State Plan
for
Genetic Services in Missouri

The attached plan is being prepared as part of the “Missouri Genetic Integrated Information System and Planning Project” funded through the Health Resources and Services Administration’s Maternal and Child Health Bureau.
Plan for Genetic Services in Missouri

I. Introduction

Genetic and genetic-related disorders have a tremendous impact on the health of the general population.

- Each year, approximately 75,000 newborns are added to Missouri’s population.
- At birth, over 2,000 of these infants will have a readily observable genetic disorder.
- An estimated 20% of all families are affected by a genetic or genetic related disorder.
- Chromosomal abnormalities occur in slightly more than 1 in 200 newborns and account for up to 60% of all miscarriages.
- It is estimated that genetic conditions contribute to 40% of all infant mortality.

Most diseases have a genetic component, whether inherited or resulting from the body’s response to environmental factors. Knowledge of genetics is expanding rapidly, partly due to the Human Genome Project, which has mapped, and aims to analyze, every human gene. This progress in genetics will result in advanced technology that will increase the understanding of the pathophysiology of common diseases, opportunities to prevent diseases, earlier and more effective treatment, more effective therapies and fewer side effects from therapies.

This plan supports the Missouri Department of Health and Senior Services’ (DHSS, known as DOH – Department of Health prior to August 28, 2001) vision of “a state of healthy people in healthy communities” through the responsible use of genetic information. The overall goal of genetic services is to reduce morbidity and mortality associated with genetic disorders. The purpose of this document is to provide Missouri with future directions over the next three years that optimize the potential benefits of new developments and new opportunities to more effectively supply genetic services to residents. This report includes a demographic overview
of the state, a description of genetic resources, assessment activities taken to identify barriers and gaps in service and goals and objectives to achieve the reduction of morbidity and mortality associated with genetic disorders.

II. Missouri Demographic Overview

Illinois, Kentucky, Tennessee, Arkansas, Oklahoma, Kansas, Nebraska and Iowa bound the state of Missouri, located near the geographic center of the United States. Existing medical referral patterns suggest that there is considerable crossing of state lines to receive genetic and other health care services.

The State covers over 70,000 square miles. The northern half of the state is part of the midwestern Great Plains and is well suited to agriculture. South of the Missouri River, the land rises to the picturesque but agriculturally poor Ozark Mountains, where tourism and lumber are important sources of revenue. The extreme southeastern Missouri River bottom counties are both economically depressed and medically under-served.

Over half (55%) of Missouri’s 5.5 million people are concentrated within the state's two major metropolitan areas, St. Louis and Kansas City. Another 13% of Missourians reside within the state's minor metropolitan areas of Springfield, Joplin, Columbia and St Joseph. The rest are dispersed throughout the remaining 92 counties, 27 of which have fewer than 10,000 people.

As of April 1, 2000, there were 5,546,338 persons living in Missouri. The 1998 population estimates revealed that 87 percent of persons living in Missouri were white; 11 percent were African American; 0.8 percent were Asian/Pacific Islander; 0.4 percent were native Americans; 1.6 percent were of Hispanic origins; and 0.4 percent were of other ethnic origins.

African Americans are the dominant minority population in Missouri -- a total population of 612,788 in 1998. In 1998, African Americans accounted for 11.3
percent of Missouri’s total population, up slightly from 10.8 percent of the state total population in 1990. While Missouri’s total population increased by 6.1 percent from 1990 to 1998, the African American population increased by 11.1 percent, and nearly twice the rate of the total population.

The African American population is highly concentrated in the two major metropolitan areas. In 1998, the African American population of the city of St. Louis was 178,676, and the corresponding population of St. Louis County was 164,018, accounting for 29.2 percent and 26.8 percent respectively of the state’s total African American population. Further reflecting the metropolitan concentration of African Americans, Jackson County had 162,373 in 1998, up from 136,914 in 1990. Those three metro counties included 505,067 African Americans in 1998 (82.4 percent of the state’s total African American population).

