The Development of the Texas State Genetics Plan and a Plan for Integrated Data Infrastructure for Genetic Services

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THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)
# Table of Contents

## Volume I

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advisory Council – Executive Committee</td>
<td>iv</td>
</tr>
<tr>
<td>State Plan Workgroup</td>
<td>v</td>
</tr>
<tr>
<td>Ethical, Legal and Social Issues Workgroup</td>
<td>vi</td>
</tr>
<tr>
<td>Data Integration Workgroup</td>
<td>vii</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>vii</td>
</tr>
<tr>
<td>I. Introduction</td>
<td>1</td>
</tr>
<tr>
<td>II. Texas State Overview</td>
<td>2</td>
</tr>
<tr>
<td>A. Introduction</td>
<td>2</td>
</tr>
<tr>
<td>B. History of Genetics in Texas</td>
<td>2</td>
</tr>
<tr>
<td>C. State Growth and Geography</td>
<td>4</td>
</tr>
<tr>
<td>D. Population Diversity</td>
<td>5</td>
</tr>
<tr>
<td>E. Income and Diversity</td>
<td>5</td>
</tr>
<tr>
<td>F. Vital Statistics</td>
<td>6</td>
</tr>
<tr>
<td>G. Concluding Remarks</td>
<td>6</td>
</tr>
<tr>
<td>III. State of the State Report on Genetic Health Care Registries/Monitoring Systems in Texas</td>
<td>7</td>
</tr>
<tr>
<td>A. Birth Registration</td>
<td>7</td>
</tr>
<tr>
<td>B. Newborn Hearing Screening Program</td>
<td>7</td>
</tr>
<tr>
<td>C. Newborn Screening Program</td>
<td>7</td>
</tr>
<tr>
<td>D. Immunization Registry</td>
<td>8</td>
</tr>
<tr>
<td>E. Birth Defects Registry</td>
<td>9</td>
</tr>
<tr>
<td>F. Cancer Registry</td>
<td>10</td>
</tr>
<tr>
<td>G. Chronic Disease</td>
<td>11</td>
</tr>
<tr>
<td>H. Texas Department of Health Genetics Work Group</td>
<td>16</td>
</tr>
<tr>
<td>I. Concluding Remarks</td>
<td>17</td>
</tr>
<tr>
<td>IV. Genetic Health Care Delivery Systems and Resources in Texas</td>
<td>17</td>
</tr>
<tr>
<td>A. Introduction</td>
<td>17</td>
</tr>
<tr>
<td>B. Texas Department of Health Genetic Service Providers</td>
<td>18</td>
</tr>
<tr>
<td>1. Children with Special Health Care Needs</td>
<td>18</td>
</tr>
<tr>
<td>2. Genetic Screening and Case Management</td>
<td>19</td>
</tr>
<tr>
<td>3. Family Planning</td>
<td>20</td>
</tr>
<tr>
<td>4. Women, Infants and Children Nutrition Program</td>
<td>20</td>
</tr>
<tr>
<td>5. Texas Health Steps</td>
<td>21</td>
</tr>
<tr>
<td>C. Other Relevant Resources</td>
<td>22</td>
</tr>
<tr>
<td>1. Cancer Genetics Network</td>
<td>22</td>
</tr>
<tr>
<td>2. MD Anderson - Clinical and Research</td>
<td>22</td>
</tr>
<tr>
<td>3. Texas Medical Schools – Clinical and Research</td>
<td>22</td>
</tr>
<tr>
<td>4. Early Childhood Intervention Program</td>
<td>23</td>
</tr>
</tbody>
</table>
5. Mental Health and Mental Retardation 23
6. Department of Human Services 24
7. Texas Education Association 24
8. Department of Protective and Regulatory Services 25
9. Texas Natural Resource Conservation Commission 25
10. Texas Department of Criminal Justice 25
D. Professional Service and Educational Organizations 26
1. Texas Genetics Society 26
2. Texas Association of Obstetricians and Gynecologists 26
3. Texas Perinatal Association 26
4. March of Dimes 27
5. Spina Bifida Association 28
6. Texas Teratology Information Service 28
7. Sickle Cell Association 28
8. Genetic Alliance 29
9. Texas Pediatric Society 29
E. Funding Sources 30
1. Title V – Genetics 30
2. Medicaid Delivery Systems 31
   a. Health Maintenance Organizations (HMO) 31
   b. Primary Care Case Management (PCCM) 31
   c. Fee-For-Service (FFS)-Traditional Medicaid 32
3. Children’s Health Insurance 32
V. Gaps in Service Delivery – Present and Future 32
A. Assessment of Needs 32
B. Summary of Report Exploring Inter-Organizational Linkages to Enhance Coordinated Genetics Services in Texas 33
C. Summary of Report on Consumer Needs for Genetic Services 37
D. Summary of Report on Provider Needs for Genetic Services 39
E. Summary of TEXGENE Data Collection Report from 1999 42
F. Summary and Analysis of Laws Affecting Genetics Activities in Texas 47
G. Summary of Report on Feasibility of Integrating the Data Infrastructure of the Texas Genetics Surveillance Programs and Associated Service Delivery Program 49
VI. The Texas State Genetics Plan 51
A. Infrastructure Building 51
   1. Assessment 51
   2. Information Systems Development 53
   3. Applied Research 53
   4. Policy Development 53
   5. Legal Framework and Regulatory Infrastructure 54
   6. Assurances 54
      a. System of Integrated Genetic Services 55
b. Funding for Genetic Services 55
   c. Training and Education of Health Professionals 55
d. Evaluation of Genetic Service Systems 56

