

PROJECT PURPOSE

Families and individuals looking for appropriate medical, educational, social service, and public health services find it difficult to locate and access the multiple programs that may be available (Agosta & Melda, 1995; Koenning, Benjamin, Todaro, Warren, & Burns, 1995; Levinson, 2002). Families in rural communities face particular challenges (Flora, Flora, Spears, & Swanson, 1992). National economic conditions, and the profound changes in welfare over the past decade, are increasing the need for services (Mathmatica, 2002). The need for community resources, however, reaches all persons in a community, not only those traditionally thought of as vulnerable. For example, the typical caller to Atlanta's health and human service call center is employed (United Way of Metropolitan Atlanta, 1999). Professionals working with families also lack information about the ever-changing programs offered by other organizations. To assist clients, many agencies attempt to maintain databases of services but find that maintaining current, comprehensive information is time-consuming, costly, and duplicative of others' efforts. In Nebraska, 141 agencies are committing nearly 31,000 hours, and the 57 agencies that disclosed expenses reported they spent well over \$4 million annually (University of Nebraska Public Policy Center, 2000). The result of uncoordinated information and referral services often means that consumers are not accessing programs and services they need, and agencies are expending scarce resources maintaining quickly-outdated and duplicative information. Increasingly, health and human services information is also seen as a vital component of homeland security/ bioterrorism response. After 9/11/2001, Connecticut's 211 system fielded calls for first responders by managing donor and volunteer information, received crisis calls, provided technical assistance to other agencies, and was able to quickly include resource information about newly-available services established for the crisis. (See Appendix for an expanded discussion about information and referral issues.)

An affordable and accurate means of coordinating and sharing health and human services information must be developed. (See Appendix for additional information and referral background.) Organizations trying to share information among software programs face technical barriers, forcing them to use less than optimal solutions that result in lost data elements or time-consuming and awkward workarounds each time services or programs change. It is not that the technological knowledge is unavailable: Rather, it has not been applied to the chronically-underfunded field of social services information systems. It is neither feasible nor desirable for the thousands upon thousands of health and human services organizations across the country to adopt a single software solution, resulting in a marketplace monopoly. Market-based competition promotes innovation. Interoperability cannot be achieved until two problems are solved:

1. Information and referral systems lack a codified data format structure to standardize the information that forms the core of a health and human services database and assists database owners in structuring their programs so they are able to interface with centralized systems. Although there are mandatory data elements for national accreditation, these standards do not currently codify how the data elements should be captured within databases. Without standardization, it is virtually impossible to merge data from disparate systems. Just as the taxonomy for human services provided a language for health and human services, a data codification will provide the syntax for communication.

2. Existing health and human services database software applications lack automated data conversion rules and routines that enable databases to define how missing or mismatched data should be mapped into a centralized database. There will be missing data because different software programs contain different data elements, indexing systems, and ways of structuring their data. Data will be mismatched because programs offer divergent selection choices within fields. For geographic tracking, for example, one database may use Zip Codes to locate service availability whereas another may define it by distance from a centralized location. User customization means that general data translation standards are insufficient to accommodate the variety of ways users structure their databases.

The project will codify the data formatting structure, develop the needed data conversion rules and routines, and demonstrate the capacity of both through a statewide, coordinated system that builds upon disparate databases maintained by community-based public and private organizations using various commercially-available information and referral software. The technological solutions developed through this project will transform the ways that human service providers identify and share resource information by capitalizing upon the information assets and community-rooted strengths of existing public and private databases, leveraging local knowledge of resources and needs, and creating a more accurate and comprehensive database of resources. Our project outcomes will be: 1) reduced time consumers and case managers must spend searching for health and human services; 2) reduced agency time maintaining duplicative database resources; and 3) improved consumer choice and access to health and human services because consumers will have greater knowledge of appropriate service options.

