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Discover Health Services Near You! The North Dakota Story: Part I

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Abstract

Since the 2003 launch of NC Health Info, the National Library of Medicine has encouraged the development of Go Local databases. A team of Go Local enthusiasts at North Dakota's only medical school library wanted to obtain NLM funding and build a resource for their rural state. Although short on staff, money, and time, the team found a way to realize a Go Local database that serves the state's residents and helps them "Discover Health Services Near You!" A team approach and collaboration with health providers and organizations worked well in this small rural state. North Dakota's Go Local project offers a low-cost model that stresses collaboration, teamwork and technology. Part I, which appears in this issue, describes the rural setting, explains how the project was conceived, and the processes necessary to begin building the database. Part II, which will appear in the next issue, details how records were created, including developing the input style guide and indexing decisions, the NLM testing and review process, the maintenance and auditing process, and publicity and promotion of the project.

Keywords

American Indian health resources; database development; Go Local North Dakota; Go Local Project; MedlinePlus; National Library of Medicine; North Dakota; rural health care services

INTRODUCTION

Over the last few years, the *Journal of Consumer Health on the Internet* has published several articles about different Go Local projects around the country.¹⁻⁴ The mosaic of unique projects that is the national composite known as Go Local offers different experiences and contrasts. Each Go Local represents an excellent example of how individual projects following a set of uniform requirements and guidelines can customize their local situations to best serve their users' needs within the parameters of their settings. In Go Local as most else in life, it is true

that one size does not fit all. Fortunately though in the case of Go Local, the framework can be stretched and modified to accommodate most of the differences.

The experience at the Harley E. French Library of the Health Sciences, University of North Dakota (UND) School of Medicine and Health Sciences, presents a different scenario and set of circumstances in this national effort. A high percentage of North Dakota's population lives in rural areas. The rural living brings some inherent difficulties when accessing health services. Often it is difficult to travel to medical facilities, and there is an unequal distribution of services especially with regard to medical specialties. The rural aspects of the state and how it impacts health services played a defining role in the shape of Go Local North Dakota.

THE RURAL SETTING

North Dakota ranks 47th among the states in population. In 2006, the state had an estimated population of 635,867 and a population density of 9.30 per square mile compared to 79.6 people per square mile nationally. There are 53 counties within North Dakota. Of these, 36 are frontier (6 or less people per square mile),⁵ and 42 are designated as health professional shortage areas which are all located in rural areas.⁶

The state is agriculturally based with 54% of its population living in non-metropolitan areas. A trend toward more urbanization began as far back as 1900 and is projected to continue into the foreseeable future. Many of those leaving rural areas are younger, so urbanization has led to a significant age imbalance within the state.

In 1980, 12.3% of the state's population base was age 65 or older; in 2000, the proportion increased to 14.7%. Nationally, the proportion of elderly is 12.4%. North Dakota also has the highest proportion in the nation of elderly 85 years and older.⁷

Census figures at <<http://quickfacts.census.gov/qfd/states/38000.html>> reveal that North Dakota's population is generally homogeneous, with white persons accounting for 91.9% of the state's population (national average = 80.1%). Racial groups in the state with levels falling significantly under national averages include African American (0.8%; national average = 12.8%), Asian (0.7%; national average = 4.4%), and Hispanic or Latino (1.7%; national average = 14.8%).

The largest racial minority is represented by Native Americans (5.4%; national average = 1.0%). There are four federally recognized tribes with tribal headquarters located in North Dakota. They are: 1) Spirit Lake Nation, 2) Standing Rock Sioux, 3) Three Affiliated Tribes, and 4) Turtle Mountain Chippewa. In addition, the offices of the Trenton Indian Service Area are located in Trenton, North Dakota, and the Sisseton-Wahpeton Oyate have tribal lands within the borders of the state.

A growing and important population within the state is made up of foreign-born immigrants, including Hispanics, Asians, and Africans. This group makes up 2.4% of the population and has increased rapidly in recent years with gains of 29% during the 1990s. The increase accounted for 80% of the state's overall population increase during the decade.⁸

With rural residents, the elderly, American Indians, and foreign-born immigrants making up significant populations within the state, it is important that Go Local North Dakota address the health concerns of these groups. The Web site of the National Rural Health Association <<http://www.nrharural.org/about/sub/different.html>> has documented significant health disparities in rural America, including lack of health care providers, drug and alcohol abuse, and increased incidences of a variety of health conditions.

