

Project Purpose

Problem Definition and Need

Recent research suggests that people with mental retardation (MR) often receive harmful or ineffective health services (Beange, McElduff & Baker, 1995; Brown & Gill, 2002; National Institute of Child Health & Human Development, 2001; May, et al., 2004). This finding is not surprising because people with moderate to severe MR often present very complex health problems. The same conditions that create MR can also cause higher than average rates of seizures, cerebral palsy, hearing loss, vision impairment, diabetes and morbid obesity (Seright, 2004). People with MR often have limited cognitive and linguistic skill levels that impede the delivery of appropriate health services. They may not understand their doctor's questions or be able to tell their doctor how they feel (Madsen, 2004).

Medical research centers: a partial solution. Forty years ago President Kennedy assembled a panel of experts that examined the quality of health care for persons with disabilities. They found that very few health care professionals had experience with this population and that people with MR were at considerable risk (Presidents' Panel, 1962). In 1968 the Department of Health, Education, and Welfare addressed this issue by funding specialized medical research and training centers that focused on the health of people with disabilities. For the past 36 years, these university-affiliated medical centers have conducted research and created innovative and effective ways to serve this difficult-to-treat population.

People living in or near urban areas have benefited most from these federally-funded medical centers. To do their work, physicians and scientists needed access to a large number of patients with MR. Since urban communities could provide that access, centers were located in urban settings. People in rural areas benefited less from these centers. Today, the likelihood of receiving appropriate medical care is inversely related to one's distance from a medical center that specializes in services for patients who have MR.

About 6,000 (nearly 100% of this population) North Dakotans with moderate to severe MR and complex health problems live between 500 and 900 miles from the nearest MR-specialty medical center. For these consumers, getting appropriate health care services is a persistent problem. The two closest centers (the Waisman Center at the University of Wisconsin and the Munroe-Meyer Institute at the University of Nebraska) do not provide direct services, consultation, or training in North Dakota (ND). There are too few people within ND to support a major MR-related medical center and distances are too great to justify travel between ND and either existing center. Local personnel charged with arranging for health services complain that they don't have consistent access to psychiatrists, neurologists, and orthopedic physicians, who have training, experience, or interest in this low-incidence population (Askvig & Ferrara, 2003).

ND does have a few experts who specialize in providing services to people with MR. For example, the Anne Carlsen Center (ACC), in Jamestown, has occupational and physical therapists that provide specialized services for people with disabilities. In Minot, the North Dakota Center for Persons with Disabilities (NDCPD) provides MR-specific Speech Pathology services. However, these services are not available on a statewide basis. In ND, there are simply too few specialists and too many miles between patients with MR.

ND is not unique. The western parts of South Dakota, Nebraska, Kansas, and Oklahoma have similar demographics. There are many communities where economics and geography prevent the delivery of competent health care services to this low-incidence population.

The problem. Although the federal government pays to develop and validate effective health services for citizens with MR, those services are rarely available in ND. ND and other sparsely-populated states have too few experts and too much geography to provide appropriate health care for people with MR.

Need and Solutions

Access to in-state experts and services. Both psychological and practical realities make telehealth services a good choice for people with MR. For example, since these patients don't drive or ride the bus alone, transportation is a major healthcare barrier. When telehealth services are delivered at a community facility, that barrier is removed. Telehealth can also reduce the impact of psychological barriers to health service delivery. People with moderate to severe MR have limited cognition and language. They can't ask questions or understand explanations. As a result, a visit to a doctor's office can be a frightening experience. Telehealth, at a community facility, provides services in a familiar environment reducing real psychological barriers to good healthcare. For the past seven years, NDCPD has delivered telehealth and other services to North Dakotans with MR. Our experience suggests that telehealth in a familiar, local environment eliminates travel and psychological barriers and has treatment outcomes that are as good, or better than, face-to-face services (Madsen & Martin, 2004).