INNOVATION

This project is innovative for five primary reasons. It will: 1) enable statewide and, ultimately, national information sharing for information and referral built upon local databases; 2) apply process innovation designed to optimize the way that critical decisions are made by stakeholders; 3) build upon existing and emerging information and referral advances; 4) leverage three TOP projects; and 5) demonstrate statewide efficacy.

This project will take isolated, local information and referral databases and create the tools to build networks of coordinated databases. These networks of coordinated databases will move the entire field of information and referral toward highly-desirable, national resource information sharing that will contribute to the movement toward a national 211 system (the three-digit dial code reserved by the Federal Communications Commission for health and human services information).

The project builds upon existing and emerging information and referral advances, such as the xml data translation standards (by the Michigan Association of United Ways, through a SBC Foundation Excelerator grant) that market-leader, database vendors will incorporate into their products within approximately two months. The AIRS/INFO LINE taxonomy standard provides the language for defining and organizing human services across North America. The proposed project accomplishes the next step by creating the tools that will prepare and codify the categorized information so that it may be exported into the XM data translation standards (see Figure 1 in Appendix) and aggregated with other resource databases. This includes both the

technological preparation as well as decisions relating to how resource information is structured, formatting, and described.

It is expected that stakeholders will bring strong positional stances and philosophical frameworks to the numerous decision points that must be addressed to effectively implement this project. The innovative process technique that will be used to make these choices is an interest-based group facilitated process. Interest-based group facilitation enables participants to dismantle any destructive aspects of conflict, to pool resources creatively, and to design innovative, meaningful outcomes. Interest-based group facilitation also ensures that groups like consumers, who often have little power to influence outcomes, have their positions fully considered as part of the decision making process. The process is discussed in greater detail in the Appendix.

The project will build upon three successful programs initiated in Nebraska using NTIA TOP funds. The project will enhance the information and referral resource available through the University of Nebraska Internet-based information and support network for foster and adoptive parents, families of children with special needs, and state services coordinators. The project will utilize the resource language translation services developed by Lincoln Action Program, and will provide end-user outreach through Lincoln Action Program's computer training laboratory.

Our hypothesis is that practical resource information sharing will dramatically improve the delivery of information and referral practices. The hypothesis will be tested through a statewide demonstration (see Figure 2 in Appendix). Five databases will provide information about resources, and in aggregate, cover the entire state. The databases are actively maintained and updated by public and private organizations, using various commercially-available software products. The statewide context will test the hypothesis across: population densities (frontier, rural, micropolitan, and urban sites); partner orientations (public and private); database software; nature and depth of available services, resources, and agency intermediaries; and racial/ethnic and socio-demographic variation of partners and users. The demonstration project will be conducted in within a state with high-need areas: Nebraska has five of the ten lowest per-capita income counties in America. No other state is similarly positioned, with partners prepared to adopt a coordinated, multi-software solution, to undertake this type of demonstration. See Appendix for additional innovative technological background and process aspects.

COMMUNITY INVOLVEMENT

The lead organization for the project, the University of Nebraska Public Policy Center (see Appendix for expanded partner information), has demonstrated expertise in achieving objectives that are complex and require the active participation of numerous groups with a diversity of backgrounds and interests. The Center focuses on statewide issues that impact the people of Nebraska, including developing projects on a state level that have national implications. The Center's board includes the Governor, the State Supreme Court Administrator, Chair of the Unicameral Executive Board, and Senior Vice Chancellors for Academic Affairs for the five campuses of the University of Nebraska. Local participating implementing partners, all of whom bring years of experience in database design and development, include: Lincoln/Lancaster County Health Department, an information and referral hub and call center for 17 counties and

participating database site; Nebraska Department of Health and Human Services, the state agency overseeing human services that will participate as a database pilot and contribute its Lifespan Statewide Respite Network and the Nebraska Resource Referral System; United Way of the Midlands, providing information and referral services for more than 23 years and the area's 211 pilot serving the five-county, two-state, metropolitan Omaha area; Volunteers of America/Panhandle Partnership, maintaining health and human services resource information for all of western Nebraska and a participating database pilot site.

