groups that were established to guide the project include consumers, families, service providers, government, advocacy groups, and members of the community at large. A Community Consensus Building Process has been used to develop working relationships that had never existed to this degree before. The three working groups - Financing, Quality Assurance, and Service Delivery - met at least bi-weekly for four months to establish a knowledge base about managed care, innovative service models, and alternative quality assurance mechanisms, and to identify priorities for the new system. Working group members continue to be utilized to review new proposals and products of project staff.

Olmsted County and its service provider and advocacy communities have demonstrated commitment to innovative approaches to service delivery. Two years ago, Olmsted County and local service providers and advocates began an initiative to change service planning from traditional habilitative models to person-centered, lifestyle-oriented models. This process continues to be refined, with training offered to stakeholders. Beginning July 1996, new HCBS recipients will be offered a self-determination component as part of their plan of supports, including person-centered planning, assessments of level of need, and individual budgets to pay for appropriate levels of support. Olmsted County also plays a lead role in Southeastern Minnesota regional efforts to improve local services, including a regional community behavioral support/crisis services program, beginning in January 1997. This group is also working on designing an alternative system of quality assurance and quality enhancement.

Olmsted County is committed to using existing service dollars for consumer-directed supports. In addition to Minnesota's cash grant program, Olmsted County has its own cash grant program to support respite options for families with members with DD. A cash grant is sent directly to 24 families quarterly, with families deciding who they want to support them and how much they

will pay them. Olmsted County will develop expanded consumer-directed initiatives as part of this project, including an enhanced cash grant program, alternative case management options, and programs of training and support for all stakeholders on how to create self-determined lifestyles.

Dakota. Although Dakota County is at an earlier planning stage in redesigning a comprehensive service system for persons with DD, it brings to the Self-Determination Project extensive experience with individually-controlled budgets. Dakota's Account Management Program began in 1990, in response to dissatisfaction with services available for individuals with DD, and allows families the flexibility to arrange for, locate, and manage their own service networks in order to build combinations of formal DD services, generic community services, and informal supports. The end result was to support family systems and make it easier to maintain children and adults in their family homes.

In the first year of the project, 12 families were chosen to participate through an organized selection process based on their willingness to complete training, submit journals, manage their own financial accounts, locate and monitor service providers, and submit monthly expenditure reports. These families were already receiving county-funded services under the traditional service delivery system. A grant was approved for the second year and the project was expanded to 25 families, including families with adult children with DD. In 1992 the program was expanded to 50 families. However, because the initial planning grant from the DD Council ended, training and journaling requirements were discontinued. The program, funded exclusively with county dollars, has continued to expand, serving 240 families in 1995.

The Account Management Program has been successful because it allows families to tailor services to individual needs, to select their own provider and arrangements, to pay for unexpected expenses, and to use money cost-effectively, which allows in turn allows them to purchase more services, to purchase goods rather than services, to modify their home, or to make other choices to assist in care giving. The program is optional; families may choose traditional service delivery.

Dakota County is ready to expand this program to include people with DD who no longer live in their family home, but to do so will require access to federal and state service dollars. Dakota

County is currently establishing its procedures to develop the values, goals, and plans for the Self-Determination Project. This includes meeting with consumers, family members, advocates, and providers to identify the existing and potential barriers to self-determination; developing conditions of support for consumers who cannot direct their own services and do not have close relationships to assist them: removing barriers to consumer control of resources in existing funding streams; improving the understanding of the liability issues faced by consumers and government agencies in moving towards more client control of resources; developing methodologies for determining the amount of resources each individual receives; developing consumer information systems and technical assistance focused on choices about support options and responsibilities in directing their own resources, including taxes, workers' compensation, and liability insurance; developing accountability processes; developing quality assurance systems and methods for measuring individual outcomes; defining roles and expectations for consumers, families, guardians, counties, and providers; developing new contracting systems; and integrating the consumer-directed resource system into managed care.

Despite the significant needs for planning of comprehensive reform, Dakota County's experience permits it to commit to providing individually controlled budgets to at least 20 consumers not living in their family homes in the first year, and to provide these consumers with intensive county support and facilitation to make self-determination work. Each year thereafter an increasing number of consumers *with* individual budgets would be added to the program, even as the county implements broader, more comprehensive system changes to promote self-determination for all citizens with DD.