There are numerous health problems present in unusually high proportions in Native American communities, such as alcoholism, diabetes, mental health problems, poor dental health, lack of pre-natal care, and high infant mortality. Through the efforts of the Indian Health Service and others, progress has been made. However, there are still many health disparities in Native American communities. Compared to other Americans, American Indians and Alaska Natives (AI AN) are 600% more likely to die from tuberculosis, 510% from alcoholism, 229% from motor vehicle crashes, 189% from diabetes, 61% from homicide, and 62% from suicide.⁹

THE BEGINNING OF GO LOCAL NORTH DAKOTA

North Dakota has one medical school located at the University of North Dakota. The school's health sciences library is the state's largest. UND librarians discussed developing a Go Local for two years prior to submitting a proposal for funding from the Greater Midwest Region (GMR) NN/LM. In the fall of 2007, the staff of the Harley E. French Library of the Health Sciences was awarded the subcontract to be the lead library for the Go Local North Dakota project. The library maintains a Web site <<http://undmedlibrary.org/>> that includes many links to free resources and services, a large number being relevant to health consumers. As the state's designated resource library, the staff conducts outreach to health professionals as well as librarians and end users, including those in Native American communities. It was the logical choice to lead the state's Go Local project.

As planning began, there was a realization that the state's rural nature along with distinct demographic groups of the state presented both challenges and advantages. Among the challenges were locating the resources available in remote areas. This included services that are targeted to special populations. It would be difficult to enlist assistance in finding the resources and then promoting the database to the widely dispersed users once it was established. One of the advantages of building a database in a rural state is that since there are fewer services available than in more populous areas, managing the process can be less complex. In addition, many service providers, such as governmental agencies, are relatively efficient and have reliable Web resources. This made finding the scarce resources easier than originally anticipated.

Another challenge was that the library has a small staff with no position that could be dedicated even on a half-time basis to Go Local. Instead of trying to find funding for a project coordinator, it was decided that a team approach would be developed, and existing staff would incorporate Go Local into their current workflows. This resulted in some team members' routine duties being discontinued or delayed until the project was underway.

The three staff members who wrote the proposal became the nucleus of the Go Local team. The duties were distributed according to each of their areas of expertise. The principal investigator who submitted the proposal for funding became the project coordinator, who oversaw the subcontract, submitted quarterly reports and communicated with NLM when necessary, coordinated the team's activities, facilitated collaboration with identified potential partners and collaborators, and focused on the inclusion of services for the state's primary minority population, Native Americans. The resource development and outreach coordinator solicited services from organizations and coordinated promotion through publicity and training. New technologies such as depositing prospective services onto a del.icio.us site and 2-1-1 data mining aided the process. The site development coordinator managed building the database, supervised indexing of resources by subject and geography using "Go Local" controlled vocabulary, and managed user accounts and local customizations. Part of the plan was to use NLM start-up funds to hire a "data input specialist" in a six month part-time student position (50%). That person would do inputting and indexing of entries in the NLM system to build the database.

Were There Existing Resources?

The team's objective was building a state Go Local that would create a freely available database of consumer health resources and services in North Dakota. Even though there were some existing lists of services, they were not as comprehensive or as accessible to the public as Go Local North Dakota was envisioned. As Richwine and colleagues noted in their article on the Indiana experience, Go Local links to and from the associated topics on MedlinePlus have the "added value of efficiency, currency of Web sites, and linking to quality filtered information."¹

As the state's existing databases containing service information were examined, the pleasant discovery was made that even in a small, rural state, there were more services available than realized when the project was conceptualized. They helped shape the robust and inclusive database that became Go Local North Dakota.

Who Could Help Build the Database?

The Go Local North Dakota team knew that enlisting assistance from other health sciences librarians in the state would be difficult. They are few in number, and many of those outside of the university manage one person libraries. They would have limited time to contribute to the effort. However, UND operates a state-wide, community-based medical training program with four clinical campuses throughout North Dakota. One clinical campus site is located in each quadrant of the state. Along with the Harley E. French Library, these clinical campuses form a network of cooperation with a long history of working together to provide library services to health care students, faculty, and health care providers. The plan was to enlist the clinical campus librarians (most of whom are paid at least a portion of their salaries from the university) as partners in the project. These librarian partners brought shared goals and common values.

The Go Local team also approached collaborators who might agree to participate in one or more key project activities at a significant level and in a systematic way. One area was the identification of services in a collaborator's geographic or subject area. It was intended that this identification would help grow the database. It was also hoped that collaborators with existing databases would share their data electronically. In addition, the vision was to have collaborators promote Go Local North Dakota to stakeholders in their geographic regions or to populations they served.