Consulting partners include: the Alliance of Information and Referral Systems (AIRS), the international organization of information and referral organizations and a national leader in developing the 211 system; Bowman Internet Systems, a leading software development firm and ASP for human services, and ServicePoint software producer; INFO LINE of Los Angeles, the nation's largest, most technologically advanced information and referral center, helping 290,000 people each year; the Mediation Center, a private, non-profit center in Lincoln, Nebraska, that works to prevent and resolve conflict; RTM Designs with a 20 year history in information and referral software (Alliance Network, Refer and ReferWeb); SunCoast, featuring its IRis software licensed to 1,100 information and referral agencies; United Way of Northeast Florida, a ten-county 211 information and referral provider and an active participant in developing the xm data translation standards; students from the University of Nebraska-Lincoln J.D. Edwards Program, an innovative, highly-selective undergraduate program integrating computer science, leadership, communication, and project management; and VisionLink with its Tapestry software used by thousands of agencies.

Partners will join consumer representatives, policymakers, and other stakeholders to implement the project (see Appendix for further details). The Statewide Project Advisory Committee will provide overall guidance and coordination for project implementation. A National Project Advisory Committee will provide an ongoing context within which the project will operate to ensure that solutions are transferable to other systems. Meetings will maximize participation through the use of distance learning and/or conference call technology available through the University of Nebraska.

Community-based participation of Nebraska's consumers and agencies in the development of this project has been longstanding and extensive. Specifically, consumers and agencies have been involved in all aspects leading up to and including this proposed project. One of the seminal activities identifying the need for information and referral was described in Nebraska's Long-Term Care Plan (1997). This plan, developed with extensive community-based participation, pinpoints information and referral services as one of a core set of services that "should be identified and given priority for funding within the system." In 1998, Information and Referral Network conferences in Nebraska revealed broad support for a statewide information and referral model. Also emerging from the statewide conferences, the Nebraska 211 Coalition spearheaded efforts to investigate the feasibility of a 211 system and commissioned the cost/benefit analysis and survey of agencies conducted by the Public Policy Center. The Nebraska Unicameral indicated its support for the concept when it conducted "an interim study to determine the feasibility of a Statewide Information and Referral System." Statewide town hall meetings conducted in 2002 (as part of a Systems Change grant from the Centers for Medicare and Medicaid Services) identified the lack of accessible information and referral

resources as a key barrier to consumer-directed services. In 2002-2003, the Nebraska Health and Human Services convened a statewide Data Team, comprising representatives from the major information and referral agencies across Nebraska. The Team compiled the previous work and created a conceptual framework for statewide data sharing, upon which this proposal is built.

For the first time, consumers will be able to access locally-generated and updated information about health and human services across the state through three means: 1) through a consumer-friendly Internet site, 2) by dialing 2-1-1 in certain parts of the state, or 3) through a helping organization using the Internet-based resources. Social marketing, an approach targeted at influencing individual action, will guide support and promotion, particularly social marketing's emphasis in including target audiences in planning and implementation. Three key end-user groups will be targeted for support and promotional activities: 1) traditionally underserved populations (i.e., low-income persons, persons with disabilities, racial/ethnic minority populations, the elderly, and rural residents); 2) intermediary information providers (e.g., call center operators, the statewide community action program association, cooperative extension faculty, library staff, schools, faith-based organizations, Health and Human Services employees and contractors, and the network of Area Agencies on Aging); and 3) information and referral database managers. See Appendix for amplification of end-user support and promotion activities.

EVALUATION AND DISSEMINATION

Evaluation and Human Subject Protection

Quantitative and qualitative evaluation techniques will address the benefits and weaknesses of the coordinated system of databases for consumers and professionals, including the ease of use and accessibility. Data collection measures will include open-ended interviews and focus groups, documentation collection and analysis, and surveys. The evaluation team will conduct outcome analyses in the form a quasi-experiment made up of pretest and post-test data (i.e., quantitative measures collected before the innovations are begun and again after they have been in place for at least 12 months). In conjunction with the Project Advisory Committee, the evaluation team will develop survey items to measure in a reliable and valid manner the efforts of consumers, case managers, and agency staff that bear directly on these outcome objectives.

