

**REAL CHOICE DATA TEAM**

**RECOMMENDATIONS**  
**ON**  
**CREATING A STATEWIDE INFORMATION RESOURCE**  
**FOR HUMAN SERVICES**

**Issued March 2003**

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## EXECUTIVE SUMMARY

Information and referral services are an important point of entry for persons seeking appropriate human services options. Across Nebraska, several key initiatives have begun laying the groundwork for statewide collaboration in data collection, sharing, and promotion activities. Consensus is emerging that developing a comprehensive, collaborative, statewide, health and human services database is both desirable and feasible.

Under the aegis of a Nebraska Health and Human Services System Real Choice grant<sup>1</sup> from the Centers for Medicare and Medicaid Services, the state convened a working group to help envision the elements that should comprise a statewide resource database. The working group, the Real Choice Data Team, met during 2002 and comprised information and resource providers and stakeholders from across the state (see Appendix for membership). The Team's goal was to make recommendations on a range of key issue areas including inclusion/exclusion criteria, key data elements of a statewide resource database, taxonomy adoption, organizational partnerships, and future statewide planning efforts.

The Data Team's recommendations are:

### **Purpose, Users, Goals, Needs, and Benefits**

1. The statewide, coordinated system of databases should provide information about health and human services in Nebraska. The purpose should not be confused with a desire to track information about clients (page 4).
2. The statewide, coordinated system of databases should:
  - a. Build on existing databases
  - b. Be accessible, current, and accurate
  - c. Be statewide in scope and flexible in design
  - d. Be inclusive
  - e. Be replicable through a variety of means and redundant in content (page 5).
3. The statewide, coordinated system of databases should be accessible to multiple users, including:
  - a. Consumers - to assist them in making informed choices by identifying where and what kinds of services are available
  - b. Agencies - to assist them in referring clients to services and to promote the services and programs they provide to other clients
  - c. Policy Makers and Researchers - to aid them in identifying gaps and strengths in service availability and need (page 6).

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<sup>1</sup> Real Choice grants were awarded to "design and implement effective and enduring improvements in community long term support systems to enable children and adults of any age who have a disability or long term illness to live and participate in their communities."

4. Integration between various levels of information and referral including self-help, assisted information and referral, specialized information and referral, and case management should be pursued. Consumers with more complex concerns should be guided to the professional services of Nebraska's assisted and specialized information and referral resources (page 6).

### **Organization**

5. An organizational philosophy to guide working with participating organizations should focus more on persuasion rather than mandate, and more on support than control (page 9).
6. A representative Affiliates Committee should be formed with balanced membership comprising organizations maintaining computerized human service databases, state agencies, consumers, information technology experts, etc. The Affiliates Committee should be responsible for directing the network and creating policies (page 9).
7. A mission statement for the statewide data resource initiative should be developed and should be compatible with the mission statements of its partners, including the Nebraska Resource Referral System (NRRS), Answers4Families, NE Help, the United Way of the Midland's 211 Pilot, and the Lincoln/Lancaster County Health Department (page 9).
8. The popularity of the NRRS Internet resource should be capitalized upon, but it should be expanded and adapted to serve as the primary, statewide, Internet-based site and main consumer access point for health and human services information (page 10).
9. The initial terms of the affiliate agreement and the process for offering formal affiliation (to organizations that meet the terms of the agreement and are willing to actively contribute and participate) should be developed (page 10).
10. Standards should be set for implementing and monitoring the submission, editing, incorporation, and maintenance of resource information (page 11).
11. The technical development of the system and its operations should be contracted (page 12).
12. Fundraising activities should be developed and coordinated through the Affiliates Committee (page 13).
13. HHSS (the Nebraska Health and Human Services System) should be retained as the general manager of the initiative and system, while ensuring partnership agreements for continuity (page 13).

### **Data Structure**

14. An Advisory Committee should be convened to evaluate the four models and select a model to develop (page 17).

**Organization of Information**

15. The AIRS/INFO LINE Taxonomy of Human Services should be adopted to categorize resources (page 19).
16. A statewide ad hoc committee should be convened to make initial recommendations on the depth of taxonomy in each of the basic service areas. The ad hoc committee should include people who maintain human service databases, assist persons seeking resources, and manage information and referral staff (page 20).
17. A statewide standing committee should be established to monitor taxonomy issues. The standing committee should include people who maintain human service databases, assist persons seeking resources, and manage information and referral staff (page 20).
18. Information about resources included in the statewide system should offer, at a minimum, standardized basic content. The minimum standard considered should be the areas of categorical overlap between Service Point, IRis, and NRRS since they are the major systems at this point (page 21).
19. A working group should be formed to confirm and define the areas of overlap between Service Point, IRis, and NRRS (page 21).
20. The database system should accommodate additional information about resources and the possibility of providing consumer-ratings of services (page 21).
21. An advisory committee should be convened to make initial recommendations on resource inclusion and exclusion criteria (page 22).

**Data Presentation**

22. A unique identity for the database should be created that emphasizes self-direction and consumer choice (page 24).

## **BACKGROUND**

Information and referral providers maintain lists or databases of providers for the purpose of linking people to services. Some agencies may exist solely to provide information and referral services; however, most organizations provide information and referral as a supplement to other services they provide, such as the provision of direct services.

Maintaining current, comprehensive information is time-consuming and costly because information about human services changes rapidly as programs and organizations adapt their programs to meet client needs and funding guidelines. **Without coordination, many organizations have found that their efforts at maintaining and providing information and referral services have resulted in duplicative efforts and overlapping services with other organizations helping the same target groups.**

Many information and referral services are unable (or do not have a clientele base large enough) to designate staff to maintain information, or to train and evaluate the staff to fully assess callers' needs. Individual information and referral services may also be limited in capacity to provide 24-hour/7 day a week services, to provide toll-free access, and to provide accommodation for persons with special needs. For example, although persons who are deaf or hard of hearing may currently use TDD/TTY relay systems, which provides a person to translate between the caller and the agency, many information and referrals are unable to provide *direct* access through TDD/TTY units and software. Many information and referrals also find it difficult to provide access to persons who do not speak English.