B. Population-Based Service 56
   1. Public Education 56
   2. Comprehensive Newborn Screening Systems 57

C. Enabling Services 57

D. Direct Health Services 58

VII. References 59

Appendices and Tables - Volume II.

Appendix A: How Medicaid Works in Texas

Appendix B: Differences Between Managed Care-HMO, Medicaid Managed Care and Fee-for-Service

Appendix C: Types of Medicaid Programs – Medical Programs for Families and Children

Appendix D: Report Exploring Inter-Organizational Linkages to Enhance Coordinated Genetics Services in Texas

Appendix E: Report on Consumer Needs for Genetics Services

Appendix F: Report on Provider Needs for Genetic Services

Appendix G: TEXGENE Data Collection Report from 1999

Appendix H: Summary and Analysis of Laws Affecting Genetic Activities in Texas

Appendix I: Report on the Feasibility of Integrating the Data Infrastructure of the Texas Genetics Surveillance Programs And Associated Service Delivery Programs

Table 1: Texas Public Health Regions

Table 2: Rate of Genetic Disorder Occurrence

Table 3: Clinical Genetic Service Providers – 1997

Table 4: Clinical Genetic Service Providers – 1998

Table 5: Clinical Genetic Service Providers – 1999
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I. Introduction

In the United States, contagious disease has been replaced as the leading cause of mortality and morbidity by congenital abnormalities, developmental and learning disabilities, and chronic diseases of adulthood and aging. For example, congenital abnormalities are now the leading cause of death in infants under 12 months. In addition, advances in genetic research have led to breakthroughs in understanding such adult disorders as diabetes, cancer and heart disease (1).

Advances in genetic research with the Human Genome Project have also highlighted the contributions that genetic knowledge and awareness can make to the changing health care system. This national initiative has served to increase the public’s awareness of genetic conditions, helping drive the growth of the public’s demand for services in this area.

For the past two decades, society has been inundated with information about the structure, function and location of genes. Genes are inherited and produce the chemical information that determines the intricate biological details of living organism. With advances in research and technology, a greater understanding of how genetics impacts human health has been gained. For example:

- More than 4,000 inherited disorders involving every organ system have been associated with changes in genetic material.
- Three widespread health problems – coronary heart disease, cancer and diabetes – have genetic or familial links.
- About half of all miscarriages may be caused by genetic factors.
- For every 100 births, between two and four infants will have a significant structural birth defect. Almost one-fourth of these conditions are thought to have genetic links.