Since 1990, Hispanics have been the fastest growing minority group in Missouri. It is now estimated that there are 118,592 Hispanics living in Missouri who now make up 2.2 percent of the total population. The Hispanic population resides primarily within the metropolitan areas. The Jewish community is centered in St. Louis and Kansas City. A significant Amish and Mennonite population is found in central and north central Missouri. Other genetically important ethnic groups, including Asians and those of Mediterranean descent are numerically small and reside primarily in the metropolitan areas of the state.

The population of women of childbearing age is increasing. In 1995, there were 1,183,100 females between the ages of 15 and 44 in Missouri. By 1998 there were 1,198,407 in this same age group.

In 1995, there were 72,804 live births in the state of Missouri, which represented a fertility rate of 61.3 percent. Between 1990 and 1995, the rate of live births among whites declined by 6.4 percent and the rate of births among African Americans for the same period declined by 18.8 percent. During this same period of time, live
births among females 15-44 whose incomes were below 185% of the federal poverty level increased by 29.7 percent. For females below 185% of poverty, the rate of increase for whites was 26.7 percent and for African Americans the rate of increase was 49%.

III. Genetic Services in Missouri

Genetic activities in the DHSS date back to 1965 with the establishment of newborn screening for phenylketonuria (PKU). In 1972, a statewide sickle cell screening, education and counseling program was established with state funds. The development of reimbursement programs for the treatment of Cystic Fibrosis, Hemophilia and Sickle Cell Anemia programs rapidly followed. In 1981, Missouri received federal funding to support the development of the Missouri Genetic Disease Program (MGDP) which consisted of a dynamic partnership between the DHSS and the four university affiliated medical centers in the state to establish a network of genetic services. When federal funding ended in 1986, state legislation (Attachment A) was passed and state funding was established to support infrastructure at the four genetic centers to continue genetic activities. With the passage of this legislation, the Governor appointed the Missouri Genetic Advisory Committee to advise the department in all genetic programming in the state. In 1988, Missouri successfully applied for federal funding to expand its targeted newborn hemoglobinopathy program to a universal newborn screening program that began in May 1989. When federal funding ended in 1991, the department identified state funding to maintain that program. In that same year, the DHSS entered into a partnership with the Department of Mental Health to fund the Healthy Children’s Initiative that expanded and enhanced genetic services. This included the development of outreach services, improved clinical laboratory support and increased genetic professional manpower.

As indicated above, Missouri has implemented many of the genetic service components identified in the Guidelines for State Genetic Services developed by the
Council of Regional Networks for Genetic Services (CORN). Those components are further described below.

A. Statewide Genetics Unit

The Bureau of Genetics and Disabilities Prevention located in the Division of Maternal, Child and Family Health houses the genetics unit. The unit consists of nine full time staff, one of whom is designated as the state genetics coordinator. This unit serves a central clearinghouse function for all genetic issues in the state. The unit also monitors and evaluates all genetic services in the state.

B. Tertiary Genetic Centers

The Department of Health and Senior Services contracts with four tertiary genetic referral centers located in Missouri’s four university-affiliated medical schools. The staff of the four centers provides genetic diagnostic evaluations and counseling, genetic screening and genetic education through regularly scheduled genetic clinics, prenatal clinics and a variety of other specialty genetic disease clinics (metabolic, Down syndrome, etc). These centers offer a complete range of diagnostic and consultative medical services essential for delivery of effective genetic services. Board certified medical geneticists, genetic counselors, data entry personnel and cytogeneticists staff these centers. Medical subspecialties that are available include but are not limited to pediatrics, obstetrics, pathology, neurology and orthopedics.

For the purpose of delivering genetic services, the state is divided into three sections corresponding to the central, western and eastern portions of the state. (Attachment B) The plan for dividing the state is based on available resources as opposed to existing medical referral patterns. The eastern section, which includes the city of St. Louis and southeastern Missouri, is served by Washington University and St. Louis University Medical Centers. Children’s Mercy Hospital, which is affiliated with the University of Missouri provides services in the Kansas City area, while the University of Missouri Hospital and Clinics in Columbia
responds to the needs of the rest of the state. These centers are located along Interstate Highway 70, which is the central corridor of the state.