The challenges of maintaining a quality information and referral service with adequate resources, accessible to clients, have resulted in collaborative efforts. Throughout the United States a growing number of states and municipalities have developed cooperative information and referral systems. These cooperative information and referral systems enable governmental entities, non-profits, and for-profit organizations to collaborate in coordinating, managing, and disseminating Information and referral services within their communities.

### **NEBRASKA EFFORTS**

In Nebraska, organizations have been providing information and referral services for many years. As in other states, information and referral services have ranged from small services (serving small populations or having a narrow focus) to larger services (serving larger populations or having a broader focus). And, as in other states, there has been great need for and interest in broad collaborations to provide comprehensive, up-to-date, easy-to-access information and referral services to all Nebraskans.

### **Long-Term Care Task Force**

There has been growing interest, additionally, in coordinating Nebraska information and referral services to improve human service delivery and reduce costs. For example, *Nebraska's Long-Term Care Plan* (May 1997) included information and referral services as one of a core set of services that “should be identified and given priority for funding within the system.” The Long-Term Care Plan *Work Team Report* (May 1997) more specifically recommended expansion of the Nebraska Resource and Referral System (NRRS). The NRRS is a statewide database of resources that has been maintained since 1988 by the Nebraska Health and Human Services System (HHSS).

Following up on its planning work, the Long Term Care Task Force pursued its’ interest in information and referral services and expansion of the NRRS by investigating the possibility of piloting a coordinated information and referral system in a geographical area of Nebraska. In early 1998 the Long Term Care Task Force approached several Omaha area, other local and regional, and statewide information and referral services to discuss interest in coordinating services and data. The meeting included representatives of HHSS, non-profit organizations, and health care providers. In subsequent meetings, the group determined that restricting the focus to the Omaha area would unnecessarily prevent investigation of an ultimate statewide information and referral service. Therefore the group decided to open the discussion to organizations throughout the state to determine interest statewide in a coordinated system.

### **Regional Conferences**

In November 1998 the group convened “Information and Referral Network” conferences in Kearney and Omaha. The conferences featured Judy Windler, Executive Director of the Texas Information and Referral Network, and presentations from Nebraska-based information and referral services. The conference revealed wide support for a statewide information and referral model.

### **Nebraska 211 Coalition**

Emerging from the conference, the Nebraska 211 Coalition was created to continue exploration of the model. Coalition members were recruited from individuals and organizations throughout the state with an interest in supporting and collaborating in the 211 model. The Nebraska 211 Coalition has spear-headed efforts in Nebraska to investigate the feasibility of a 211 system and has joined the national 211 Initiative as a Collaborative Partner.

### **Legislative Initiatives**

Parallel to the efforts of the Nebraska 211 Coalition, during the Ninety-Sixth Legislature (First Session) Senator Jim Jensen introduced Legislative Resolution 49 (LR 49), which was subsequently passed by the Unicameral. LR 49 called for “an interim study to determine the feasibility of a Statewide Information and Referral System,” to be reported to the Legislative

Council by December 1, 1999. Among other activities initiated through LR 49, a series of public hearings have been conducted to ascertain statewide support of the 211 system.

### **Survey and Cost/Benefit Analysis**

In June, 1999, HHSS and the United Way of the Midlands entered into a contract with the University of Nebraska Public Policy Center to survey existing information and referral services and conduct a cost/benefit analysis of a statewide 211 model (University of Nebraska Public Policy Center, 2000).

### Agency Commitment

In Nebraska, of the 191 self-identified information and referral provider agencies, **74% actively sought resource information** to provide information and referral services and committed nearly **31,000 hours** annually to the task. A great majority of the agencies, indicated that they provide information only for specific target populations (e.g., the elderly, persons with disabilities, etc.) or confine their information to geographical areas (e.g., city, county, or some regional service area).

### Comprehensiveness

Although each Nebraska county has agencies that provide information in at least **one** of ten service categories (basic subsistence, consumer services, criminal justice and legal services, education, environmental quality, health care, income security, individual and family life, mental health care and counseling, and organizational/community services), there nine Nebraska counties that do not have access to a **single** information and referral that provides **comprehensive** information about existing services. This means that persons must make calls to a number of agencies before information could be obtained on a variety of topics.

### **Real Choice Data Team**

In May 2002, Nebraska Health and Human Services convened a statewide "Data Team," comprising representatives from the major information and referral agencies across Nebraska. The work of the Data Team was supported through Real Choice Systems Change funds from the Centers for Medicare and Medicaid Services. The Data Team was established to make recommendations about statewide standards, protocols, inclusion/exclusion criteria, and sharing data as part of a statewide resource database.

This report summarizes the work of the Data Team. The Data Team's recommendations are summarized in the following Issue Areas:

- Purpose, Users, Goals, Needs, and Benefits
- Organization
- Data Structure
- Organization of Information
- Data Presentation

## RECOMMENDATIONS

### PURPOSE, USERS, GOALS, NEEDS, AND BENEFITS

#### Purpose

The purpose of the statewide coordinated system of databases is to provide information about health and human services for persons looking for Nebraska resources. This purpose should not be construed to imply an underlying desire to use the system to track information about clients or users of services. Thus, these recommendations relate to information about resources, not about client tracking mechanisms.

**Recommendation:** The statewide, coordinated system of databases should provide information about health and human services in Nebraska. The purpose should not be confused with a desire to track information about clients.

#### Goals

The development of a statewide database is a potentially daunting and expensive undertaking. It becomes more so if the system is envisioned as entirely *new*. Because there are many qualified organizations committed to maintaining health and human services databases, it was determined that a statewide effort should **build on**, rather than duplicate the work already being done.

By building a coordinated system of databases rather than a single, centralized database, Nebraska will:

- build on assets and strengths of current systems
- maintain commitment and support of many organizations
- leverage local knowledge of resources that will likely lead to more comprehensive and more current information
- reduce duplication

To be useful, the information provided through the database must be **accessible, current, and accurate**. The information must be user-friendly and formatted in a way that enables a variety of users to find needed information quickly and easily. Standardization in how the information is presented and organized will help users quickly identify the information being sought. Quality assurance standards and training are important strategies to address the currency and accuracy of information.

