

PROJECT PURPOSE

The Problem

Over the last thirty years the nation has seen a shift in individuals with Mental Retardation or Developmental Disabilities (MRDD) moving from large residential institutions to smaller, supported living settings in the community, as a component of strategies to improve health outcomes and contain increasing costs associated with long-term care. Like other Americans, these individuals go to school, earn a living and manage money, and grow old. They struggle to lose weight or quit smoking, face tooth decay, try to manage asthma or depression, and otherwise deal with all of the regular problems faced by the rest of society. But this population faces disproportionate challenges in staying healthy and accessing appropriate care in the community, their needs historically neglected by society. Individuals with MRDD face a higher incidence of other mental illnesses, obesity and other health problems.⁵ Confounding the problem is a critical shortage of physicians willing to accept them as patients, due in part to a lack of training and understanding of their special needs. Reimbursement is complicated as most systems were designed decades ago when life expectancies were much shorter and life was confined to institutions. High support staff turnover and communication difficulties further exacerbate the problem, putting these individuals at greater risk for abuse, malnutrition, medication errors, and delays in seeking necessary care.⁶ (Appendix A: Case Study on Nutrition)

Tennessee alone has seen its population with MRDD in residential institutions fall from 2,163 in 1982 to 848 in 2001.⁷ Currently 1,705 MRDD individuals in west Tennessee are receiving Home and Community-Based Services, while another 865 remaining on a waiting list. The Family Support Program assists 923 MRDD families in the region, while another 1,369 await enrollment. Waiting lists continue to grow annually and are known to be underestimates of actual needs. Based on service codes billed, 54% of west Tennessee services are delivered in Shelby County, 15% in Madison County, and 7% in Chester County. Of the remaining counties in west Tennessee, no county receives more than 3.5% of services.⁸ While most experts agree that incorporating individuals with MRDD into an active community life can be extremely beneficial in terms of patient outcomes and expenses, most communities are ill-equipped to deal with the myriad of patients' needs, resulting in poor quality of life and undue strain on local resources.⁹

In Tennessee in 2001, 16.9% of the population lacked access to mental health care, compared to 12.5% nationwide.¹⁰ But mental health care is only one of many services needed by the deinstitutionalized MRDD population. Evidence of underserved needs can be found in a review of current utilization patterns and understanding of the

⁵ White, Jane V. PhD, "On Health Status and Needs of Individuals with Mental Retardation Senate Appropriation Committee", American Dietetic Association, March 5, 2001.

⁶ US Public Health Service. *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*, Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, 2002.

⁷ Prouty, Smith et al, 2002.

⁸ Personal communication, Kim Briley, TNMRDD; March 10, 2003.

⁹ Krieg, R. *An Interdisciplinary look at the Deinstitutionalization of the Mentally Ill*, The Social Sciences Journal, Vol 38, #3, Autumn 2001; 367-380.

¹⁰ HealthCare State Rankings, 2002. Morgan Quinto Press, p. 470. Source: "Selected Statistics of Health Professional Shortage Areas, as of December 31, 2001", US DHHS, Div. of Shortage Designation.

dynamics of the long waiting list for services. (Appendix B: Utilization of Services) The Tennessee Division of Mental Retardation and Developmental Disabilities convened in November 2002 to identify shortages and develop targeted action items, which lead in turn to the partnership with UTHSC and this project proposal. (Appendix C: Gaps in Service Meeting Minutes Nov 15, 2002) This baseline data demonstrates the critical need for expanded services and the inability of most communities to meet those needs.

The Solution

The Mental Retardation and Developmental Disabilities Telehealth project will establish a partnership to unite the resources of the Telemedicine Department of UTHSC, the clinical and educational services of the UT Department of Psychiatry and the UT Center for Developmental Disabilities, patient participation in project development through the advocacy groups of ARC and People First of Tennessee, and planning, support and coordination with the Bureau of TennCare. The network will include twenty-five residential facilities (covering each of the counties identified in Appendix C: Gaps in Service) and 55 residential homes of deinstitutionalized MRDD residents. The network will be served through dedicated units on the UT campus and supported by a 24/7 video Help Desk manned by trained social workers for patient concerns. Recent advances in technologies have made Video Phones a feasible technical solution for this network, affording the best balance of reliable connectivity to remote locations, cost and functionality. The exciting potential of serving as a test bed for a newly developed video bridge for POTS systems increases potential applications and educational opportunities.