Project Activities and Demonstrations to Support the Local Programs

Minnesota has developed a wide range of initiatives and activities that directly relate to the Self-Determination Project. Many of these are short-term efforts to plant the seeds of change. Some are focused on catchment areas other than the initial Project sites. A number are financed by research and demonstration grants with time-limited funding. The grant will concentrate and sustain these

efforts within the comprehensive programs of the Project sites. As part of this concentration, a "tool kit" and technical support will be available to the sites in the areas listed below. The "tool kit" and technical support will be developed from existing curricula and experienced personnel who are able to provide county staff, parents, consumers, and advocates the knowledge, skills and support to begin to implement self-determination on an individual basis. The areas of critical importance to Minnesota's vision of self-determination and the resources currently available to assist in program development are described below.

Assisting People to Define and Plan Lifestyles They Want

Person-Centered Individual Planning. Minnesota is currently engaged in a major effort, backed by Medicaid demonstration funding, to expand the cadre of trainers and facilitators of person-centered planning and to enhance public awareness and expectations about person-centered planning. To date, activities have been designed to target the communities participating in the Alternative Quality Assurance Demonstration, but the program will be expanded to include Project sites. Public awareness materials and facilitator training programs and curricula are being developed by the RTC/ICI.

Self-Determination Assessment and Training. The RTC/ICI has developed a range of self-determination curricula for individuals, families, and human services agencies with federal and foundation funding. The focus of these programs is to support "self-determination" as both an opportunity and ability, derived from environments that provide options, experiences in trying options, opportunities to make real choices, supportive individuals who respect and honor choices, and creative people who can design and develop accommodations to allow people to carry out their choices. RTC/ICI staff have also developed and field-tested instruments that can be used by consumers, families, agencies, or other evaluators to assess the quality and extent of self-determination in people's lives.

Assisting People to Know What They Can Have **In** Life

Parents as Case **Managers.** For a decade, the Parents as Case Managers (PCM) program has operated throughout Minnesota to provide parents, consumers, family members, and others with

information about the nature of the service system, innovations in service practices to raise expectations, training in skills of assertiveness and policy advocacy, and sharing of useful materials to help families know what they want and get what they expect from the service system. The PCM program provides workshops staffed by RTC/ICI staff, community colleagues, and parents. To reach rural areas, the program has trained trainers to serve their own "outstate" communities. Recently, PCM in Communities of Color has supported trusted organizations within minority communities with materials and training as they sponsor and educate members of their communities about services and supports to persons with DD, This program is supported by a federal grant.

Partners in Policymaking. Partners in Policymaking is a nationally recognized program of education and training in policy making, political effectiveness, and individual and system-wide service improvement for individuals with disabilities, family members, and other committed individuals. This program was designed and initiated by the Minnesota DD Council, but is now replicated in a majority of states. This program not only assists people in understanding what they might expect from a person-centered system, but is designed to provide skills, motivation, political savvy, networking, assertiveness, and other aspects of effective (self) advocacy. This program continues to be produced and funded by the DD Council.

Common Vision. Advocating Change Together (ACT) is a grassroots, member-controlled organization whose mission is to empower people with developmental and other disabilities to speak for themselves and take control of their lives. One of ACT's primary initiatives is Common Vision, a four-year community organizing project with people with developmental and other disabilities. The immediate goal of Common Vision is to build the leadership capacity of people with developmental disabilities in key Minnesota communities so that they can identify and organize around issues affecting people in their communities; the long-term goal is to establish a state-wide network of persons with developmental disabilities that can organize on issues of disability and poverty. Twenty-four individuals will participate and serve as core leaders, with over 200 other people involved in four separate issued campaigns. Special efforts will be made to recruit people of color, women, and people between the ages of 18 and 24.

Consumer-Controlled Housing Guidebook & **Workshops.** Consumer-controlled housing is a foundational aspect of people developing and fulfilling lifestyles that they choose. Minnesota has undertaken significant efforts to raise expectations that people with DD should own or rent their own homes and increase knowledge about how they can. A *Guidebook on Consumer-Controlled Housing for Minnesotans with Developmental Disabilities* was developed by the staff of DHS and the RTC/ICI, printed with funding from the Minnesota Housing Finance Agency (MHFA), and is distributed through Arc-Minnesota and the RTC/ICI. The *Guidebook* is the curricular basis of community housing workshops provided by Arc-Minnesota.