Collaborators included a number of libraries, such as the North Dakota State Library, the health sciences and hospital libraries in the state, and the tribal college libraries. The five tribal college libraries in North Dakota also serve as public libraries for the Native American communities in which they are located. The librarians and staff have partnered on health information projects in the past with the Harley E. French Library of the Health Sciences.¹⁰

In addition to libraries, other collaborators identified were the state's 58 public health units and their coordinating agency, the North Dakota Department of Health <<http://www.health.state.nd.us/>>. Tribal Health Departments were also identified as sources for information about services available on reservations.

The Center for Rural Health, located at the University of North Dakota, <<http://www.med.und.nodak.edu/depts/rural/>>, and the Rural Assistance Center, U.S. Dept. of Health and Human Services <<http://www.raconline.org/>>, also housed at the Center for Rural Health were invited to collaborate. Their many projects and connections with rural North Dakota were extensive, and they would be a valuable resource in identifying services. They could also potentially assist with promoting Go Local to their rural constituents.

Other organizations viewed as potential collaborators were Mental Health America of North Dakota <<http://www.nmha.org/>>, providers of the 2-1-1 service in North Dakota, and AARP North Dakota <<http://www.aarp.org/states/nd/>>. AARP North Dakota is a state affiliate of AARP <<http://www.aarp.org/>>, a nonprofit, nonpartisan membership organization for people age 50 and over. The association maintains a Web site, direct mailings, programming, and other outreach activities to members in the state. Tapping into AARP's resources and communication network to reach the 50+ population would be vital.

Who Would Benefit?

Go Local North Dakota saw health consumers, in general, and special populations specifically, benefiting from access to health service information at a local level. Targeted populations included library users, health care consumers, rural residents, Native Americans, the elderly, and the general public.

The project used the term "stakeholders" to apply to institutions and other entities serving these populations directly, or serving other institutions that served these populations. Stakeholder institutions or entities possessed a high visibility within a region or within the state as a whole. They were viewed as able to advance the goals of the project through their influence. Institutional stakeholders included libraries, health care providers, and rural communities (see Figure 1).

The Go Local North Dakota team saw a project built upon a framework of partnership and collaboration with varied enterprises. This network of cooperation could strengthen the project by sharing expertise and resources and allow the development of a database that would best serve the rural state.

BUILDING THE DATABASE: IDENTIFYING SERVICES

After the project proposal was approved by NLM in September 2007, the focus shifted from planning how the project would be constructed to procedural issues relating to identification of services and creation of their corresponding records. The remaining three months of calendar year 2007 was spent preparing for the start of record input. NLM's input manual was particularly useful as were the policies and procedures of other sites available via the Go Local Extranet. Staff familiarized themselves with NLM's input system. Searching other sites both within the input system and the public interface gave insight into how other sites had approached record creation.

Project staff worked to develop guidelines for selection of services and record input. These guidelines can be found on the Go Local Extranet which is available to Go Local participants. Limited staff resources, a tight time line for implementation, and lack of experience with Go Local prompted reliance upon information found in documents from other projects when creating Go Local North Dakota policies. The repetition of basic elements encouraged the adoption of key points, which were synthesized into a document containing guiding principles. Changes were made to accommodate personal preference and local circumstances. Final guidelines reflected procedures unique to the Go Local North Dakota project, yet they were firmly grounded in the experience of other Go Locals.

Funds received from NLM allowed the hiring of a .5 FTE position for data entry. The job description for this position, data input specialist, was written during this period. The position was advertised, and interviews were conducted in late November and early December. The goal was to have the position filled by the end of December with a start date beginning the early part of spring semester. The position was filled on schedule with a graduate student

possessing relevant skills and experience gained from positions previously held in the School of Medicine and Health Sciences.

With the core staff of three full-time librarians incorporating Go Local into their regular work routines and one half-time data input specialist, it was clear that there would be a lot of work ahead. Despite the challenges, the goal was always a quality product ready to launch on schedule that would serve the residents of the state. To accomplish this, shortcuts would have to be taken, and practical decisions would need to be made. North Dakota did not have an existing consumer health database or directory from which records could be tapped. Creativity was needed to identify sources of information from which to build upon. In the process of writing the proposal, a number of relevant data sources and options for collecting data were identified.

Health System Data

Database creation was central to Go Local North Dakota. The goal was to have a minimum of 2,400 records publicly available by the time the database went live in August 2008. The project's partner clinical campus librarians were asked to contact larger health care systems in their geographical areas to obtain data. This data would then be imported to Go Local with indexing added for services and the areas served. It was thought that data from smaller systems could be generated directly from their respective Web sites. Records were to be created at both the system and departmental levels so that users would have the option of being linked directly to services rather than being required to dig down once taken to a site.