From its initiation, the system should be conceptualized as having a **statewide** focus and mission. The system should be developed to accommodate **flexibility** for future alterations, expansions of partners and information, and technological and other improvements.

A coordinated system of databases should recognize the value of multiple organizations' participation in contributing information and operate from a position of **inclusiveness**.

**Replication** (i.e., availability through a variety of means) and redundancy (i.e., back-ups to information) will help to ensure on-going accessibility to the information. Duplication (e.g., keying in the same information multiple times) is a waste of resources and may contribute to inaccuracies.

The above considerations led the Data Team to endorsing the following philosophy in its work:

**Recommendation:** The statewide, coordinated system of databases should:

- Build on existing databases
- Be accessible, current, and accurate
- Be statewide in scope and flexible in design
- Be inclusive
- Be replicable through a variety of means and redundant in content.

### **Users of the Database**

Nebraska currently has hundreds of organizations that actively collect information about health and human services available to Nebraskans (University of Nebraska Public Policy Center, 2000). Databases may be used primarily by services coordination or case management staff, may be developed primarily as a “self-help” tool for consumers, or may serve a variety of audiences.

A structure of a statewide, coordinated system of databases should meet the needs of various constituencies:

#### Users

- Be user friendly
- Be accurate
- Empower and protect consumers by disclosing the information and its limitations

Participating Organizations

- Have built-in accountability of organizations providing information
- Have quality control mechanisms
- Be flexible
- Be accessible for organizations to participate in sharing information (e.g., making entry of information easy, allowing organizations to key in information once, making connection to share the information easy)
- Recognize the "identities" of participating databases that are contributing to site

Administration

- Be cost effective both initially (i.e., to build, setup, and implement) and as it operates (i.e., to monitor and maintain)
- Be simple, easy, and efficient
- Minimize labor required to maintain to achieve sustainability

**Recommendation:** The statewide, coordinated system of databases should be accessible to multiple users, including:

- Consumers - to assist them in making informed choices by identifying where and what kinds of services are available
- Agencies - to assist them in referring clients to services and to promote the services and programs they provide to other clients
- Policy Makers and Researchers - to aid them in identifying gaps and strengths in service availability and need.

**Recommendation:** Integration between various levels of information and referral including self-help, assisted information and referral, specialized information and referral, and case management should be pursued. Consumers with more complex concerns should be guided to the professional services of Nebraska's assisted and specialized information and referral resources.

**Benefits**

The Data Team identified a variety of benefits to developing a statewide database/system of coordinated databases:

- Availability of more complete information about health and human services
- Ease of access to information, and ability to make accessible (e.g., disability, language) to consumers and agencies
- Ability to “publicize” programs and services
- Reduction of duplication of effort, both of agencies attempting to maintain information as well as for agencies providing information
- Enhance consumers’ ability to choose services that best meet their needs
- Better quality information

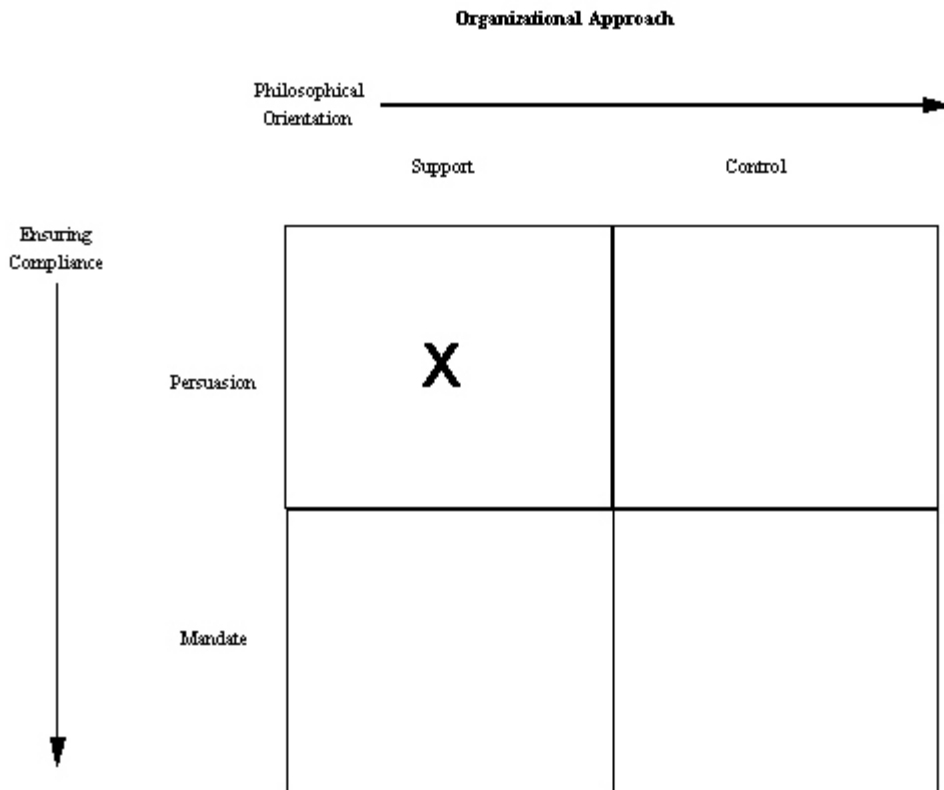
## ORGANIZATION

### Philosophical Framework

Developing, implementing, monitoring, and evolving a statewide coordinated system of databases will require significant coordination among many stakeholders, including agencies, the State of Nebraska, consumers, researchers, policymakers, and others. The system envisioned by the Data Team builds upon existing resources and relies on voluntary participation. However, “voluntary” participation does not imply that participating agencies may be lax about adherence to agreed-upon standards. An organizational structure must be developed that:

- recognizes the voluntary nature of the activity
- promotes the value of inclusiveness in recruiting participating organizations
- is supportive of organizational participation (as compared to controlling)

The Data Team developed the following schematic to represent philosophical framework that may guide interactions with participating organizations:



**Recommendation:** An organizational philosophy to guide working with participating organizations should focus more on persuasion rather than mandate, and more on support than control.