C. Outreach Services
To make medical genetic services available to geographically and/or culturally remote areas of the state, a network of outreach clinics have been established. This involves sending a genetic team from one of the genetic centers to an identified area for one day every three months. Due to the increasing demand for genetic services in southern Missouri, it was necessary to increase the frequency of the outreach clinics to every two months and monthly in one area. Attachment B describes the location of the nine outreach clinics. These locations were chosen because each serves as a secondary referral center for a large population area.

D. Newborn Screening (NBS)
State law mandates that all infants born in Missouri are screened for PKU, galactosemia, congenital hypothyroidism, and abnormal hemoglobinopathies. Each submitting hospital is charged a newborn screening fee of $13 for each infant tested. This fee is used to pay for newborn screening only.

The centrally located state public health laboratory conducts initial tests for each of these disorders. Those infants who are positive on the initial newborn screen for a particular condition are followed up to determine if either a repeat newborn screen or a confirmatory test has been done. Those infants found to be positive are entered into a system of health care. It is at this point that the Missouri newborn screening program falls short in that it provides only short-term tracking; once the infant is enrolled into a system of health care the department’s involvement with that child ends.

Newborn screening is more than just testing – it should always be part of a system that includes screening tests, follow-up, diagnosis, treatment, and evaluation as necessary. The primary objective of each state’s newborn screening system
should be to ensure that every newborn screened receives appropriate and timely services. The current newborn screening program does not provide long term tracking of these children nor does it contract with a treatment center to provide long-term tracking.

A system that allows the department to partner with health care providers is needed to provide long-term tracking of infants who are positive for one of the four conditions.

E. Newborn Hearing Screening (NBHS) Program

The NBHS program began in 1999. House Bill 401 mandates screening the hearing of all newborns born in Missouri beginning January 1, 2002. See Attachment A.

The purpose of this program is the early identification and referral for treatment of infant hearing loss to reduce serious delays in social, emotional, cognitive and academic growth. Statistics show that 1 in every 1,000 infants is born totally deaf (profound hearing loss) and that 1 in 22 infants has hearing problems. Approximately 50% of severe or profound hearing loss are caused by genetic factors and the average age of identification of hearing loss remains close to three years of age. In Missouri, it is anticipated that approximately 75 infants will be born deaf (profound hearing loss) based upon a birth rate of 75,000.

A needs assessment conducted by Southwest Missouri State University in 1999 revealed where the state is currently and what is needed in the newborn hearing screening program. The Bureau of Genetics and Disabilities Prevention then worked diligently with the Newborn Hearing Screening Program Advisory Committee to incorporate recommendations from a needs assessment into program guidelines and education and resource materials for facilities and families throughout the state.
Referral for suspected hearing loss is very important, but will be perhaps the most time consuming aspect of the hearing screening and intervention process, especially if resources are not readily available or easily accessible. Therefore, it is the goal of the Newborn Hearing Screening Program to assist facilities to ensure that follow-up audiologic and medical evaluations are provided before three (3) months for infants requiring care. This would include tracking and follow-up of infants who have had their hearing re-screened but the results haven’t been forwarded to the department.

The program also collaborates with the Department of Elementary and Secondary Education and community agencies to ensure that access to intervention services is provided before six (6) months of age. This would include ensuring those infants found to need corrective services are enrolled in a medical home.

Early identification efforts will be enhanced as new technology is developed that would be specific for detecting hearing loss during infancy. These capabilities could, in fact, contribute to the discovery as to what percentage of hearing loss is actually congenital and not a postnatal occurrence. The role of early hearing detection programs can be a vital link in research about the genetics of hearing loss.