Fannie Mae Demonstration-Homeownership for Persons with Disabilities. In June 1996, Minnesota was selected as one of 11 states to participate in a three-year Fannie Mae lending experiment, "Homeownership for Persons with Disabilities." This experiment will make five million dollars available to Minnesotans with disabilities or families with disabled members to buy homes. The primary marketing component to this project will be public awareness and training based on the *Guidebook* and workshops described above. Staff of local Arc affiliates will be trained to provide counseling and support to individuals and families who wish to pursue ownership options. Other participants in this program include the DHS, MHFA, Arc-Minnesota, the RTC/ICI, the DD Council, and the American Bank in St. Paul.

Individual Advocacy for Persons under Public Guardianship. Public guardianship is a major impediment to self-determination for the 4,800 wards of the Commissioner of DHS. Alternatives to the present system, in which county staff act as both case manager and guardian for persons under public guardianship, can be tested through the self-determination project. For example, contracts could be established with a private agency or individual, who is not a service provider for the ward, for provision of guardianship services. The individual or agency would act independently of government in fulfilling guardianship responsibilities but also advocating for maximum individual control of life decisions. Implementation of this effort will require the development of curriculum and training, support, and evaluation of effectiveness.

As part of the Alternative Quality Assurance Demonstration, local Arc affiliates have

matched paid staff and skilled volunteer advocates with individuals who have no living or involved family members. Staff and advocates come to know each individual as a person and participate in planning and quality monitoring activities. Training for these individuals is provided through materials developed by the RTC/ICI, the Human Services Research and Development Center (HSRDC), and Arc-Minnesota. These efforts are financed by a federal demonstration grant and Arc operating funds.

Assisting Service Providers to Reassess **Their Mission and Practices**

Person-Centered Agency Design. The Person-Centered Agency Design program is operated by the HSRDC. It was modeled after the *Framework for Accomplishment* program developed by John and Connie O'Brien, but has been tailored and tested in Minnesota through grants from the Bush and Hugh Anderson Foundations. The purpose of the program is to redirect the mission, goals, and performance of agencies away from bureaucratic and operationally defined procedures to focus on the desires and aspirations of the people being served, through commitment and involvement of agency teams. The program serves a wide range of agencies, from individual service provider agencies to all agencies within a two-county area.

Transition and Natural Supports in the Workplace. Minnesota was one of only six sites selected for a federally-funded project to promote the use of natural supports for employment for *persons* with developmental disabilities. PACER Center, an organization providing information and training for parents of children and adults with disabilities, was the lead agency for this project, which also involved providers of employment services, school districts, and the RTC/ICI. The project helped employers build their internal capacity to hire and support persons with severe disabilities and address issues raised by workforce diversification. The project used alternative sources of job development and job support, and worked with education and outreach channels within the business community to broaden their goals and services to include employment of persons with disabilities.

Best Practices Documentation and Dissemination. Minnesota has a number of models of best practices documentation and dissemination, ranging from the *Reinventing Quality* database

maintained by the RTC/1CI, which provides descriptions of innovation in quality assurance and enhancement activities from around the US, to internal best practices reporting forms of individual agencies. Print and workshop information on innovative efforts related to self-determination will be provided to sites and efforts will be made to develop intra- and cross-site documentation and recognition of "best practices."

Measuring Performance by Consumer-Desired Outcomes

Alternative Quality Assurance/Performance-Based Contracting Demonstration. Minnesota is engaged in a Medicaid 1115 waiver demonstration to test alternative approaches to quality assurance to achieve desired consumer outcomes while maintaining health and safety standards. The Outcome-Based Performance Measures of the Accreditation Council on Services to Persons with Disabilities were selected by participating key constituencies as the basis of the system. This demonstration is yielding experience in developing, implementing, and staffing a quality assurance system that defines and monitors quality based on the outcomes for consumers, providing participating agencies an opportunity to provide services that emphasize consumer choice, increased responsiveness to individual preference, and increased independence and community involvement. Local work groups of representatives from service providers, county staff, advocates, families, and others have been meeting for over a year to develop each provider organization's alternative quality assurance framework and to plan and secure support for the systems change process.

Independent Assessments of Quality of Life and Satisfaction. Minnesota has developed and continues to expand numerous data bases related to the goals of the proposed Self-Determination Project. These data bases not only provide tested instrumentation for collecting relevant evaluation data but, because these instruments have been, and are being, used in evaluations of other projects related to individual outcomes (e.g., Minnesota's HCBS waiver program), they also yield comparative data sets of potential importance to the Self-Determination Project.