Although NDCPD's telehealth efforts have been generally successful, they have been delivered over the public Internet which has limited utility for health-service delivery. Our data suggest that teleconferencing software requires at least a 512 Kbps data transfer rate to be minimally acceptable for Speech Pathology and Audiology services. Other health services require better video quality and even more bandwidth. The dial-up modem and asynchronous DSL service found at many community facilities are simply inadequate. These sites can't access our services. Even Internet sites with synchronous broadband capabilities have serious problems. We've found that, during peak traffic periods, the data transfer rate between two broadband Internet sites can drop below the 512 Kbps quality threshold. Our experience suggests that the data loss and unpredictable data transfer speeds of the public Internet can quickly interrupt a service session. The Internet can also be insecure and certain telehealth services and data require a higher level of security. Because of these problems, the availability of our telehealth services is limited and North Dakotans with MR have little access to our in-state experts. *A secure, broadband, wide area disability service network with nodes at community facilities for MR and at ND's centers for MR-service provision would make in-state expertise available to more people.*

Services from an MR-specialty medical center. Although ND has experts in MR-service delivery, the services they provide are geographically scattered and categorically incomplete. People who live near federally funded, MR-specialty medical centers have access to more complete services. Since these centers are located on the campuses of major universities, all have access to Internet2, a broadband university-to-university data network. Through this project, Minot State University (MSU) can connect ND's disability service network to Internet2. *An Internet2 gateway would provide broadband connectivity between federally funded medical centers and community facilities for North Dakotans with MR.*

Development and validation of new telemedicine service protocols. Telehealth protocols are rules and practices for telehealth service delivery. These protocols include communication scripts, step-by-step procedures for establishing connections, rules for equipment placement, and instructions for community facility nurses. Validated telehealth service protocols

for people with MR have been developed in Psychiatry, Speech Pathology, Personal Fitness and Audiology. A literature review found no such protocols for Neurology, Orthopedic Medicine, Occupational Therapy, Behavior Analysis, or Physical Therapy (Sebastian, 2002; Martin & Madsen, 2004; Seright, 2004; Froelich, 2003). *New MR-specific protocols would improve our ability to deliver more comprehensive telehealth services in ND.*

Access to supervised, realtime, hands-on training. NDCPD currently operates the Rural Disability Wellness Program (RDWP), a physical education program for people with MR. In the project, an on-line personal trainer helps staff at community facilities provide individualized physical fitness programs to people with MR. The trainer uses teleconferencing technology to observe site activities and give realtime instruction to staff and service recipients. The program is helping staff at distant community facilities learn to prompt and maintain exercise behaviors that maximize benefits and minimize risks. Although it was unplanned, realtime observation and feedback is proving to be an extraordinarily powerful teaching tool.

For the past 20 years, MSU has operated the Community Staff Training Program (CSTP), a state wide staff-training project for community service providers across the US. CSTP staff provide training texts and modules that support the in-service and pre-service education of community facility staff. Many of these training materials address health-related procedures and require knowledgeable trainers to observe trainees and provide immediate feedback.

In ND, knowledgeable health-related instructors are rare. Since trainers are not always available, health-related training opportunities may be untimely and expensive. If sufficient network bandwidth were available, teleconferencing software's powerful observation and feedback capability could be used to improve access to both in-state and out-of-state instructors. *A wide area, broadband network with nodes at community facilities and an Internet2 portal could deliver timely training and supervised practice to community facility staff.*

Need statement. North Dakotans with MR could benefit from competent local health services. These services can be made available over a broadband network that connects in-state experts, remote MR-specialty medical centers, and ND's community facilities. There is a need for a network that can be used to: 1) provide validated telehealth services from in-state experts; 2) make distant MR-specialty medical centers' expertise available to North Dakotans; 3) develop and validate telehealth protocols for new MR services; and 4) increase the number of experts who can supervise and provide realtime feedback to ND trainees. The development of such a resource could be exported to help meet the needs of people with MR living in other frontier states.

Outcomes. 1) We expect to build a secure HIPAA-compliant, broadband, wide area disability service network with nodes at community facilities for MR and at ND's centers for MR-service provision. 2) We expect to provide an Internet2 portal that provides broadband connectivity between federally-funded medical centers and community facilities in ND. 3) Additional validated protocols will be available for the delivery of telehealth services to people with MR. 4) Cost-effective and timely, supervised practice will be available to trainees at ND's community facilities.

Innovation

ND's rural telephone cooperatives and ND state government have worked together to create the Dakota Carrier Network (DCN). DCN provides high-speed (2.5 Gbps) data transfer throughout ND. Currently, DCN maintains four government-supported wide area networks for:

1) state government offices; 2) K-12 schools; 3) post-secondary schools; and 4) public libraries and tribal governments. Since community facilities serving people with MR are private non-profit organizations, they do not currently use DCN.