F. Missouri Teratogen Information Services (MOTIS)

Missouri Teratogen Information Services is a statewide program whose goal is to prevent birth defects. MOTIS maintains a hot-line (a toll free phone number) for obstetricians, family practitioners, other health care providers and the general public that addresses questions regarding possible teratogenic exposure during the prenatal period. MOTIS responds to approximately 400 calls per year from health care providers and the public. Such teratogens may include medications used during pregnancy, exposure to viruses during pregnancy and exposure during pregnancy to various chemicals used both indoors and outdoors.
Educating members of the community and professionals about teratogens is a major activity of the program. At least three lectures and symposiums per quarter are provided to the medical community and the general public. The program also develops and distributes written information on teratogen exposure to the general public.

MOTIS is unique in that the program offers physical, neurological and developmental postnatal follow-up to all families that contact the program. MOTIS maintains data on these individuals in hopes that the information will inform the teratogenicity of questionable agents. MOTIS has collected data for five years, yet it is not enough data to establish, support or deny teratogenicity of agents registered in the program.

G. Sickle Cell Anemia Program

The Sickle Cell Anemia Program provides information to the public and health professionals about sickle cell anemia and sickle cell trait, and promotes and provides screening, testing, referral, counseling and follow-up services for Missouri citizens’ at-risk for sickle cell disease. Sickle cell disease affects about 1/500 African Americans. It is estimated that approximately 1,000 individuals in Missouri are impacted by sickle cell disease in Missouri. Another 50,000 individuals in Missouri have sickle cell trait, the carrier state of the disease. The program ensures that sickle cell services are available in areas of the state where large segments of the target population reside. Program activities are contracted through two city health departments and five resource centers.

Education efforts stressing inheritance are directed at the general public, health professionals, and targeted populations. Educational presentations are conducted reaching approximately 5,000 individuals yearly. In addition, written information is developed and distributed in the form of pamphlets, brochures and posters.
All infants in the state are screened for sickle cell conditions. Each year approximately 30 babies are born with sickle cell disease in Missouri. The purpose of newborn screening is to identify infants with the condition and ensure that appropriate treatment is initiated. Other age groups are also tested, but on a much more targeted basis, i.e., family members of an individual identified with sickle cell trait.

Individuals or parents of an individual identified with sickle cell trait conditions are offered educational genetic counseling. Counseling sessions are non-directive and include information on inheritance. Approximately 1,500 individuals with sickle cell trait are identified each year through the screening component. The program goal is to counsel 80 percent of those identified.

Five resource centers are located throughout the state to provide expertise in: hematology; the treatment of sickle cell disease; follow-up on clinically significant test results; ensuring confirmatory testing is completed; and to facilitate patient linkages with medical care. Each resource center is located in a hospital that provides inpatient, outpatient and emergency care. The resource center staff are available for clinical consultation to providers and patients served outside of the center.

Sickle Cell Coalitions, located in the two metropolitan areas of Kansas City and St. Louis are made up of representatives from agencies in the community that provide services to individuals with sickle cell conditions. The goals of the Coalitions are to improve the delivery of service to individuals and their families and to improve the efficiency and effectiveness of service delivery systems.

**H. Adult Cystic Fibrosis, Sickle Cell and Hemophilia Treatment Programs**

These treatment programs provide assistance to individuals 21 years of age and over who meet the eligibility criteria. Medical eligibility is documented with a
written diagnosis. Financial eligibility is at or below 185% of the U.S. Department of Health and Human Services' Poverty Income Guidelines.

These programs provide financial assistance for outpatient and inpatient services, prescription medications, home medical equipment, emergency care and service coordination. In addition the Hemophilia Treatment Program provides financial assistance for blood factor products.

Currently the Hemophilia, Sickle Cell and Cystic Fibrosis treatment programs offer participants a complete treatment package designed to address the medical needs of affected individuals. However, members of the Missouri Genetic Disease Advisory Committee as well as treatment center staff, continue to reiterate that the programs are not reaching the people that desperately need the help. They report that the affected families facing access to care issues are Missouri's "working poor" - those individuals who are working at low paying jobs without health insurance while earning just enough to make them financially ineligible for services.