An interactive video network will allow healthcare agents to provide interactive training and clinical services to isolated patients and their caregivers. Targeted programs will include topics designed for specific needs. MRDD patients will receive training in adaptive skills essential for daily functioning (examples: self-care, home living, social skills, health and safety, smoking cessation, reading). Caregivers and nurses treating MRDD patients will be trained on specific techniques and clinical protocols. Currently, isolated patients and caregivers do not have a resource to turn to for urgent questions or to ensure that care is being provided properly. With this interactive video system, support can be provided directly at the bedside with virtually no delays even to the most remote or isolated communities.

The telemedicine connectivity will also be utilized to provide access to clinical care, including diagnostics, counseling, and medication monitoring and management. A multi-disciplinary team at UTHSC will provide isolated patients with a comprehensive care plan built upon assessments in intellectual and adaptive behavior skills, and psychological, physical, and environmental considerations. In addition to access to psychiatric and social work services, this connectivity can be used to provide MR patients with access to other medical specialties already available in the established telemedicine network, including dermatology, pediatrics, cardiology, and endocrinology. The Bureau of TennCare has proposed that the Network place a primary focus on behavior supports, and professional consultation services such as nursing, nutrition, and physical, occupational, and speech therapy. Quality assurance monitoring of the state subsidized residential facilities will also be conducted, improving accountability and ensuring consistent level of care across the state, while reducing overall expenses relating to such monitoring. (see Appendix D: Service Locations, for additional detail)

The Expected Outcomes

The outcomes of improved access and efficient utilization of services are expected to result in better health status and quality of life for patients *and* their caregivers, and a significant reduction in re-institutionalization rates. The Objectives of the MRDD Telehealth Model are designed to closely mirror the Goals and Action Steps of the Surgeon General's report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation – 2002*.¹¹ (see Appendix E: Project Matrix)

Goal 1: Integrate health promotion into community environments of people with MRDD

Outcome 1.a.: Identify resident's needs and promote awareness through the involvement of the Tennessee Disability Coalition and the Arc of Tennessee.

Outcome 1.b.: Provide health education to 25 residential and day-hab facilities.

Outcome 1.c.: Implement Coalition's Family's Voice program over video network.

Goal 2: Improve access and quality of healthcare for children and adults with MRDD

Outcome 2.a.: Provide 1,000 interventions annually through 24/7 access to HelpDesk social workers, to 25 fixed sites and 55 home-based units.

Outcome 2.b.: Provide 200 medical interventions with scheduled specialists relating to behavioral health, dermatology, occupational and speech therapies, etc.

Goal 3: Train healthcare providers in the care and treatment of MRDD populations.

Outcome 3.a.: Provide 1,000 interactive training or educational sessions with caregivers of individuals with MRDD.

Outcome 3.b.: Reduce support staff turnover in targeted locations by 20%.

Goal 4: Develop sustainable reimbursement strategies to ensure continued access

Outcome 4.a.: A replicable model for the state to provide access to essential services utilizing technology to overcome traditional barriers to care and training.

Goal 5: Increase overall understanding of health in MRDD populations, and report.

Outcome 5.a.: Provide baseline data on issues relating to access of care for MRDD populations in rural or isolated environments.

Outcome 5.b.: Disseminate findings in journals and conference proceedings.

Goal 6: Provide testbed for POTS-based MCU designed by Tandberg, USA.

Outcome 6.a.: Feasibility testing of a H.264 (POTS) compliant MCU video bridge.

Outcome 6.b.: Design and development of a H.264 compliant MCU.

Outcome 6.c.: Use the MRDD Telehealth Network as a test bed for H.264 MCU.

INNOVATION

Recent events in the news have introduced the general public to the potential of video phones in providing interactive video and audio communication to remote, isolated, and sometimes mobile environments. While the technology has not appealed to the general public as some manufacturers had hoped, it has tremendous potential to serve remote locations with a minimum of telecom infrastructure, making it ideal for rural communities or temporary connections, as other Telehealth programs have found in the past. Alternative technical solutions were explored, analyzed, and discussed, with a final decision made to build upon advanced in vid-phone technologies. (Please see Appendix F: To IP or Not to IP) The MRDD Telehealth project will build upon the past experience

¹¹ US Public Health Service. *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*, Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, 2002.

of video phone networks serving other patient groups, and traditional Telehealth networks focusing on behavioral health and MRDD populations in particular. (Please see Appendix G: Lessons Learned)