Establishing Individual Budgets

Functional and Support Assessment for Individual Plans and Budgets. DHS has

contracted with Mankato State University for the development of a functional assessment instrument to replace existing evaluations, assessments, and protocols for use in planning services under local capitated dollars. This will serve to develop one of the primary data bases for the DD Pilot and Self-Determination Projects.

Evaluation of the Minnesota HCBS Waiver Allocation Structure. Minnesota has implemented a structure which allocates resources to counties to serve newly enrolled HCBS waiver participants based on individual need. Although this structure links the resources allocated to services for an individual and the assessed level of need of that individual, the allocation does not go to the individual but to a county pool of resources. The county is then responsible for purchasing services. Despite the significant difference between this approach and direct allocations to individual accounts, this structure has important implications for establishing individual accounts in the Project sites.

Managing Individual Budgets.

Family Support Grant. State Family Support Grants provide direct cash support to families maintaining children with DD at home. Over $1.6 million was dedicated in 1995 to help over 700 families directly purchase supports and services. These grants give families more control and flexibility over support services as well as incentives to use less costly informal and community support services.

Consumer Support Grant. The Consumer Support Grant program was recently authorized to provide monthly grants that enable consumers with functional limitations (including DD) or their families to purchase and control their own care, services, supplies, and equipment directly, as well as allowing them to obtain services from friends or neighbors rather than from agencies or professionals. Counties are allocated funds for grants that they distribute to consumers and families.

Semi-Independent Living Services Grants. County social service agencies are authorized to provide vouchers or cash grants to eligible recipients of state-funded semi-independeni living services to allow them to purchase their own services as well as one-time housing allowances of up to $1,500 to them to pay for items such as damage deposits and furniture not fundable through other

public sources.

Electronic Benefits Transfer (EBT). The self-determination project will test the use of the EBT system, currently used for AFDC recipients, to assist with the management and tracking of individual accounts. This system will have the capacity to make direct payments to vendors, as authorized by consumers, and will provide consumers easy access to various methods of payment from their accounts.

Implementation of the Self-Determination Project

Timelines for the implementation of the Self-Determination Project will be linked to the timelines for the DD Pilot Projects, although the Self-Determination Project will begin first and provide the framework for implementation of the Pilot Projects. The first six months of implementation will focus on three levels of activity (see Table 1). First, DHS and its partners will begin the process of collecting, modifying, and disseminating materials (the "tool kit") and designing and providing workshops for the education of consumers, families, advocates, and providers about the goals of the project. Second, during this period, the current DD Pilot sites will continue the work of their local advisory boards, consisting of the stakeholders described previously, to plan local implementation and establish linkages with local, non-human services, community organizations that can provide informal networks of support. These activities will be initiated in Dakota County, benefiting from the experience of the Blue Earth and Olmsted initiatives. To assist in these efforts, in addition to the "tool kit" materials and activities, sites will be provided access to technical assistance in areas of special importance to local site advisory committees.

Third, a state-level advisory committee will also be formed, consisting of a representative from each of the local projects as well as selected state-level representatives from advocacy, providers, health plans, and county and state agencies. Broader policy perspectives will be sought in this committee, including the input of legislators, business people, and other concerned citizens. The role of the state advisory committee will be to assist sites in negotiating and renegotiating roles and responsibilities with state entities. The state advisory committee will assist the Commissioner of

DHS in establishing appropriate expectations for locally-developed, outcome-based quality assurance systems; reviewing and approving the cross-site functional and support assessment system; advising on processes and factors associated with individual budget determination; guiding the issues and goals of the process evaluation; and developing a protocol for the enrollment of other sites. This committee will be part of the advisory committee for the Managed Care Demonstration Project.

Another major task for implementation is developing Minnesota's ideal for individually-controlJed budgets and identifying barriers, if any, to using state and federal dollars in such ways. If changes are required to the HCBS plan, these changes will be made. If a Medicaid 1115 waiver is needed to implement the preferred design, we will attempt to amend our existing managed care 1115 waiver, the MinnesotaCare waiver, to provide us with the necessary flexibility. In the event that amendments are needed for an "ideal design," interim payment systems will be developed that meet current Medicaid requirements.

Activities across the remaining 30 months of the project will continue to focus on these three levels of activity. There will be time and effort devoted to coordination across the three sites and the enrollment and involvement of other interested sites, including a state-level coordinator, use of videoconferencing across sites, and conferences to bring together interested parties from across the state. The state advisory committee will continue to meet regularly.