Clinical campus librarians made contact with public relations and IT staff at two of the state's largest health systems. Contacts were initially optimistic that data could be extracted and provided in spreadsheet form as requested, but this ultimately did not prove to be the case. Even though clinical campus librarians followed up with their contacts several times, the factors contributing to the ultimate failure of systems to supply data were never fully understood. In one case, the system began a major reorganization that included staff cutbacks shortly after the request had been made. Another simply said that the data would not be available. Whatever the reasons, each site maintained an excellent Web site from which Go Local records could be manually constructed, and this method proved satisfactory.

In the case of smaller health systems, clinical campus librarians attempted to build spreadsheet data by visiting system Web sites. As the project moved along and the data input specialist became more proficient, it became apparent that formulating the records at the point of input would be more efficient than relying on spreadsheet data from a third party. Although data import using spreadsheets was initially seen as the preferred mechanism for record creation, this was abandoned in favor of using copy functionality and other mechanisms existing within the Go Local input system for small data sets. This may have been due to personal preferences regarding workflow on the part of input staff. Certainly the inability to index records outside of the input system played a role. Since data had to be created anyway, there was no clear advantage in working outside of the system for smaller sets of data.

Data Sets and their Review

Aside from health systems, much of the data was available through MS Excel files. Import of records into Go Local from spreadsheet data was seen as a clearly superior workflow when it came to large data sets obtained from a variety of sources. Since a significant amount of data was already contained within the spreadsheets, editing capabilities and other mechanisms for data manipulation available within standard spreadsheet software sped up the record creation process. Import of records using the system's import feature consistently went smoothly and became a regular part of the workflow.

Once data files were obtained, the first step was for staff to check records against existing records in Go Local for duplication. Sometimes this was not a straightforward process. For example, an agency's program may have already been indexed as part of a record for the agency in Go Local but included as a stand-alone entry on the spreadsheet. Once identified, duplicates were deleted from the list. The remaining records were then reviewed using the selection guidelines and ranked by selectors according to the three designations "1," "2," and "D." Records ranked with numeral one indicated a service with the highest priority that should be added prior to the site being launched. These usually included clinical services, nursing homes, and other facilities providing direct patient care. Records ranked with numeral two indicated services seen as meeting selection guidelines and within the scope of Go Local North Dakota but which should be given a lesser priority. Records in this class were viewed as supporting healthy living but did not necessarily reflect services that provided direct patient care. They would be added but their inclusion prior to the site's launch was dependent upon time available for input. Examples of sites in this category include social service agencies and county extension offices. Records ranked with the letter "D" indicated services judged to be outside of the scope of Go Local and/or not meeting established selection guidelines. These sources were not to be included in Go Local and were deleted from consideration. Ultimately, staff was able to create records for selected sites ranked with both numerals one and two (i.e., highest and secondary priorities) prior to launch.

In addition to using the project's selection policy as a guide when considering a site for inclusion, attention was given to the core service terms found in NLM's Local Service Term Priority Checklist

<<http://www.nlm.nih.gov/medlineplus/golocaldocs/>

[local_service_termpriority_checklist.doc](http://www.nlm.nih.gov/medlineplus/golocaldocs/local_service_termpriority_checklist.doc)>. The checklist was created to help developing Go Local sites prioritize entry of local services. The checklist uses a numerical ranking. Service terms ranked with the numeral one are designated as important services. Sites approved for launch should include a broad range of services dispersed throughout its geographical coverage area that reflect most of priority one terms. Service terms ranked with the numeral two are seen as being also important. But sites may launch without some of these entries. Service terms ranked with the numeral three are viewed as being nice to have but are not necessary for a site to launch. NLM encourages sites to add records in underrepresented areas after launch, and priority three sites can be added later.

Spreadsheet data for a variety of health related facilities was supplied by NLM. This included Medicare data for the state covering pharmacies, home health care agencies, nursing homes, hospices, hospitals, and dialysis services. The North Dakota Medical Association provided data for similar categories with identification of additional services for clinics, ambulatory surgery centers, and ambulance services, as well as various agencies, organizations, and associations. Data was also received from the Rural Assistance Center, one of the designated project collaborators. A database of tribal services available within reservation boundaries was obtained from the Rural/Reservation Community Partners, AmeriCorp *VISTA Project <<http://rsd.ndgro.com/Portals/17/Projects%20Flash/MHA%20Directory%20Total%20Final%2010252007.swf>>.