The Division of Maternal, Child and Family Health has explored options for enhancing the program so that more people with these conditions could receive services. It has been proposed that the programs contract with treatment centers to provide direct services to any individual diagnosed with this condition regardless of income or insurance coverage. This collaborative effort will allow a greater number of people to receive the comprehensive care that is needed.

I. Metabolic Formula Distribution Program

The Metabolic Formula Distribution Program assists with the purchase of prescribed dietary formula and provides an annual examination to children and adults diagnosed with medically eligible metabolic disorders such as PKU or Maple Syrup Urine Disease (MSUD). Financial eligibility is at or below 185% of the U.S. Department of Health and Human Services' Poverty Income Guidelines.
An adjustment of $10,000 is added to the participant's income to allow for additional expenses for medical food that the program does not provide. Service coordination is available regardless of income.

J. Birth Defects Registry
This Registry is a passive system that identifies infants with birth defects by monitoring information submitted on the birth certificates, hospital patient abstracts, death certificates, and special health care needs information systems.

K. Missouri Genetic Information System (MOGIS)
This System collects demographic and clinical data on individuals receiving clinical and prenatal services from the four genetic centers and five sickle cell resource centers in the state.

L. Missouri Genetic Disease Advisory Committee
The Missouri Genetic Disease Advisory Committee is a governor appointed advisory board, which advises the Department on the provision of genetic services. The Committee meets twice a year, and insures that genetic programs are responsive to the needs of the entire state and equitably funded. To address specific issues, the Committee has four Standing Committees: the Newborn Screening Standing Committee; the Cystic Fibrosis Standing Committee; the Sickle Cell Anemia Standing Committee; and the Hemophilia Standing Committee. The Standing Committees also meet twice a year and make recommendations to the Advisory Committee regarding emerging issues and program direction.

IV. Other Genetic Related Services in the Department of Health

A. Bureau of Special Health Care Needs (BSHCN)
The BSHCN provides services for children and their families with disabilities, chronic conditions, and birth defects who meet financial and medical eligibility
guidelines. Services focus on early identification of children with special needs and funding for preventive, diagnostic and treatment services. Service coordination is provided by staff located in ten regional offices throughout the state.

Many of the conditions covered by the BSHCN have either a genetic origin or genetic implications that would benefit from genetic counseling and evaluation services. Referral between the BSHCN and the genetic service system is necessary to assure that families are receiving needed services.

B. Chronic Disease

The Division of Chronic Disease Prevention and Health Promotion directs statewide programs that are designed to combat the major causes of premature death, illness, disability, and medical costs in Missouri such as heart disease, cancer, stroke, diabetes, and arthritis. These programs are primarily conducted through three bureaus and one office within the division: the Bureau of Health Promotion; the Bureau of Cancer Control; the Bureau of Chronic Disease Control; and the Office of Surveillance, Research and Evaluation. As more is learned about the genetic implications of common chronic diseases, genetics will play a major role in the development of strategies to prevent and/or lessen the complications associated with these conditions.

C. Nutritional Health

Part of the strategic plan for Missouri is to improve the nutritional health of Missourians. The Division of Nutritional Health and Services (NHS) recognizes the need to integrate nutrition services for improvement of disease outcomes. Conditions such as Cystic Fibrosis, Sickle Cell Disease, and PKU require nutrition intervention for successful management of these conditions.

Researchers have found that nutrition counseling is also a vital component of the care of children with genetic conditions. Thus, an objective of the genetic service
programs is to collaborate with NHS and other partners to assist families with the coordination of these services. This will include identifying appropriate diet practices and increase access to nutritional health services.

In addition to improving and protecting the health of these citizens, nutrition intervention can save a significant amount of health care dollars. However, the current challenge is to include nutritional services as part of the multidisciplinary treatment approach.

V. Assessment Activities

Assessment activities conducted during this planning process were based on the following goals:

- To define the population currently served or in need of service,
- To describe the existing services, and
- To determine gaps in service and needs.

To address these issues, the following action was taken.