The innovativeness of this project is two-fold. The first is the creation of a 24 hour, 7 day a week video phone support network to serve and support deinstitutionalized MRDD individuals. In and of themselves, home Telehealth, home care for MRDD patients, and the concept of a phone (audio only) 24/7 support network are nothing new, but at this point an interactive video support system for deinstitutionalized patients making the transition back to their local communities is an untested strategy for overcoming some of the significant access barriers faced by this population. A video network is ideal to support the educational and clinical needs of this population, and 24/7 support is seen by the clinicians and Bureau of TennCare as appropriate in reducing emergency room visits, relieving caregiver anxiety and stress, and addressing problems before they develop into serious health issues. By forging a creative partnership with provider (UTHSC), payor and gatekeeper (Bureau of TennCare) and patients (ARC and the TN Disabilities Coalition), the MRDD Telehealth project expects to establish a model for similar collaborative partnerships in other regions of the nation.

The second innovative feature is the development and testing of a Tandberg produced Multi-Point Conferencing (MCU) video bridge that supports the H.264 protocol of video phones (using the “Plain Old Telephone System” – POTS). At this point, no video bridge exists in the public market that can link video phone calls into conference calls, such has been done for traditional IP and ISDN video conference systems. The efficiency of being able to broadcast educational and training programs to multiple sites is currently not available on POTS networks. Video phones had not reached the market potential originally forecast by their vendors but new markets are emerging. The recent conflicts overseas have seen an expansion of video phone reporting from the front lines, demonstrating their ability to provide reliable interactive connectivity from remote and isolated places across the globe. While common home use may never become the reality that vendors had hoped for, certain markets in healthcare, emergency services and disaster relief, news reporting, and distance education are exploring the technology and stand to benefit from an economically feasible POTS MCU. Technical design and product development will be undertaken by Tandberg, with UTHSC participating as a design partner and initial test-bed in the MRDD Telehealth network. The staff of UTHSC has a strong background in innovative telecommunications and engineering, bringing a high level of expertise in networks and making an ideal partner to test a developed MCU. The feasibility of creating an economical POTS MCU is still unknown but expectations are high and the potential benefits could be enormous for locations that can't rely on IP or ISDN. (Appendix H: Letter from Jay Myers, President of ISI, Inc.)

A multi-point conference video bridge for POTS will allow this network the following:

- Educational and training programs will be able to be delivered to a broader audience, increasing the efficiency of distance education, similar to the model enjoyed by H. 320 and H.324 protocol systems with MCUs.
- Homebound individuals with MRDD and their caregivers will be able to participate in regular meetings of patient advocacy groups (ARC, TN Coalition) increasing their participation and providing an outlet for their concerns.

- Individuals will be able to participate in group counseling, including interactive support groups for specific issues, building upon the model of video support groups for other behavioral health issues (i.e.: Alzheimer's), employed by UTHSC.
- Administrative meetings among caregivers participating in operational sessions or on the job training of moderate to large groups.
- Guest speakers hosted by UTHSC others invited to present on a range of topics.

COMMUNITY INVOLVEMENT

In a project to support the deinstitutionalization of MRDD patients, the community is obviously of tremendous importance and has been a concern at the forefront of all project designs and implementation planning. The community must be actively involved in every stage of such an effort, to ensure the long-term sustainability of the project. To provide better project planning, representatives from all key stakeholders have contributed to project design and are expected to continue in the following roles:

1) UTHSC: College of Medicine, Dept of Telehealth and Center for Research

Role: The Department of Telehealth will assume the role of project leader in coordinating new sites and services, network design, installation, training and maintenance of equipment, marketing in rural communities, development and sustainment planning. The Dr Grant Somes of the Center for Health Science Research will contribute in year one in the design of outcome measures for evaluation, and then again in year three for final evaluation, reporting and dissemination.

2) UT Health Science Center: College of Medicine, Departments of Adult Psychiatry and Boling Center for Developmental Disabilities (Pediatrics), the College of Nursing and School of Social Work

Role: These various departments and agencies on campus will provide the clinical and educational material available over the network. Clinical services will be coordinated by Dr. Kelly Askins, Chair of Psychiatry, and Dr. Jerry Heston of the Center for Developmental Disabilities. Educational sessions and training programs will be developed in direct response to end-user needs, based on surveys and requests for services from those locations, coordinated by the Department of Telemedicine.