### **Organizational Structure**

The coordinated system will rely heavily on the participation of organizations and agencies. These organizations and agencies, therefore, should be key stakeholders in developing an organizational structure for the statewide system. In addition, representation should include consumers, information technology experts, and state agencies.

**Recommendation:** A representative Affiliates Committee should be formed with balanced membership comprising organizations maintaining computerized human service databases, state agencies, consumers, information technology experts, etc. The Affiliates Committee should be responsible for directing the network and creating policies.

### **Organizational Functions**

#### Mission

A vision for the statewide coordinated data system should be developed to guide its growth. It should recognize and be inclusive of other agencies and initiatives that are currently providing information and referral to Nebraskans.

**Recommendation:** A mission statement for the statewide data resource initiative should be developed and should be compatible with the mission statements of its partners, including the Nebraska Resource Referral System (NRRS), Answers4Families, NE Help, the United Way of the Midland's 211 Pilot, and the Lincoln/Lancaster County Health Department.

#### Providing Access

One of the key functions of the organization will be to provide access to the data. It may include maintaining the database or contracting out the maintenance. To facilitate Internet access, it should include hosting the information on a server, maintaining a website that links to participating organizations, or contracting out the hosting with an application service provider. Other means of access should also be explored including hard copy directories.

**Recommendation:** The popularity of the NRRS Internet resource should be capitalized upon, but it should be expanded and adapted to serve as the primary, statewide, Internet-based site and main consumer access point for health and human services information.

### Participating Data Sources

The system of coordinated databases requires decisions about which data sources will contribute to the resource information. The participation of a variety of data sources should be encouraged. However, inclusiveness should be balanced with the need for the information to be accessible, current, and accurate.

The Data Team identified a number of questions that should be addressed:

- Who will determine which data sources participate?
- Who will recruit data sources?
- Who will set and what will be the criteria for participation?
- Will we have a monitoring or probation period?
- How will geographic coverage of the entire state be achieved?
- How will gaps in resources be evaluated, and how will they be filled?
- How will databases covering the same resources be managed?
- How should questions and problems be resolved?

**Recommendation:** The initial terms of the affiliate agreement and the process for offering formal affiliation (to organizations that meet the terms of the agreement and are willing to actively contribute and participate) should be developed.

### Gathering, Maintaining, and Inputting Resource Data

To ensure that the information is accurate, current, credible, consistent, and reliable, standards governing the gathering, maintenance, and inputting of information about resources is vital. It is important that agencies who are the contributing sources of information, be provided clear guidance on minimum standards for gathering and maintaining information about resources.

Policies should be established that address:

- How regularly should information be updated/verified after inclusion in database?
- How closely should credentials be checked?
- How will resources listed in the database make/effect changes to their information?
- How will other users make suggestions (additions, changes) to information?
- What is the approval process for initial inputting? It is the same or different for changes to information about existing resources? Will there be one or several steps?
- What is done with agencies that don't respond (for initial inclusion/updating)?
- How should resources be identified? Is it okay to pull from secondary sources (other directories/listings)?
- Who will approve and/or synthesize information for database?
- How will data be contributed to the system?
- How will standards for data inputting, maintenance, etc. be monitored? What are the consequences for not meeting standards?
- How should questions and problems be resolved?

**Recommendation:** Standards should be set for implementing and monitoring the submission, editing, incorporation, and maintenance of resource information.

### Training and Technical Assistance

To assist participating data sources effectively participate in the statewide, coordinated system, training and technical assistance should be provided. In addition, opportunities for networking should be developed. Currently, there is no opportunity for organizations involved in resource collection to share experiences and information and train each other. Ending this type of isolation will be an important function of providing training and technical assistance. Training and technical assistance should be made available to administrators and managers, as well as staff doing the resource identification and inputting data.

Key areas that should be covered in training and technical assistance should include:

- The policies and minimum standards for gathering, maintaining, and inputting data
- Quality assurance standards, methods, and tools
- Using the taxonomy
- Resolving questions and problems

### Subcontracting

It may be necessary to subcontract out work to implement and manage the statewide, coordinated system. One of the organizational functions should include the authority and responsibility to select contractors. Included in this responsibility should be policies and procedures for fiscal and programmatic accountability.

**Recommendation:** The technical development of the system and its operations should be contracted.

### Promotion/Outreach

Promotion of the statewide data system is an important step in reaching the target audiences of consumers, agencies, policymakers, and researchers. Promotion should also facilitate acceptance and participation. Promotion may include traditional promotional techniques (e.g., brochures, novelty items, presentations, billboards, mailings) as well as new techniques (e.g., posting on listservs, seeking links from related Internet sites, registering with widely-used search engines).

### Marketing

Marketing includes those activities that may result in revenue opportunities. The statewide data system may find that the data has financial value. Contributing organizations may wish to market their information. Additionally, some resources (e.g., for-profit organizations) may be asked to pay for inclusion in the database.

Policies should be determined to address:

- Who owns what data?
- Who will be allowed to profit from the data?
- What are the revenue sharing opportunities?
- Who should manage marketing?

### Budgeting/Funding

Building on existing databases will be a less costly approach than building a new system. However, developing and maintaining a statewide system will require funds to accomplish. The organization should have the authority and responsibility to develop a business plan, develop and monitor budgets, encumber and expend funds, and seek and manage grants and contracts. To the extent possible, the statewide coordinated system should be built and developed with sustainable funding. It is important to note that it does cost money to gather and maintain resources. Participating organizations may, or may not, have the ability to assume all the costs to do so.

Possible funding sources include:

- Local and state governments
- Private foundations
- U.S. Housing and Urban Development’s Continuum of Care
- Federal bio-terrorism funds

**Recommendation:** Fundraising activities should be developed and coordinated through the Affiliates Committee.

#### Evaluation and Reporting

The impact of the statewide coordinated system should be evaluated and reported to the public, agencies, policymakers, contributors, researchers, and others. The evaluation of its success should focus on the outcome and that is its impact on users.