Collection, modification, and dissemination of materials will continue and be expanded to new sites. Much of this activity will need *to focus* on several areas of technical assistance and support that are not covered by ongoing initiatives, including retraining case managers to become self-directed service brokers, assisting existing agencies to assume new roles as fiscal intermediaries and personal brokers (or developing new agencies to assume these roles), and changing financial monitoring requirements to be consistent with individual budgets.

Project sites will balance their efforts between infrastructural development and implementation of person-centered planning and individual budgets. It is anticipated that at the end of the three year period of the project, approximately 10% of the current consumers in each site (30

in Blue Earth County, 50 in Olmsted County, and 100 in Dakota County) will have individually controlled budgets and the needed support and facilitation to make self-determination work. These consumers will include both persons living in their family homes and persons not living in their family homes. A crucial aspect of implementation will be providing consumers who are new to the service system with individual budgets and the support necessary for self-determination from the beginning.

Revised January 16, 1997

APPENDIX A

BUDGET NARRATIVE

SELF-DETERMINATION FOR

MINNESOTANS WITH DEVELOPMENTAL DISABILITIES

The budget for this proposal includes the state costs for personnel and other costs directly associated with implementation. Minnesota is requesting a grant of $400,000 from the Robert Wood Johnson Foundation. If the Foundation awards Minnesota this grant, the Department of Human Services (DHS) will use its Medicaid option for matching administrative dollars. With federal and local agency match, the total dollars available because of the grant will be $895,000. The total state contribution for the project will be approximately $1.3 million. These grant funds will provide the tools that Minnesota and local management entities need to demonstrate and refine self-determination models.

The state will also take responsibility for funding this initiative after the grant period through regular Medicaid administrative funding by reallocating existing resources to support ongoing and expanded self-determination efforts.

I. **Personnel**

Most of the personnel for the pilot project will be existing state and local staff who have been assigned to work on the demonstration. The state will commit three full-time equivalents (FTEs), including a project coordinator. DHS is requesting grant funds to hire one full-time project coordinator to be responsible for project management, communications, and reporting for the three-year period of the grant. This person's responsibilities will include managing the development and dissemination of consumer assistance and support materials and "tools," supervising the development and refinement of the allocation system for determination and management of individual budgets, maintaining communication among local and state stakeholders, communicating

with local project staff and other states involved in the self-determination project, and supervising project contract activity. This person will participate in the Managed Care for Persons with Disabilities Demonstration Project development team and will report to that project's manager

	One year	Three years
Personnel (salary and benefits)	$57,600	$172,800
Supplies, equipment, travel	$5,733	$17,200

II. Other Direct Costs & Office Operations

1. Supplies. The costs of supplies include pencils, paper, office supplies, and computer printer refills, etc. This cost estimate ($556 per year per FTE) is based on DHS guidelines for estimating administrative expenses for new staff.

2. Printing/Duplicating. Includes the costs of copying and printing of project related materials. These costs are estimated at $3,333/year and will be absorbed by the state agency.

3. **Telephone,** Includes the costs of installation ($150), instrument purchase ($150), annual service charges ($175), and annual long distance charges ($400) for the project coordinator.

4. Postage. Includes the cost of mailings related to the grant administration, written communications with the project sites, and other project related activities, including responding to and corresponding with other states involved in self-determination projects. Estimated costs for mailings are $167/year.

5. **Equipment Rental/Service Agreements.** Includes annual rent charges ($4,500), office furnishings ($7,500), and chairs ($650) for the project coordinator.

6. **Communications/Marketing.** Includes the cost of video-conferences between the state and the project *sites* for project-related activities. This cost was estimated based on 10 hours of video-conferencing at $66.33 per hour per site for three sites.

Revised January 16, 1997

III. Project Staff Travel

This includes the mileage charges ($0.27/miIe), meals, and lodging for the project coordinator for demonstration activity. Two of the pilot sites are located 80 miles from DHS central office and the project coordinator will be visiting these sites on a regular basis. This cost estimate ($3,000 per year per FTE) is based on DHS guidelines for estimating administrative expenses for new staff adjusted for the additional travel to and from demonstration sites. All travel costs for the project coordinator will be expended according to the travel and reimbursement procedures established for DHS employees.