3) The Bureau of TennCare (Please see Appendices I: MOU and J: Letter of Support)

Role: Coordinate and establish a Steering Committee comprised of network members, advocacy groups, healthcare providers, and patient representatives charged with the task of providing oversight and coordination of activities. The Steering Committee will ensure that families know how to access and bill for developed programs, as well as conducting ongoing needs assessments and surveys to respond to changing needs in the targeted communities. TennCare will continue to negotiate with project partners to develop contracts for providing appropriate services. An active role in program development will help to ensure that essential services are being provided and reimbursement strategies exist for their ongoing sustainment. Access to databases and outcomes measures will also contribute to the evaluation components of this research project. TennCare's interests will be represented on this project by Joanna Damons, Coordinator of MRDD services, Patti Killings, Contracts and Reimbursement, Dr. Moore,

Medical Director of MRDD services and Manny Martins, Deputy Commissioner for Finance and TennCare Director.

4) The Tennessee Disability Coalition and ARC of Tennessee (Appendix K and L)

Two patient advocacy groups will round out the key players in the MRDD project. The Tennessee Disability Coalition will be represented by their Director, Carol Westlake. The Coalition is a non-profit organization whose mission is to protect and advocate for the rights of individuals with disabilities to ensure they have an equal opportunity to remain productive and respected members of society. The Association of Retarded Citizens (ARC) of Tennessee is a family-based organization committed to securing for all people with mental retardation or other disabilities the opportunity to choose and realize their goals of how they live, learn, work and play, represented on this project by Walter Rogers, the liaison for the state chapter.¹²

Role: a) Needs identification and program planning; b) Dissemination of available services to the patient base; c) Develop strategies and provide resources for overcoming barriers, including local transportation to the telehealth clinic or other participating agencies; d) Provide first-hand experience for developing and broadcasting training programs; and e) Provide information via interviews for research component of this project, assisting with the ground work on the gap analysis. The Coalition will also utilize the interactive video network as a vehicle for their Family Voices program, providing family-to-family support groups, question and answer sessions, and support.

EVALUATION AND DISSEMINATION

Evaluation Questions The main research objective is to determine if the MRDD Telehealth project will be able to result in better health status and quality of life for MRDD patients *and* their caregivers, and significantly reduce re-institutionalization rates for the individuals with MRDD that have been placed in the 25 residential facilities and 55 residential homes that are a part of this project. Specifically, after the project has been implemented for one year, the year pre-intervention will be compared to the intervention year for the test facilities, and the test facilities will be compared to other similar facilities in the state not a part of the MRDD Telehealth project. The time (before/after intervention within facilities in the project) and place (intervention facilities to other similar facilities) comparisons will be made on staff turnover rates (the main caregiver variable of interest) and hospitalizations of MRDD individuals (the main patient variable of interest) among other variables.

Evaluation Strategy The design will incorporate comparisons both across time and place. Comparison sites will be randomly selected from around the state. Investigators will select 25 residential facilities and 55 residential homes to compare to a like number that are part of this project. Data will be gathered on the outcomes (dependent variables) of interest for the year prior to initiation of the project and during the project. A comparison will be made at one year after initiation of the project. Other potential co-variables will include age and gender of the caregivers and patients, caregiver experience, and number of years the individual has been classified as MRDD.

Data Analysis and Collection Plan The data may be represented as a two by two design with one between variable (intervention sites vs. control sites) and one within variable (pre vs. post-intervention). The data will be analyzed within type of facility and compare the intervention and control sites over time within both the residential facilities and homes. Within a residential facility there are subjects or caregivers (between 3 and 57, with an average of 18 years old) nested within facility and facility within intervention (yes vs. no). All variables will be adjusted for significant co-variables that will be included in the model. For the caregiver outcome (same caregiver throughout year) these include caregiver experience, age and sex. For the patient outcome (hospitalization during the year) the co-variables include patient age, sex, and years classified as MRDD. The important variable in this split-plot design is the interaction of the intervention over time. That is, is the difference in the outcome over time different for the intervention homes vs. the control homes? Clearly, we expect (the alternative hypothesis) that there will be less caregiver turnover and fewer patient hospitalizations during the intervention year for those sites a part of the intervention.