A Statewide Network Supporting Disability Services

In the spring of 2004, DCN agreed to allow use of its high-speed lines for a fifth service: the Flatlands Disability Network (FDN). Through its nucleus at NDCPD in Minot, FDN will ultimately support secure, high speed (at least 1.5 Mb and up to 2.5 Gbps) intranet connections to 26 community facilities, four Centers for Independent Living, State Developmental Center, Anne Carlsen Center (ACC) and non-profit disability advocacy groups such as The Arc and Families First. The map in Appendix C shows long term plans for the FDN. The FDN components will be added when need justifies cost and money becomes available.

In 2003, NDCPD received funding for RDWP, the physical education program for people with MR described above (HRSA 1D1BTH01045-01-00). The Internet circuit between NDCPD and two RDWP service sites (Harvey and Mandan) was so unreliable that service sessions were regularly interrupted. To solve this problem, NDCPD purchased and installed FDN's first three components; the core equipment at Minot and spokes that connect community facilities in Harvey and Mandan. This project will add seven new FDN spokes. One spoke will connect Physical Therapy and Occupational Therapy experts at ACC. The project will also expand the network to six additional community facilities (two facilities already have FDN-access). After these new spokes are connected, about one-third of all ND community facilities will have FDN-access to the experts at NDCPD and ACC. ***As a result of this project, ND will have a network that connects one-third of the state's community facilities for MR with in-state expertise.***

Internet2 and Medical Centers

Internet2 is a consortium being led by 206 universities working in partnership with industry and government to develop and deploy advanced network applications and technologies (Internet2, 2004). Every university that houses a federally funded MR-specialty medical center is an Internet2 member and the Munroe-Meyer Institute (MMI), at the University of Nebraska has agreed to be a project partner.

North Dakota State University (NDSU), at Fargo, is an Internet2 member and is charged with developing and supporting Internet2 projects within ND. NDSU has agreed to connect FDN to Internet2. The Internet2 gateway will connect FDN to all federally funded, MR-specialty medical centers. ***As a result of this project, there will be a broadband telemedicine-capable circuit between eight ND community facilities and the nation's best MR-specialty medical centers.***

New Telemedicine Services for People with MR

Delivering health services from a distance requires more than connectivity. For example, NDCPD's distance audiology project was a line of research that began with hardware and software development. After a series of validation studies, training manuals were disseminated. Once the science was complete, other funding, licensure, political, and public acceptance issues needed to be addressed.

Although NDCPD has developed a few health-related services, our lack of connectivity has kept us, and our constituents, on the fringe of both the telehealth and MR health communities. ND's professional community has not participated in the design of experimental

interventions and North Dakotans with MR have not been members of validation samples. As a result, many innovative interventions are flawed because they assume resource levels which rural communities lack and may never have.

In addition to providing high-speed connectivity, FDN staff will work with the MMI and other medical centers to include rural people with disabilities in their studies. We will use FDN's connectivity to leverage additional grants and contracts for MR-related research, training, service, and dissemination activities. *As a result of this project, there will be new MR-specific protocols that improve our ability to deliver effective telehealth services in ND and other rural states.*

Realtime Observation and Supervised Practice

Remote realtime observation, feedback, and supervised practice is an extraordinarily powerful teaching tool. In ND, CSTP provides training for direct support staff at 28 community facilities. Training includes modules that cover health-related topics. Seizure management, oral hygiene, sexuality, and seven other health-related CSTP training modules will be modified to include FDN-based realtime observation by knowledgeable health-related instructors. *As a result of this project, training for staff at ND's community facilities will include realtime observation and supervised practice.*

Community Involvement

Stakeholder involvement. Four major stakeholder groups helped craft FDN'S conceptual model: people with disabilities (consumers), those who have disability-related expertise in a variety of healthcare disciplines (experts), those who provide direct support services to people with disabilities (service providers), and those who manage the community agencies and programs serving the disability community (managers). Over the past year, these stakeholder groups have participated in six planning and development meetings. They represent a diverse group of private, non-profit, and public entities including residential schools, group homes, sheltered workshops, advocacy groups, medical centers, university teaching hospitals, university research centers, and fee-for-service clinical programs. Both formal and informal needs assessments have been used to match the needs identified by people with disabilities and the community-based programs serving them with the expertise and resources of specialty disability-related health care providers.