A. Key Informant Meetings

To inform this planning process, input was gathered in various forums that allowed input from the genetics community as to the needs and gaps in the provision of genetic services in the state. This included obtaining input from the Genetic Disease Advisory Committee and a group of key informants called together by the Director of the Department of Health. Additionally, input was provided by a Quality Assurance workgroup that looked at existing genetic testing (newborn screening) that is being conducted in the state lab and identifying areas of need and future direction.

This planning process also included the Rural Missouri Genetics Services Project Advisory Council which is made up of consumers, community leaders and genetic professionals that provide expertise and guidance to the
development of a model system of care for children with complex genetic disorders/special health care needs in rural Missouri.

And most recently, feedback on ways to improve the NBS program in Missouri was obtained through a technical assistance visit by the National Newborn Screening and Genetics Resources Center. This review was very intensive and identified many ways to improve and the program. A summary of the more prominent recommendations is as follows:

- A timely review and revision of the state law as needed;
- Development and distribution of a Practitioner’s Manual;
- Expansion of the Newborn Standing Committee to include broader representation;
- Continued development of a comprehensive integrated data system;
- Identification and funding of pilot studies for testing of metabolic diseases;
- Development of a formal education program for the public, professionals and patients;
- Development of a screening practice quality assurance program with goal oriented improvement strategies; and
- Maintenance of long-term tracking and outcome evaluations.

B. Surveys

To obtain additional input regarding existing services and future needs, a survey of significant stakeholders and advisory committee members was conducted. Individuals were asked to review the draft plan and provide comments. The stakeholder feedback primarily focused on the following:

- The need to ensure appropriate newborn testing;
- The need to prepare for the impact of advancing technology on genetic service delivery;
- The need to maintain and increase funding to ensure equitable access to genetic services; and
• The need to ensure that data collection effort is reflective of all genetic populations (not just newborn screening).

**Data Analysis**

The Missouri Genetic Information System (MOGIS) collects information on residents who are currently receiving genetic services. MOGIS has three data collection components. The first component, referred to as General Genetics, consists of information describing individuals receiving genetic evaluation and counseling services via genetic centers. The second component, known as PREG, consists of information files on individuals receiving prenatal genetic evaluation and counseling services via the genetic centers and their outreach components. The third component is the sickle cell data system that is relatively new and has yielded minimal information to date. Information is collected on individuals served via one of the sickle cell genetic treatment centers. The MOGIS database is limited to information collected in those centers supported via the MGDP. Past data and experiences indicate that about 75% of individuals and families impacted by genetic disorders are seen at one of the four genetic centers in the state.

Data from MOGIS is included in Attachment C and contains the following tables:

• Clients by Age for FY2000;
• Clients by Age and Sex for FY2000;
• Clients by Race for FY2000, FY1999 and FY1998;
• Percent of Clients by Residency for FY2000, FY1999 and FY1998;
• Clients and Visits for FY2000, FY1999 and FY1998;
• Clients by Race for FY2000, FY1999, and FY1998;
• Percent of newborns served in the Genetic Clinics by Calendar Year;
• Clients per 100,000 population by county by Calendar Years 1990-1999;
• Prenatal Care Clients and Visits by FY2000, FY1999 and FY1998;
• Percent of Prenatal Care Clients by Fiscal Year and Residency; and

Based on the data, the following points are shared:

• Children fifteen years of age and under make up 86% of individuals receiving genetic evaluation and counseling services via the genetic centers.
• There is little difference between the incidence of genetic conditions among males and females.
• The percentage of minority populations receiving genetic evaluation and counseling services via the genetic centers closely reflects the overall percentage of minority populations in the state (11%). However, the percentage of minorities served in the prenatal component is noticeably higher (20%).
• Slightly over three-fourths of all individuals receiving genetic evaluation and counseling services via the genetic centers reside in Missouri. The rest are dispersed among the eight states that border Missouri. Significantly more prenatal clients served in Missouri reside in neighboring states (35-50%).
• Of individuals served 20 to 30% returned to the genetic centers for additional visits.
• The number of individuals served by the genetic centers by county has increased over the last ten years, particularly in areas where outreach clinics are located.