For the residential homes comparison researchers will utilize the same model except there will be one patient and caregiver per home. All four models (outcomes for caregiver and patient within residential facilities and the residential homes) will use Generalizing Estimating Equations since observations (patient or caregiver depending on the outcome) are correlated over time and within residential facility. For the comparison among the residential homes the project will have 80% power to detect a difference of 20% between the intervention homes and the control homes during the intervention year. This assumes a two-tailed level of significance. For the residential facilities researchers expect even more statistical power.

Lastly, the project will compare individuals with MRDD on the care they receive for other medical specialties already available in the established telemed network (including dermatology, pediatrics, cardiology and endocrinology) to other patients that receive that care through the traditional UT telemed network.

Evaluator Grant W. Somes, Ph.D. will serve as the primary evaluator for the project. Dr. Somes is a statistician with extensive research experience in a variety of applied areas (e.g., hypertension, epilepsy, obesity, exercise) as well having a number of theoretical statistical publications on data analysis techniques. He currently serves as the evaluator on two projects with the Shelby County Health Department.

Dissemination (please see Appendix M: for details on Dissemination Plan)

As of December 31, 2001, there were 674 Community Mental Health Centers across the nation certified by CMS to participate in the Medicare/Medicaid programs;¹³ a significant number of agencies that would benefit from the creation of a replicable model. Each member of the MRDD Telehealth network is committed to sharing the findings of this project, with the potential of reaching very different audiences. The Bureau of TennCare is a nationally recognized Medicaid waiver program, recognized as a leader in innovative alternatives to providing appropriate medical services across the state. TennCare is uniquely poised to disseminate findings directly to other states interested in similar reforms. The patient advocacy groups have their own newsletters

¹³ HealthCare State Rankings, 2002. Morgan Quinto Press, p. 221. Source: US Department of Health and Human Services, Centers for Medicare and Medicaid Services OSCAR Report 10 (February 21, 2002).

and national associations, with conference proceedings and publications available. Likewise, UTHSC can disseminate findings directly to providers and policy makers.

PROJECT FEASIBILITY

Technical Approach The technical approach is rather straight-forward and utilizes the same type of equipment that has proven effect in other healthcare networks in Michigan, Kansas, and Mississippi. (see Appendix G: Lessons Learned) In essence, at its implementation, this will be a network of video phones with removable camera, utilizing traditional phone systems. There is a high degree of confidence in the equipment's reliability and ease of use, based on conversation with other healthcare vid-phone applications. The technical approach utilizing a developed POTS-compliant video bridge has not been proven, as no such equipment currently exists, but will be designed along the same approach utilized by H.320 and H.323 systems.

Applicant Qualifications To facilitate the success of this project, a broad range of subject matter experts have collaborated to design this study, drawing upon the fields of social sciences, psychiatry, nursing, rehabilitative therapies, telemedicine, research and evaluation. UTHSC is the lead applicant and employer of Karen Fox, the Principle Investigator for this project. Ms. Fox brings to the project a firm understanding in issues of network interoperability, years of experience developing telemedicine systems, and the resources of an existing infrastructure to support the proposed project. Dr. Kelly Askins of the Department of Psychiatry at UTHSC will coordinate Behavioral Health services, education and training programs. Dr. Grant Somes, Chair, Department of Preventive Medicine will assist with developing outcome measures and oversee the statistical analyses. The Program Manager and technical staff are employed by UTHSC and will work in coordination with TennCare staff to implement this research project, generate reports on their findings, and disseminate to interested parties, including grant reporting. (Please see budget narrative for bio sketches).

Project Implementation and Completion If the project is awarded with grant funding, the initial three months will be utilized to reexamine priorities, meet again with project partners, and refine implementation plans. Social workers will be hired to man the help desk and assist in the development of training programs. The work is expected to take a total of three years, phasing in the deployment of 90 individual units. For details, responsibilities and timetable please see the project workplan in Appendix E.

Privacy and Security The sensitive nature and stigma that can be associated with developmental disabilities was one of the deciding factors in drafting a solution that uses dedicated vid-phone technologies rather than relying on less secure Internet Protocols. Every member of the UTHSC staff has been certified with HIPAA compliance training and is familiar with the issues regarding patient's privacy and rights in these matters. Calls that are both scheduled (i.e.: clinical appointments) and unscheduled (for help desk) will be treated with the same amount of security. All medical records are paper-based and will be the responsibility of the treating clinician. Privacy notices will be provided to all patients upon enrollment in the project.

Sustainability (Please see Appendix N: Sustainability for plan details)