Partners. The FDN will connect three centers of excellence on disability health care to eight community service providers (see map in Appendix C). NDCPD at Minot State University has 15 years of experience in providing speech/language therapy, audiology, and behavioral interventions to the adult developmental disabilities (DD) population. Over the past five years, NDCPD has developed and validated protocols for using telehealth networks to deliver these services. The ACC in Jamestown, ND is a national leader in medical, residential, educational, and therapeutic services to children with significant and complex needs. For over 80 years, ACC has served ND children with disabilities. More recently, the program has broadened its mission to include outreach services to more isolated communities, expanding its service population to include those with DD, MR, and youth transitioning into community programs. The MMI at the University of Nebraska Medical Center has provided clinical services to people with developmental disabilities, physical disabilities, and special health-care needs since 1959. MMI provides 22 specialty clinics at outreach locations throughout Nebraska. Clinical expertise is

provided in topics such as ADHD, augmentative communication, autism, behavioral health, braces and artificial limbs, diabetes, fetal alcohol syndrome, genetics, metabolic disorders, neurology and neurobehavioral disorders. Eight non-profit community service providers will also participate in the FDN (see Table 1). These programs provide direct supports for ND adults who have MR. Letters of support from the partners are included in Appendix B.

Table 1. Non-profit Community Service Providers

Program	Community	Contact
Able, Inc.	Dickinson, ND	Mary Anderson
HIT, Inc.	Mandan, ND	Ron Beck
MVAW, Inc.	Minot, ND	Sue Weston
ETC	Fargo, ND	Terry Paulson
Open Door Center	Valley City, ND	Mary Simonson
HAV-IT Services	Harvey, ND	Tim Huseth
Frasier, Ltd.	Fargo, ND	Sandra Leyland
Alpha Opportunities	Jamestown, ND	Don Nelson

Evaluation Plan

The proposed project will employ a two-phase approach to program evaluation. The first phase will use formative evaluation to gather quantitative and qualitative data providing continuous feedback and improvement during the operational phases of the project. The second phase will use summative evaluation to quantify and describe the program’s outcomes.

Throughout the duration of the project, data will be gathered on progress in completing project activities and tasks. Detailed timelines and person loading charts are provided in Appendix D. Data will be reported at weekly project meetings on the progress of each activity. Additionally, qualitative data from project participants (service providers, consumers of health care services, and participating health care providers and experts) about the utility of the FDN will be gathered through surveys and interviews. Appendix E provides a listing of the data elements that will be tracked during Phase 1 evaluation efforts.

Phase 2 of the evaluation plan gathers summative data to describe the impact, outcomes, and quality of the products developed and services delivered by the project. Project archives, final version products, published reports, and other deliverables will be used for Phase 2 evaluation along with end-of-project ‘snapshots’ of process data. Appendix E summarizes the data elements that will be gathered in Phase 2.

Evaluation of the project will be conducted by Dr. Eric Rudrud of St. Cloud State University in Minnesota (see Vita in Appendix A). Dr. Rudrud provided consultation in the design of this evaluation approach and has considerable experience conducting external evaluations of disability service programs. Additionally, the evaluation plan will document the technical reports, engineering designs, and training materials so that elements of the project can be replicated in other locations.

Feasibility

Plan of Operation

Goals. This project seeks to achieve three goals: 1) It will create a telehealth-capable network connecting ND's community facilities with in-state experts and MR-specialty medical centers; 2) North Dakotans with MR will receive online health services and; 3) FDN will create new online training and service opportunities. A PERT chart in Appendix D lists 15 activities, shows inter-activity dependencies, and anticipated timelines.

Key personnel. Appendix D contains person-loading charts that show anticipated staff-days per activity. *Dr. Bryce Fifield*, as FDN Director, will be responsible for communication with DoC, partner sites, and collaborators. He will also supervise all project activities and evaluate staff performance. *Mr. Steven Peterson* will be FDN's Service Coordinator arranging for the delivery of services and planning the development of new service. *Ms. Mary Mercer* will manage FDN's staff training activities and develop training modules. *Mr. Jesse Smith* and *Mr. Darren Seifert* will install, test, and maintain FDN's hardware and software. Vitae provided in Appendix A show that the proposed staff have demonstrated they can complete their FDN assignments.