Information describing the types of financial resources clients used to pay for Genetic Services in Missouri from 1992-1999 is described in Table 1. Most individuals served had some type of third party reimbursement with private insurance and Medicaid being the largest purchaser of genetic services. This information will be used in future analysis to understand how consumers pay for genetic services and to develop new and enhance existing funding sources.
Table 1

Genetic Services In Missouri

Genetics Client Count

by Financial Resources by Calendar Year

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<td>20</td>
<td>22</td>
<td>16</td>
<td>29</td>
<td>22</td>
<td>10</td>
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<td>83</td>
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<td>Health Maintenance</td>
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<td>8</td>
<td>71</td>
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<td>Medicaid</td>
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<td>50</td>
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<td>Total</td>
<td>3,193</td>
<td>3,125</td>
<td>3,256</td>
<td>3,521</td>
<td>3,336</td>
<td>3,039</td>
<td>2,563</td>
<td>3,229</td>
<td>17,891</td>
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To understand how economic status impacts utilization of genetic services, the educational and economic status of users in Missouri is collected. Table 2 shows the income level of individuals served, however only a small percentage chose to share that information over the years. Table 3 shows that few people who utilized services shared information regarding educational level. Existing program efforts focus on identifying methods to increase the number of individuals that this information is obtained for in the future.
Table 2
Genetic Services in Missouri
Genetic Client Count by Economic Count by Calendar Year

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<th>Year</th>
<th>$0 - 9,999</th>
<th>$10,000 - 19,999</th>
<th>$20,000 - 29,999</th>
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<th>$40,000+</th>
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Table 3
Genetic Services in Missouri
Genetic Client Count by Education Level by Calendar Year

<table>
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<th>11 Years</th>
<th>12 Years</th>
<th>13 Years</th>
<th>14 Years</th>
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<th>18+Years</th>
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</table>
Accessibility of genetic services in Missouri is an additional area being assessed. In Attachment C, a table titled “Clients per 100,000 population by County by Calendar Years 1990-1999” shows the breakdown by county of the number served. Future analysis will include this information in comparison to the number of genetic health professionals in each area.

IV. Goals and Objectives

The following goals and objectives are based on the premise that current systems of care must be continuously evaluated and revamped to be responsive to the demands of the “new genetics”. They do not provide a detailed description of how genetic services will be finally implemented in Missouri, but rather provide guidelines for the best ways to guarantee the continuation of quality services in the face of evolving genetic technologies.

Goal 1: Develop a statewide surveillance system for genetics by integrating and enhancing existing surveillance systems.

Objectives:

- Develop and implement a web-based system for capturing NBS and NBHS data. (January 1, 2002)
- Develop and implement NBS and NBHS systems with the capability of providers obtaining client information electronically. (January 1, 2002)
- Establish data linkages with genetic counseling and evaluation centers. (July 1, 2002)
- Integrate NBS and NBHS information with other child information on immunizations, lead screening, Special Health Care Needs and WIC participation. (May 31, 2003)
- Develop web-based birth certificate system that is integrated with NBS and NBHS. (January 1, 2003)
- Integrate genetics tertiary care center information and NBS follow-up information. (May 31, 2004)
Goal 2: Evaluate and improve the availability and accessibility of genetic services.

Objectives:

- Evaluate and revise the newborn screening system to ensure the long-term follow-up of affected individuals and their families. (January 1, 2004)
- Conduct annual review of all genetic service components. (Ongoing)
- Create mechanisms to routinely assess evolving genetic issues. (Ongoing)
- Maintain the genetic service network composed of genetic centers, outreach clinics and specialty programs for conditions with high prevalence rates. (Ongoing)
- Develop and implement a case management information system for NBS and NBHS. (January 1, 2002)
- Investigate the feasibility of expanding telemedicine activities to outstate locations. (January 1, 2003)
- Conduct joint trainings for service coordinators of children with special health care needs, consumers, and genetic health care providers to facilitate the collaboration between agencies and families. (May 31, 2003)
- Develop, define and report on newborn screening process measures. (May 31, 2003)
- Develop, define and report on newborn screening outcome measures. (May 31, 2003)
- Develop and implement an information system to obtain outcome information on children with sickle cell disease. (July 1, 2003)
- Establish a process to monitor compliance of screening and testing protocols and improved standards for treatment therapies. (July 1, 2003)
Goal 3: Increase the awareness of patients, professionals, and the general public of the impact of genetic information on health.