The evaluation team will employ process evaluation efforts to describe the activities of relevant consumers, professionals, and agencies in the State of Nebraska. Qualitative display tables and thick narrative descriptions will summarize the main findings from these efforts. In addition, the team will conduct appropriate quantitative analyses of the coded process data whenever such approaches are appropriate.

Statistical scaling of data from outcome surveys collected in Nebraska and a control state will produce indices to measure consumer, professional, and agency information use, efficiency, and service accessibility. Differences between the pretest and post-test scores across states showing greater increase in the affected areas in Nebraska will demonstrate that the program successfully improved service information accessibility, use, and efficiency. The evaluation team will use Ordinary Least Squares (ANOVA and multiple regression models) and/or Log-Linear

approaches to analyze the resulting data, depending upon the statistical properties of the final instruments. The University of Nebraska-Lincoln follows federal regulations (45 CFR 46 as amended and published in the Federal Register on June 18, 1991) for the protection of human subjects involved in research.

The evaluation will be led by Dr. Richard L. Wiener, a research social psychologist and statistical/methodology expert who applies methods and models of social psychology to problems of social policy and has published widely in the program evaluation literature. Dr. Wiener has been the principle investigator on several federal evaluation projects.

Dissemination

Communities and agencies that want to create coordinated, distributed human services databases will want to use the routines and standards developed through this project. It is expected that one immediate and direct-to-agency dissemination method will be through the software vendors who will actively promote upgrades that improve data import/exporting. The project will develop and post materials on the Public Policy Center website. Project staff and partners will actively seek opportunities to share information through AIRS (through listservs, websites, trainings, and conferences), and its regional and statewide associations, as well as other national organizations (e.g., National 211 Initiative, United Way of America, National Association of County and City Health Officials, Public Health Data Standards Consortium). To ensure that there is a permanent record of the work and its outcomes, articles about the process and products will be published in peer-reviewed, practitioner and academic journals, such as *Information & Referral* and *State Politics & Policy Local Quarterly*.

PROJECT FEASIBILITY

Technical Approach

Similar to current national initiatives for database interoperability (e.g., U.S. Department of Housing and Urban Development's Homeless Management Information Systems and the Centers for Disease Control National Electronic Disease Surveillance System), this project will build upon locally-maintained information that uses commercially-available software. The distributed database architecture, or batch system structure, will enable database owners to store data locally, and regularly connect through the Internet to a central server to send a copy of their database to a central data repository, where aggregate information will be stored. The distributed architecture allows database owners the ability to share only designated database elements, and maintain other elements for their agency use only. Aggregate data stored at the centralized location will be web-enabled. A vendor will be retained to operate the central server and provide hosting services. The vendor will be required to accommodate future development and enhancements, including scalability (i.e., the robustness of the system) and flexibility (e.g., project-defined features and look) and supporting the ability to import and export data using the xm data translation standards. It is expected that a robust package (e.g., SQL, Oracle) will be implemented. The database will be populated with data observing the codified data format structure, which will emphasize prescribed formats (e.g., fixed-answer responses, fixed-format responses).

Alternative approaches were considered, such as writing a new software product. However, commercially-available software products already exist and benefit from market forces for innovation and upgrading, which would not be similarly supported through a customized application. Centralized (permanent connectivity with full access rights to the Systems Administrator) or decentralized (which quickly grows unmanageable for more than just a few sites and may be organizationally cumbersome) architecture would not provide the economical, scalable solution to database owners' desire to manage their information locally. Internet connectivity will be used as it is less expensive and more reliable than creating an independent Wide Area Network (especially across the distances this project entails) and should minimize software requirements and avoid technical issues associated with installing software, fixing bugs, and providing other technical support.