#### Type of Agency

Across the country a variety of structures have been devised to achieve coordinated systems of databases. Options include:

- State government establishing standards and certifying agencies that “buy in,” and/or subcontracting with organizations to handle data within given regions
- Private, nonprofit organizations assuming responsibility for an entire state
- Alliances of organizations with memberships and representatives managing standards and providing oversight for regional group processes
- Regional “accrediting” groups of larger organizations overseeing (e.g., a state AIRS chapter)
- Using a combination of entities to manage various aspects of the system

Because, currently, there are not funds available to promote and pursue the statewide system, and because the State of Nebraska Health and Human Services has played a key role in promoting the concept, the Data Team supports the continued role of Health and Human Services as the organizational lead.

**Recommendation:** HHSS should be retained as the general manager of the initiative and system, while ensuring partnership agreements for continuity.

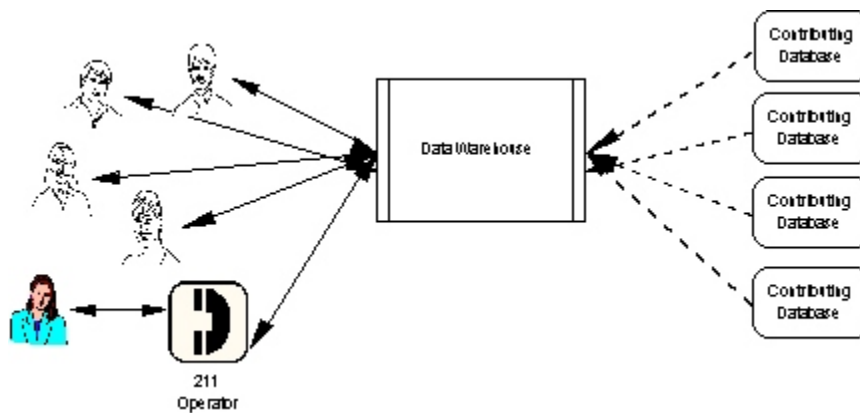
## DATA STRUCTURE

### Options for the Structure of the System

Four structural approaches were discussed and recommended as possibilities: 1) a Data Warehouse, 2) a Card Catalogue, 3) a Portal, and 4) a Hybrid. In each approach the users include those who access *directly* (through an Internet connection or paper directory), as well as those who may access *indirectly* (through an 800 number dedicated to information and referral or through an service organization that includes information and referral to other providers). Each of the four approaches and their benefits and drawbacks are discussed below:

#### Data Warehouse

The Data Warehouse model provides a single repository for the coordinated database. Contributing databases provide updates to the data warehouse asynchronously (denoted by the dashed lines). Users request information of the database and receive results back in real time (denoted by the solid line).



#### Benefits.

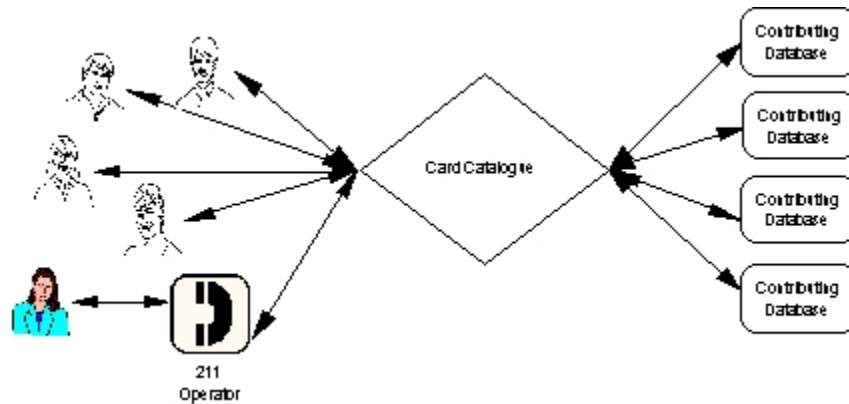
- A Data Warehouse likely provides the greatest control over content

#### Drawbacks.

- A Data Warehouse may be the most expensive option
- Contributing databases may resist combining their data with others and “lose control” over it
- The approach will require uniformity and standards for data inputting and coding resources
- The approach, which may be better suited to more static information, would require frequent updating by contributing databases to keep the information current

### Card Catalogue

The Card Catalogue model provides a tool (e.g., search engine, key words, assessment questions) to retrieve information from relevant databases. Database information remains in the domain of organizations that maintain them and thus is available synchronously (denoted by the solid lines) to users' requests. Users request information of the database and receive results back in real time (denoted by the solid line).



### Benefits.

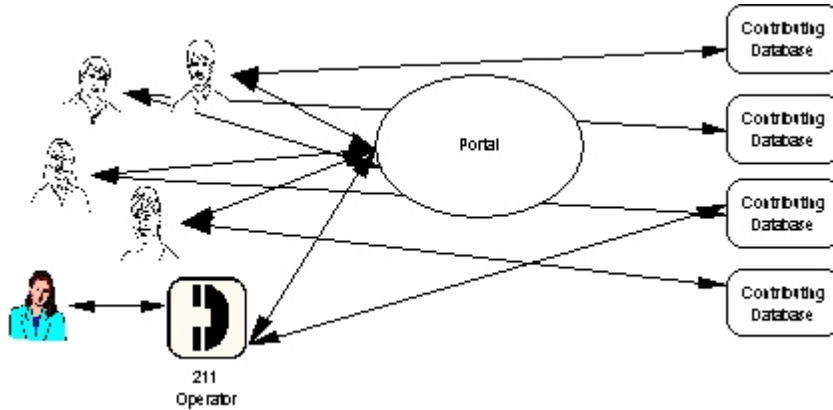
- A Card Catalogue builds on existing databases
- This approach enables “immediate” updating of information by providers

### Drawbacks.

- A Card Catalogue may present an inconsistent look
- The information may be difficult for users to navigate quickly

### Portal

The Portal model provides links to take users to relevant databases. Contributing databases' information continues to be maintained by them and is available synchronously (denoted by the solid lines) to users' requests. Users request information of the database and receive results back in real time (denoted by the solid line).