Objectives:

- Develop a web site to increase access to resources for NBS and genetic conditions that will serve as a link between the DHSS home page and other genetic information services. (May 31, 2002)
- Design and implement targeted instructional opportunities for audiences for whom the subject is personally or professionally relevant. (May 1, 2003)
- Design and implement selected informational activities for defined high-risk groups that provide detailed knowledge to impact behavior and prevent complications. (September 1, 2003)
- Develop a NBS Practitioner’s Manual that outlines the protocols for the NBS system. This manual will be available on the web and hard copies will also be provided to primary care providers in Missouri. (May 31, 2002)

Goal 4: Establish partnerships to support genetic service systems.

Objectives:

- Enhance Advisory committee and Standing Committee memberships to include a wider representation of individuals and specialties, such as a medical ethicist, epidemiologist, genetic counselor, pediatrician, lawyer, representatives from the public sector, and an increased number of consumers. (January 15, 2002)
- Establish an internal DOH genetics workgroup to ensure that a genetic component is added to other programs in the department as needed (e.g. chronic disease, environmental and nutrition programs). (September 1, 2002)
- Establish collaborative partnerships with other agencies to enhance the availability and quality of future genetic services. (Ongoing)
- Enhance mechanisms to offer public and professional input on the ethical dimensions of any aspect of research, including new initiatives in genetic screening and testing. (September 1, 2002)
Goal 5: Establish evidence-based genetic services.

Objectives:

- Conduct newborn screening pilot programs for metabolic conditions and other disorders that may benefit from earlier diagnosis, such as congenital adrenal hyperplasia (CAH). (April 1, 2002)
- Analyze the impact cultural and social differences have on utilization of genetic services and develop appropriate interventions. (January 1, 2003)
- Develop measures to evaluate the outcome of genetic services. (July 1, 2003)

V. Evaluation

The five goals included in this plan are each followed by a list of objectives with target dates for completion. These tasks have been distributed to the appropriate Bureau of Genetics and Disabilities Prevention staff for inclusion in the program work plans. The major form of evaluation for this plan will be determining if the objectives have been met by the specified target dates.

Several of the goals include development of performance measures. These measures will be developed in concert with the appropriate medical and consumer representatives. After these measures have been developed, they will be used to evaluate whether the health and services for genetic services are improving in Missouri. It is planned that this information will be available through the MOHSAIC data system by May 31, 2004.

A final form of evaluation will consist of sharing the progress with the Missouri Genetic Advisory Committee and the subsequent standing committees. Input from these medical and consumer representatives will serve as a vital link to the Bureau’s perception of goal attainment.
ATTACHMENT A
MISSOURI STATUTES

Copies of the following statutes are contained in Attachment A:

- 191.300 Definitions
- 191.305 and 191.310 Genetic Advisory Committee
- 191.315 Establishing Genetics Programs
- 191.317 Confidentiality of tests
- 191.320 Genetic Diagnostic and Counseling Services
- 191.323 Prevention and Treatment of Genetic Diseases
- 191.325 Cost of Services
- 191.331 Infants to be Tested for Metabolic and Genetic Diseases
- 191.335 and 191.340 Hemophilia Program
- 191.365 and 191.370 Sickle Cell Anemia Program
- 191.375 and 191.380 Cystic Fibrosis Program
- 191.925 Screening for Hearing Loss in Infants
- 191.931 Early Intervention Services
- 191.934 Newborn Hearing Screening Advisory Committee
- 191.937 Rulemaking Authority
- HB 279—Newborn Screening Expansion