In 2000, there were 363,325 babies born in the state of Texas, of these approximately 10,000 were born with some birth defect. The majority of these defects are now recognized as having genetic components. All racial, ethnic and socio-economic groups are affected by these disorders. (2)
II. Texas Overview

A. Introduction

As one of the fastest growing states in the nation, Texas’ unique population will have a definite impact on the planning, scope and availability of genetic services and resources. Among the highlights, Texas ranks nationally:

- Second in population.
- Second in states with the highest birth rates.
- Third in the percent of residents under 18 years of age.
- Third in the number of persons below the poverty level.
- First in the highest number of persons without health insurance.
- Forty-fifth in government expenditures per capita.

Other statistics come into play in an overview of health-care related state demographics. For example:

- Forty-seven percent of state residents are Hispanic, Black or other minority group.
- Eighty percent of the population lives inside metropolitan areas.
- Thirty-one percent of the state’s population is young adults between 25 and 44 years.
- Women of childbearing age make up about twenty percent of the population.
- More than fifteen percent of state residents are living below the poverty level.

In an average week in Texas:

- 6,582 babies are born.
- 964 babies are born to mothers who receive inadequate prenatal care.
- 489 babies are born of low birth weight.
- 42 babies die before their first birthday.(3)

B. History of Genetics in Texas

In 1978, the Texas Genetics Network (TEXGENE) was formed as a statewide consortium of individuals and organizations involved in providing genetic services or who represented people with genetic conditions or birth defects. The goals of TEXGENE were to: 1) alleviate the suffering the anxiety of patients and families; 2) provide treatment or information about the genetic disease; and 3) to decrease the incidence of genetic disease through education. TEXGENE was supported by a Special Project of Regional and National Significance (SPRANS)
grant from the Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services. A Steering Committee and seven subcommittees were established. These committees provided information and insights that were tremendously helpful in organizing genetic services in the state. TEXGENE also served as the leading advisory group to the Interagency Council for Genetic Services, which, by statute, reports to the Texas Legislature.

The Interagency Council for Genetic Services (IAC) was established by the 70th Texas Legislature and again reappointed by the 71st Legislature to:

a. Survey current resources for genetic services in the state;
b. Initiate a scientific evaluation of the current and future needs for the services;
c. Develop a comparable data base among providers that will permit the evaluation of cost-effectiveness and the value of different genetic services and methods of service delivery;
d. Promote a common statewide data base to study the epidemiology of genetic disorders;
e. Assist in coordinating statewide genetic services for all state residents;
f. Increase the flow of information among separate providers and appropriation authorities;
g. Develop guidelines to monitor the provision of genetic services, including laboratory testing; and
h. Identify state entities that serve persons who are affected by or who are at risk of having children who are affected by environmental genetic disorders and coordinate activities with those agencies.

Prior to 1996, the Texas Department of Health operated genetic clinics at 22 locations throughout the state through the Genetic Screening and Counseling Service (GSCS). The program was headquartered in Denton and from that location, professional staff traveled to various clinic locations. GSCS also operated a genetics laboratory. Funding for the GSCS program was provided from a general revenue appropriation and generation of third-party user fees.

As of January 1, 1996, Texas Department of Health genetic clinics were closed with the exception of one clinic in El Paso operated through the TDH Genetic Screening and Case Management Division. Transfer of direct provision of genetic services was accomplished by a competitive grant application process that resulted in awards to private and university genetics providers. In addition, the University of North Texas was contracted to operate a statewide teratogen information service. The GSCS laboratory in Denton, Texas, became the TDH Genetics Laboratory. This lab was closed in October 2001. At that time triple screens and DNA testing were transferred to the Bureau of Laboratories in Austin.