### Benefits.

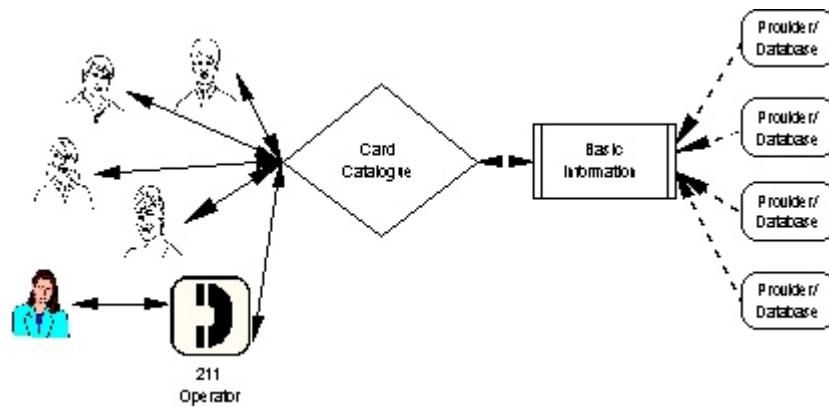
- The Portal is likely the least expensive model as it is a series of links

### Drawbacks.

- Users are linked to sites “outside” the portal which makes it more difficult to conduct additional searches
- This approach lessens the likelihood of uniformity of information and its presentation since each site maintains their own data
- May require users to sift through information to obtain needed information

### Hybrid

The Hybrid model provides a tool (e.g., search engine, key words, assessment questions) and retrieves information from a single repository. Contributing databases provide updates on basic information to the repository asynchronously (denoted by the dashed lines). Users request information of the database and receive results back in real time (denoted by the solid line).



### Benefits.

- A Hybrid approach builds on existing databases
- This approach enables “immediate” updating of information by providers
- This model overcomes the drawback of the “inconsistent look,” presented by the Card Catalogue approach, by using a coordinated database repository

### Drawbacks.

- The approach will require specific uniformity to standards for data inputting and coding
- The approach, which may be better suited to more static information, would require frequent updating by contributing databases to keep the basic information current

**Recommendation:** An Advisory Committee should be convened to evaluate the four models and select a model to develop.

## **ORGANIZATION OF INFORMATION**

The heart of a database is the information that “populates” it: what information may be included or excluded, and how it is organized. The system of coordinated databases will potentially include information about thousands and thousands of organizations and the programs and services they provide. Important issues must be addressed such as:

- How will information be categorized?
- How precise will the categorization be?
- How much information about each resource should be available?
- What resources should be included or excluded from the database?

### **Categorization**

A “taxonomy” is an orderly classification of information that provides a common language for defining services. Without a common language different people and organizations may use different terminology to refer to the same service or the same terminology to refer to very different services.

A taxonomy provides a framework and standardization to the way services are defined and provides a common ground for organizations wishing to share information about available resources. An agreement on a taxonomy is often the first logical step to build a coordinated system of databases.

The Data Team determined that the taxonomy adopted through this process should:

- Interface with major information and referral software
- Offer the potential to link to databases outside Nebraska
- Be easy to use

The AIRS/INFO LINE Taxonomy of Human Services is the standard for defining and organizing human services across North America. The taxonomy was created by INFO LINE of Los Angeles (one of the largest human services information and referral services) and is endorsed by the Alliance of Information and Referral Services<sup>2</sup> (AIRS) and the United Way of America. Numerous additional national organizations have recognized the AIRS/INFO LINE taxonomy including the National Association of State Units on Aging, the Public Library Association, the Library of Congress, the U.S. Department of Health and Human Services, the Council of Chief State School Officers, and the Institute for Nonprofit Organization Management. In Nebraska,

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<sup>2</sup> AIRS is a membership organization for professional information and referral providers in public and private organizations. AIRS promotes the professionalization and development of the field of information and referral. AIRS website is: <http://www.airs.org>

although there is no “standard” taxonomy, several of the major providers of information and referral services are already using the AIRS/INFO LINE . The taxonomy interfaces with some of the major information and referral software, and plans are underway to provide coding that will enable even broader use among, and sharing between, other software programs.

The AIRS/INFO LINE Taxonomy of Human Services, in its position as a widely-adopted taxonomy, is constantly being updated and expanded as needs arise. Currently the taxonomy contains more than 6,300 terms within a structure of ten basic service categories: Basic Needs, Consumer Services, Criminal Justice and Legal Services, Education, Environmental Quality, Health Care, Income Security, Individual and Family Life, Mental Health Care and Counseling, Organizational/Community/International Services, and Target Populations. Within the basic service categories are levels of increasing specificity. Through these levels, the taxonomy allows users to provide as much, or as little precision in categorization of services.

**Recommendation:** The AIRS/INFO LINE Taxonomy of Human Services should be adopted to categorize resources.

### **Depth of Taxonomy Hierarchy**

The AIRS/INFO LINE Taxonomy of Human Services provides a series of hierarchical levels within the ten basic service categories. For example, the Basic Needs category is broken down into five levels to reach the categorization specifically dedicated for “Missions”:

Level I B **Basic Needs**

Level II BH **Housing/Shelter**

Level III BH-180 **Emergency Shelter**

Level IV BH-180.850 **Homeless Shelter**

Level V BH-180.850-50 **Missions**

An important decision is the minimum standard depth for each taxonomy category that will be required. Compliance with a minimum level of coding ensures that resources may be differentiated and searchable to an agreed level of preciseness. Although more precision in locating the type of resource is generally desirable, the more precision will require greater resources to maintain (e.g., staff time to input, training, quality assurance, and monitoring). The challenge is to specify a depth that provides specific enough information to be useful, but general enough so that all agencies will agree to observe. A further determining factor is the number of resources within any one category. That is, if there are only a small number of resources within a given category, it may be less important to provide tools for differentiating.