IV. Consultant Travel

Expenses for consultant travel will be incorporated into the contracts specified in section VII and will be paid according to the travel and reimbursement procedures established for DHS employees for in-state and out-of-state travel.

V. Indirect Costs

This includes the indirect costs (accounting and financial management, personnel, executive office, *etc.) of the* project coordinator ($5,000/year) and the local costs/real locations that will be made for the project, estimated at $111,111 per site/year. County agencies will be claiming federal Medicaid administrative reimbursement on these costs. County agencies involved in the project will also be reallocating case management effort to person-centered planning effort.

VI. Equipment

Cost for equipment includes the cost of purchasing a computer and network software ($3,000), and a printer ($406) for the project coordinator.

VII. Consultant/Contractual Agreements

Revised January 16, 1997

1. Consumer and Provider Support and Assistance Total $.130,000

This project component provides consumers, their families, service providers, and local agency staff the tools necessary to assure that consumers receive the needed assistance and support to make informed decisions about their needs and plans, to access the supports necessary to meet those needs, and to evaluate the quality of the support that they receive. This component includes:

a. Developing local capacity for person-centered planning ($100,000). Training local person-centered planning facilitators, providing person-centered planning assistance and support to consumers and families, and refining existing curricula. This assistance will be secured through contracts with local advocacy and self-advocacy groups, parent groups, and the ICI/RTC. This effort will build on the work of the Performance-Based Contracting project, and the local project coordinators will devote approximately one-third of their time to providing training and assistance for person-centered planning.

b. Contract with Human Services Research Institute ($10,000). Since issues related to consumer support and assistance are complex, it is important to secure nationally recognized expertise in helping resolve these issues. This contract will provide assistance to DHS and demonstration sites in reviewing materials and curriculum that address: minority access issues; incentives to consumers to be prudent, efficient, and creative purchasers of services; strategies to address consumers waiting for support; adjusting consumer support systems to apply to persons with other disabilities; and development of fiscal intermediaries.

c. Providing access to consumer support & materials ($10,000). Develop "consumer-friendly" support materials, including alternative formats and Internet-based formats. Includes curriculum materials, directory assistance, and materials to assist consumer problem-solving. Minnesota also plans to contract with minority agencies, such as the Institute for Minority Development, to assure that the materials and supports for consumers are meaningful and culturally appropriate.

d. Assessment of consumer needs and provider capacity ($10,000). This component will

include focus groups with consumers, parent, family members, providers, and county staff in each of the project sites to better determine needs and desires related to project implementation. This component may include other activities such as training provided by PACER Center for families and providers on facilitating supported employment using a natural supports approach and identifying non-traditional sources of job development and support, including working with education and outreach channels within the business community.

2. Individual Budget Development and Management **Total $30,000**

Provide demonstration sites with the tools necessary to manage an individual budgeting system and fairly and consistently establish individual consumer budgets. Assistance will also be provided with legal issues related to greater consumer control over services. This component includes:

a. Contract with MEDSTAT ($10,000). Tax, legal, and quality assurance issues are some the most critical in the development of individual budgets and greater consumer control over services. MEDSTAT will provide Minnesota with assistance in resolving those issues by providing a national perspective, based on their years of experience with these issues.

b. Systems development and programming ($20,000). One critical issue is the management of information related to individual budgets and service selection. A stand-alone FoxPro system for the management of individual budgets at the demonstration site level will be developed, based on a system developed for the management of the waiver allocation structure. This system will incorporate the profiling methodology used by that structure, as a starting point for the development of individual budgets. This activity will be completed by contractors.

3. Local Development and Implementation Grants **Total $490,000**

Provides demonstration sites with local project management support, including coordination, communications, and reporting. There will be one full-time equivalent hired for each demonstration site over the three year period of the grant. This person's responsibilities will include managing local consumer assistance and support activities, assisting with individual budget development and

management, communication with stakeholders on the local level, and communication with other demonstration sites. This will be completed through contracts with the demonstration sites.

	One year	Three years
Personnel (salary and benefits) for three sites	$147,866	$443,600
Supplies, equipment, travel	$15,467	$46,400

4. Formative Evaluation Contract with RTC/ICI **Total $40,000**

This project component provides DHS and demonstration sites with independent formative evaluation support, including evaluation of the effectiveness of consumer support and assistance tools, assessing the impact of methodologies used to determine individuals budgets, and overall effects of the project on quality of services and supports received by consumers. This evaluation will occur during the first two years of the project and will contain recommendations for project approval.