2-1-1 Data

One of the more comprehensive sources of data identified early in the project as a collaborator for Go Local North Dakota was Mental Health America of North Dakota. The organization administers the 2-1-1 database and phone service in the state which connects people with important community services <<http://www.mhand.org/211/index.asp>>. The database provides 24-hour access to information on providers of housing, food, health, and other human

services. Programs include city, county, state, and federal government programs, as well as programs operated by nonprofit organizations or community groups.

The story of how 2-1-1 data was extracted and made available to Go Local North Dakota began with an inquiry made to the MPLUS-GOLOCAL list (Go Local Participants Discussion List) concerning the extraction of data. Kevin Hatfield, Systems Manager at Mercer University School of Medicine's Medical Library, responded that he had written a program to harvest records directly from Web sites similar to and also affiliated with 2-1-1. The program used to obtain the records was written in Perl and ran on a Debian distribution of Linux. The 2-1-1 Web site gives information in small groups with links to further details such as addresses and descriptions. It is designed for use by human eyes and mouse clicks. The Perl program retrieved the records using virtual Web browsers, posting the expected content for each search, and following every link. AWK and PHP programs were used to clean up the downloaded data, parse it into Go Local's upload format, and convert the records into CSV files suitable for editing with Microsoft Excel. Although the process did not achieve conversion between 2-1-1 taxonomy and Go Local health service terms, other fields including site names, addresses, phone numbers, URLs, and site descriptions were present and could be imported into Go Local. This was a significant contribution to the project and allowed the efficient creation of records for a large number of services throughout the state.

Other Data

In addition to service information supplied in spreadsheet form from sources already mentioned, the project was able to obtain compilations of records for a number of specific service types. These were available in PDF files downloadable directly from different organizations' Web sites. Windows Notepad was used to format data into tab delimited fields before cutting and pasting into an Excel spreadsheet. Files were then converted to CSV format and imported into Go Local. Hundreds of records were created in this way for service types such as libraries, food pantries, support groups, and ambulance services.

In one case, a survey was developed to gather service information. There are 58 local public health units in the state. Since no single source of information reflecting services offered by these units could be identified, a questionnaire was developed. Choices consistent with topical terms mapped from NLM's service term "Public Health Services" were enumerated in order to coordinate responses with the NLM vocabulary. Out of nearly fifty surveys sent, less than ten responses were received. This was admittedly a labor intensive process that resulted in little benefit. Fortunately, later investigation found detailed information to be present on the North Dakota Department of Human Services' Web site, so quality records could nevertheless be constructed.

Health service information was widely available directly on the Web. This presence provided another option for identifying services useful to state residents and to build the database. Some of these were national in scope, such as those identifiable through *Toll-Free Numbers from the National Library of Medicine* <<http://healthhotlines.nlm.nih.gov/index.html>> and NLM's *Useful Sites for Building Go Local* available through the Go Local extranet. In-state services were identified using the North Dakota Department of Human Services Web site <<http://www.nd.gov/dhs/>>. This Web site brings together services under a number of categories including adult and aging, children and family, child support enforcement, financial help, Medicaid and other medical services, mental health/substance abuse, and services to individuals with disabilities. The site was helpful when verifying human service information from all sources. Other services within the state were identified using FirstLink's Web site <<http://www.myfirstlink.org/index.html>>, a regional organization working to link people and resources in the area. FirstLink maintains a comprehensive list of services, many of which fit into the scope of Go Local North Dakota.

Web sites were consulted that supported the special population groups targeted by our proposal. Information for nursing homes and assisted living facilities was available from the Web site of The North Dakota Long Term Care Association <<http://www.ndltca.org/index.html>>. A wealth of information was found via the ND Senior Info Line <<http://www.nd.gov/dhs/onlineserv/ndseniorinfo/index.aspx>>, which is maintained by the North Dakota Department of Human Services. Resources specifically serving North Dakota's Native American population were consulted. Tribal program listings on tribal Web sites maintained by the tribes in the state along with the *Tribal Resources Directory* <<http://www.ndhealth.gov/ndiac/directory/directory2.asp>> were helpful in establishing records for this population group. The directory integrates services for the tribes and is searchable by tribe, resource/service, and city.

USING THE EXISTING RESOURCES AND NEXT STEPS

Unique albeit unforeseen challenges were encountered as work began on getting the data into Go Local. Some of the assumptions made in the early stages of the project proved incorrect. Remaining flexible and open to abandoning those assumptions proved vital as database creation moved forward. Part two of this article, which appears in the next issue of the *Journal of Consumer Health on the Internet*, will examine the process by which records for identified sources were constructed, detail record clean-up and maintenance issues, discuss local customization features used to give the site its distinct "personality," and highlight steps taken to promote the site to intended users.

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FIGURE 1.
Go Local North Dakota Organizational Chart