Most databases will enable greater specificity of resources to “roll up” into the desired minimum. For example, an emergency housing organization may want to keep much more specific categorization than the statewide standard. This “rolling up” enables all resources to be captured and categorized within a given level.

The decision about depth of hierarchy is a fairly technical one that requires knowledge of the range of services, the needs of persons seeking services, and the resources needed to make inputting decisions.

**Recommendation:** A statewide ad hoc committee be convened to make initial recommendations on the depth of taxonomy in each of the basic service areas. The ad hoc committee should include people who maintain human service databases, assist persons seeking resources, and manage information and referral staff.

After minimum standards are determined, there will likely be an on-going need for monitoring and adjustment of standards.

**Recommendation:** A statewide standing committee should be established to monitor taxonomy issues. The standing committee should include people who maintain human service databases, assist persons seeking resources, and manage information and referral staff.

### **Breadth of Information**

Each resource may potentially have an extraordinary amount of information that describes its service, location, eligibility criteria, contact information, hours of operation, fees, language accessibility, intake procedures, directional landmarks, accessibility for persons with disability, geographic coverage, and so on. An important decision to make is what minimum amount of information should be available about each resource and what additional information may be needed.

#### Minimum Information

Users of the system of coordinated databases should have access to a standard minimum amount of information for any resource. Because the Nebraska system will build upon existing databases, the Data Team reviewed the information that is currently being collected by some of the major information providers. Service Point (the software used by the Panhandle Partnership for Health

and Human Services, <http://www.nehelp.net/>), IRis (the software used by the Lincoln/Lancaster County Health Department and the United Way of the Midlands), and the Nebraska Resource and Referral System (NRRS, with its own propriety software) were chosen because Service Point and IRis are two of the major software programs currently in use in Nebraska, and NRRS is a major state-developed database.

**Recommendation:** Information about resources included in the statewide system should offer, at a minimum, standardized basic content. The minimum standard considered should be the areas of categorical overlap between Service Point, IRis, and NRRS since they are the major systems at this point.

A preliminary review of the categorical overlap between Service Point, Iris, and NRRS include: name of resource, address, contact information, and type of service. A working group of major database users and other stakeholders should be convened to review and confirm the categorical areas of overlap between Service Point, IRis, and NRRS. The task of the working group would be to identify the information and determine standard fields for capturing the information. For example, one database may include the City, State, and Zip Code information all in one field while another database may contain the information in separate fields.

**Recommendation:** A working group should be formed to confirm and define the areas of overlap between Service Point, IRis, and NRRS.

#### Other Information

There may be additional information that should be made available to consumers to help them make decisions about whether resources may meet their needs. That information may include links to maps or websites, additional contact information, accessibility, and so on. Eventually, the system may include instituting a new accountability among human service providers by permitting consumers to rate and comment on the quality and efficacy of services.

**Recommendation:** The database system should accommodate additional information about resources and the possibility of providing consumer-ratings of services.

### **Resource Inclusion and Exclusion**

It is important to explicitly state what criteria qualifies a resource and what criteria disqualifies a resource for inclusion in the data system.

The Data Team identified that the criteria should not be so exclusive as to rob individuals the ability to choose from an array of choices.

Some considerations for inclusion and exclusion criteria include:

- Should for-profits and governmental programs be included?
- When should for-profits be included? Always? When they provide services not otherwise met in the community? Should they be charged a fee?
- How should organizations promoting bigotry and racism be considered?
- What about organizations that don't want to be included?
- Should individual providers be included?
- Should civic and business associations be included?
- Should support groups be included?
- If a service is licensed or certified, should only those with licenses or certification be included? How will that be verified?
- Will resources be on a “probation period”?

The AIRS/INFO LINE Taxonomy provides a general framework for making some initial determinations, but the inclusion and exclusion of resources merits additional discussion.

**Recommendation:** An advisory committee should be convened to make initial recommendations on resource inclusion and exclusion criteria.

### **Health Insurance Portability and Accountability Act**

The Health Insurance Portability and Accountability Act (HIPAA) contains privacy provisions that “apply to health information created or maintained by health care providers who engage in certain electronic transactions, health plans, and health care clearinghouses” (United States Department of Health and Human Services, n.d.). Some of the participating partner organizations may have to comply with HIPPA regulations, however, since it is not envisioned that the statewide, coordinated system of databases is neither a client-tracking system nor a payment system, it is unlikely that HIPPA compliance will be necessary for the system. Georgia Sales, author of the AIRS/INFO LINE Taxonomy, indicated to the Data Team that the Taxonomy is somewhat reflective of ICD9's International Classification of Diseases, but without the detail, since taxonomy is not a tool in diagnosis. She further indicated that Taxonomy may be expanded to include HIPAA, if necessary.

## **DATA PRESENTATION**

The data should be user-friendly, accessible, multi-modal, and provide information upon which users can make informed choices.

### **Access Points**

The information should be available in formats accessible to consumers, agencies, policymakers, and researchers. The system should accommodate, at a minimum, access through:

- Internet searchable database
- Phone intermediaries (e.g., 211, agency services coordinators)
- Paper directories

The Data Team notes the significant hits to the Answers4Families website and suggested that its URL ([answers4families.org/nrrs](http://answers4families.org/nrrs)) may provide a ready address for the Internet-based search engine. See page 9.

### **Special Needs**

Special consideration should also be made to ensure that the information is as widely-accessible as possible to a variety of audiences. The special needs of persons with disabilities, such as sight-impairments and cognitive limitations, should be considered. The special needs of persons that do not use English should also be considered.

The Data Team notes that there are a number of strategies to accommodate these types of special needs including:

- Web-based translation services
- “Bobby” approved formatting for websites. Internet sites that pass “Bobby” testing (<http://bobby.watchfire.com/bobby/html/en/index.jsp>) comply with the Web Accessibility Initiative's Web Content Accessibility Guidelines (the May 5, 1999 version) and the U.S. Section 508 guidelines for accessibility adopted by the Architectural and Transportation Barriers Compliance Board (Access Board) of the U.S. Federal government.
- Enabling “text only” capacity for browsing websites
- Using words and phrasing that are understandable to those with low comprehension skills

### **Consumer Ease of Use**

It is important, especially for consumers, to be able to navigate easily through the information. However, the terms that human service providers use to describe services may not be the terms familiar to consumers. Additionally, the AIRS/INFO LINE Taxonomy is fairly complex and requires some human service sophistication to understand.