Technical Approach

Statewide network. Although relatively low priced equipment was selected for FDN, it is capable of providing the QoS required for high quality video conferencing and Internet2 connectivity. Each site will have at least one desktop computer system that is optimized for video conferencing service.

Personal computers at each FDN site will connect to a Cisco 2950 24 Port Switch and each switch will be connected to FDN through a Cisco 2650XP Router with an ATM advanced integration module. T1 (1.544 Mbps) lines will connect sites to the nearest node on DCN's Synchronous Optical Network (SONET). SONET uses Nortel OC-48 equipment (2.488 Gbps) and is designed to grow to OC-192 (10 Gbps).

Internet2 gateway. NDSU has agreed to sponsor FDN as an affiliate member of ND's Internet2 consortium. FDN will provide Internet2 connectivity by adding additional memory to sites' routers. This memory upgrade will allow additional ATM routes and a software upgrade will provide QoS service. The Cisco LS 1010 router, already in place at MSU, will connect the sites to NDSU's Internet2 core router. Later, MSU may purchase its own core router.

Video conferencing support. FDN will use Wave 3 Software's Session to support the project's service delivery activities. Session's flexible video conferencing suite includes software that enables firewall navigation, a registration server for easy communication with mobile users, a multipoint server to enable multiple endpoint conferencing, and software to manipulate devices attached to distant computers. The software can easily be configured to provide additional resources for either video or audio without exceeding a predetermined bandwidth limit.

Network security. Although FDN will be a closed data network, it will have an Internet2 gateway. FDN's servers and routers will be protected from Internet2 incursion by cascaded firewalls. One firewall will be placed behind the Internet2 gateway and additional firewalls will be placed behind each site's router. Encryption routines will be used for all data transfers and video-conferencing.

Although on-site data management and storage will be dictated by the policies and practices at each site, all FDN sites will use HIPAA-compliant software and data storage systems. Each site's HIPAA implementation policies will be reviewed and final engineering decisions will assure network-wide security for sensitive information.

Previously validated services. NDCPD and the MMI currently provide online Speech Pathology, Audiology, Physical Fitness, and Psychiatric services that are either billable or supported by non-DoC funding. Project staff will make these services available to persons with MR at FDN sites.

New health services. Six proposed activities are related to new service development. First, project staff from NDCPD, ACC, and MMI will work with FDN sites to identify potential new online health services. Once potential services are identified, project staff will develop a preliminary set of protocols for delivering each new service. Next, project staff will work with their respective Institutional Review Boards (IRB) to develop iterative research and development designs that are consistent with good science and the protection of human subjects. Project staff will then implement research and development programs that produce validated, replicable service protocols (Gall, Gall & Borg, 2003). Finally, project staff will collect summative data and conduct other activities that address any non-scientific barriers to service delivery (e.g., licensure issues and insurance concerns).

New training opportunities. Two additional activities are associated with the development of new online training opportunities. Project staff will participate in CSTP's training module revision meetings to identify existing modules that might be improved through the inclusion of online, realtime observation and practice. Then project staff will develop draft modules that include remote, realtime observation. Once these drafts are completed, staff will obtain IRB approval, and conduct research, development, and follow-up activities described in the previous section of this proposal.

Sustainability

FDN will become an integral part of ND's MR Service provision infrastructure. Previous experience with data networks suggests that agencies can often save funds in one area of operations (e.g., travel) and use those funds to support network connectivity. NDCPD's experience with telehealth applications suggests that they are cost-effective and timely. This savings can be an incentive for long term FDN support. NDCPD also expects to expand the market for telehealth by adding more FDN sites. Project staff will track each site's FDN-related costs and make changes that maximize cost reduction opportunities.

Replication and Dissemination

Over the years, NDCPD has successfully validated innovative service systems and packaged them for dissemination and replication. NDCPD currently maintains an online products catalogue. Project staff will add narrated PowerPoint presentations describing FDN, telehealth services, training and support materials to the NDCPD products site. Technical papers describing key FDN components will be developed and distributed through national associations of service providers (e.g., ANCOR, NAQ, AAMR), professional associations of care providers (e.g., AAMR, AUCD, CEC, ASHA, etc.), and to policy makers such as legislators and the National Association of State Directors of MR/DD agencies.