This project builds upon databases already being maintained in communities using commercially available software. Because the project builds upon commercially-available software, vendors retain the incentive to continue to innovate and upgrade their products, but will now have xml and data formatting standards to improve their interoperability. The language for database, the AIRS/INFO LINE taxonomy, is continuously updated and contains more than 10,000 terms.

This project is being undertaken with the express intention of providing a model that may serve as an approach for national sharing of health and human services information. Software vendors will have incentives to make the products widely available. Because the xml data translation files are freely available, any other software vendors may create code to utilize them.

Applicant Qualifications

We have assembled a Nebraska and national team with outstanding qualifications to successfully implement the project. For example, the University of Nebraska Public Policy Center's Nancy Shank (see Appendix for expanded qualifications for bolded partners), principal investigator for the project, has successfully managed a previous TOP grant as well as a technology-based Special Projects of Regional and National Significance (U.S. Health & Human Services). She has authored reports being used as models by other states as they have developed information and referral projects. A project manager will be recruited to manage the project (see Appendix for job description). Kathleen Cook, Lincoln/Lancaster County Health Department, with more than 20 years experience in information systems, has been active in national efforts to set information technology standards and policies that must be implemented at a local level. She supervises the 17-county database in southeast Nebraska. Mary Jo Iwan, Nebraska Health and Human Services, in her role overseeing all State services for aging and special populations, administers two statewide health and human services databases and has successfully managed numerous national demonstration projects. Jean Jensen, Volunteers of America/Panhandle Partnership, has expertise in creating organizational alliances in rural areas and has developed a successful, web-enabled resource database that serves 11 counties, comprising approximately one-third of the state. Jamesena Grimes Moore, United Way of the Midlands, has developed a sophisticated, urban information database and call center, and she also connects to national initiatives in her capacity as Board Member and Human Resources Chair of the Alliance for Information and Referral Systems. Consulting partners include: Peter Bishop, Project Director at the United Way of Northeast Florida and the Chair of the AIRS Technology Committee, who has

been instrumental in developing the xm data translation standards; Paul Ladehoff, Interim Director of the Mediation Center in Lincoln, who brings extensive expertise in facilitating group decision making in public policy contexts using consensus-based processes as well as more traditional processes; Georgia Sales, INFO LINE of Los Angeles, who authored the now-standard AIRS/INFO LINE Taxonomy for human services and has worked with organizations to successfully develop national classification standards; and, Lori Warrens, a nationally-recognized leader in I&R for many years, who is the Executive Director of the international Alliance of Information and Referral Systems and created the nation's first 3-digit number dedicated to community information and referral. Additional consulting partners will be recruited as needed.

Project Implementation and Completion

The first year of the project will be devoted to: codifying the data formatting structure; creating, testing, and implementing the data conversion rules and routines; establishing the Internet-based interface; gathering baseline data; and developing administrative standards. The second year will be devoted to: refining the structures, rules, routines, and standards developed in year one; promoting to end users; providing training; and completing the evaluation. See Appendix for detailed time line information.

Privacy and Security and Sustainability

This project will not gather any individually identifiable information or otherwise work with any protected health information (i.e., HIPAA-related data). The project is solely focused on resource information, not client tracking. Although privacy of users is not an issue, security of the information is important because the information must be credible and accurate. One of the vendor platform specifications for the central system and server used for the central data repository will require bidders to determine how they will ensure data security. Processes will be developed for urgent updating (e.g., license revocation of a child care provider) and for removing resources (e.g., a provider chooses not to be included).

Once established, it is expected that costs to maintain the coordinated data system in Nebraska will be fairly modest (i.e., technology costs less than \$15,000 annually). This is based both on experience in Nebraska, as well as based on consultation from other states on their information and referral efforts. Additional costs will include staffing for oversight, quality assurance, and training. Because a coordinated, statewide database system will fulfill mandates or program goals for information and referral from within specific federal and state programs, funding will be explored with existing programs, and funding collaborations will be pursued with private supporters including additional United Ways, charitable foundations, and businesses. Support from organizations using the database will be solicited through annual memberships.