There are a number of options that should be considered that will assist consumers in finding information:

- Enable consumers to search using Key Words and include common misspellings and synonyms
- Use "See Also" categories to prompt users to different, similar categories
- Contact other information and referral organizations that are developing extensive Key Word tables (e.g., Pennsylvania)
- Take advantage of AIRS' preferred taxonomy synonyms available through the Internet

### **Assisting Consumers Evaluate Information**

In order to make informed decisions, consumers must be given enough information to evaluate it for themselves. Some strategies to help consumers evaluate the information include:

- Providing the "age" of information (e.g., "this information last updated xx/xx/xx") to help people assess the accuracy
- Identifying when information that is provided is beyond the bounds of the system of standards. For example, when linking to another website, a pop-up box could indicate that the user is navigating away from the database
- Using disclaimers to identify that the resources are not being promoted or endorsed.

### **Levels of Accessibility**

Consumers may require a more basic level of access to resource information than will agencies, policymakers, or researchers. Some data systems provide basic access to all users. Other information systems have developed levels of access that adapt to the level of sophistication of the user. Other systems have areas of the database that are secured and only accessible to specified users.

**Recommendation:** A unique identity for the database should be created that emphasizes self-direction and consumer choice.

Some questions that should be considered in determining whether there should be levels of accessibility are:

- Is there information that should not be publicly available because of its sensitivity, value, or specificity?
- Would the development of levels of accessibility benefit users with varying levels of sophistication in human services or in accessing information about resources?
- Will different users need to access different types of information?

- How can the system be designed so that it is widely promoted and adopted and useable for different audiences?
- Might there be an opportunity for profit-making that outweighs the desire to provide information to all persons in Nebraska?

## **FURTHER IMPLEMENTATION ACTIVITIES**

Additional further issues must continue to be considered such as:

- What are the first steps?
- Who else should be involved and at what step in plan development/implementation?

In order to successfully implement a statewide, coordinated system of databases, there are some principles the Data Team believes are important to incorporate in the process:

- The vision for the system must be built and promoted
- The system should be implemented in small, doable, basic steps that can be done well – we will walk before we are able to run
- The system should be built so that it is expandable and adaptable
- A concrete plan for development and implementation should be developed
- Communication of the vision to all stakeholders is key
- The system must value participating local organizations

Options for further development of the system may include:

- Actively soliciting feedback on this report from stakeholders
- Surveying organizations throughout Nebraska regarding how they collect their data and what they need in order to have them participate in a coordinated system
- Continued integration of this effort and the 211 pilot

## **REFERENCES**

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## **APPENDIX**

Letter of Invitation

Roster of Data Team Members

Consultants

Bibliography

## LETTER OF INVITATION

March 3, 2003

Address Block

Dear :

Information and referral services are an important point of entry for Nebraskans seeking appropriate human services options. Across the state, several key initiatives have begun laying the groundwork for statewide collaboration in data collection, sharing, and promotion activities. Consensus is emerging that developing a comprehensive, collaborative, statewide, health and human services database is both desirable and feasible.

The Nebraska Health and Human Services System was recently awarded a federal *Real Choice* grant from the Centers for Medicare and Medicaid Services. Real Choice grants were awarded to “design and implement effective and enduring improvements in community long term support systems to enable children and adults of any age who have a disability or long term illness to live and participate in their communities.” Partial resources from the Real Choice grant will be devoted to planning for a statewide health and human service information and referral coordination.

We are inviting approximately 12 information and resource providers and stakeholders from across the state to join together as a working group, the **Real Choice Data Team**, to help envision the **elements** that should comprise a statewide resource database. Some of the areas we expect the Real Choice Data Team to focus on include: 1) determining inclusion/exclusion criteria; 2) identifying key data elements of a statewide resource database; 3) use of AIRS taxonomy for indexing data; 4) relationships / partnerships; and so on. We also would expect that the Real Choice Data Team would help define *how* and *when* recommendations should be communicated to other stakeholders. I am requesting your participation in the Real Choice Data Team because of your experience in developing collaborative human services databases. The Real Choice Data Team’s recommendations will form a basis for future statewide planning efforts in the areas of administrative structures (the “who” should do it), technology (the “how” it should be done), and funding (the financial commitments to support it).

Your agreement to participate in the working group will mean attendance at approximately four to five meetings over the course of the next six months. The first meeting will be on **Wednesday, May 1, 2002** from **9:00 am to noon** in **Room 6Z** (sixth floor) of the **Nebraska State Office Building**, 301 Centennial Mall South, (map and parking instructions enclosed).

Please RSVP by April 15, 2002 to the University of Nebraska Public Policy Center (402-472-5678) with your intention to join the working group *and* for your availability for the May 1 meeting.

Sincerely,

Becky Veak  
Real Choice Grant Coordinator

## **ROSTER OF DATA TEAM MEMBERS**

### **Members**

Beatty Brasch - Lincoln Action Program (at issue of the report had retired from Lincoln Action Program and has founded the Center for People in Need)

Jeff Chambers - Center on Children, Families and the Law

Kathy Cook - Lincoln/Lancaster County Health Department

Steve Frederick - Nebraska Department of Regulation and Licensure

Mary Jo Iwan - Nebraska Department of Health and Human Services

Jean Jensen - Volunteers of America

Robin Mahoney - United Way of Lincoln

Jamie Moore - United Way of the Midlands

Bob Moyer - Family Violence Council

Rick Nation - Blue Valley Community Action

DeLayne Peck - Lincoln Area Agency on Aging

Victoria Rasumussen - Nebraska Department of Education

Becky Veak - Nebraska Department of Health and Human Services (at issue of the report has joined the Nebraska Health Care Association)

### **Facilitators**

Paul Ladehoff - Lincoln Mediation Center

Nancy Shank - University of Nebraska Public Policy Center

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