When Texas Department of Health closed the Genetic Screening and Counseling Service and contracted services out, general revenue support for genetic services
was cut 28 percent. Of paramount concern was the loss of access to genetics services. TEXGENE data reports have documented that utilization of genetic services declined dramatically after these changes were made.

Further, although mandated by the Texas Legislature, there are no funds appropriated for the Interagency Council for Genetic Services. When TEXGENE was operational, it was able to facilitate some of the more significant IAC activities such as tracking and reporting the decline in utilization of genetic services to policymakers. Unfortunately, the TEXGENE grant officially ended on August 31, 2001.

Despite these challenges, the Texas genetics community has continued to search for ways to ensure the people of Texas have access to genetic services. Texas has successfully competed for Special Projects of Regional and National Significance (SPRANS) grants and parlayed this support into programs to improve provision of genetic services. Under the guidance of Celia I. Kaye, M.D., Ph.D. four SPRANS grants were awarded to the State of Texas. These projects were:

- “Genetic Service Provision for Primary Care in South Texas”
- “Reducing Cultural Barriers to the Provision of Genetic Services in South Texas”
- “Reducing Cultural and Linguistic Barriers to the Provision of Genetic and Maternal and Child Health in South Texas”
- Texas Genetics Network

The future of genetics in Texas must start with funding. The Texas State Genetics Plan will outline conventional and non-conventional funding sources. The Texas Legislature must allocate more funds and additional funding sources must be tapped if quality genetics services are to be available and accessible to the people of Texas. (4)

C. State Growth and Geography

The state of Texas covers more than 26,727 square miles, or 7.4% of the nation’s total area, in the southwestern segment of the contiguous United States. Its borders are New Mexico, Oklahoma, Arkansas, Louisiana, Mexico and the Gulf of Mexico. Texas has an extremely diverse geography and climate. It has 90 mountains a mile or more high, with Guadalupe Peak in West Texas at 8,751 feet being the tallest. Average yearly rainfall totals in West Texas are less than 8 inches, while in East Texas rainfall totals exceed 56 inches.

Seventy percent of the population of Texas lives within 200 miles of Austin. Texas possesses three of the top ten most populous cities in the United States – Houston, Dallas and San Antonio. (5)
D. Population Diversity

Just as diverse are the residents of Texas. According to data from the U.S. Census Bureau, Texas has grown in population from 14.2 million in 1980 to 20.9 million in 2000, an increase of nearly 47.2 percent. Increased births and net migration are equally dominant factors driving Texas population growth. Projections indicate continued growth of the racial/ethnic diversity of the state. Forecasts predict that by the year 2030 the Texas population will reach approximately 34 million. By 2030, it is estimated that 46 percent of the population will be Hispanic, 36 percent Non-Hispanic White, ten percent African American, and eight percent other (primarily Asian). (6)

E. Income Diversity

The per capita income in Texas for the third quarter of 1999 was $26,060 compared with $23,850 in 1997. Personal income is expected to grow at approximately 5.8 percent between 2000 and 2005.

The seasonally adjusted unemployment rate in Texas for March 2000 was 4.6 percent. Yet, while the state unemployment rate was very low, some regions of Texas were still experiencing double-digit rates of unemployment. The Texas Workforce Commission 2000 estimates showed that unemployment rates ranged from a low of 2.1 percent in the greater Austin area to a high of 27 percent in some counties along the Texas-Mexico border.

Although economic indicators overall suggest a stable economy for Texas, poverty rates indicate that segments of the population still struggle with scarce financial resources and the increased health risks associated with a lower economic standard of living. According to the U.S. Census Bureau, 16.5 percent of Texans lived in poverty in 1999. This is an increase over 1998 when the Texas poverty rate was estimated to be 15.9 percent.

There remains a significant poverty rate by age, region and ethnicity in Texas. The 17 years of age and under group remains proportionately the largest group in poverty. In 1999, 24 percent of those age 17 years and under lived at or below the poverty level. Hispanics and African-Americans continued to represent a disproportionate number of those Texans living under poverty conditions. The latest data indicated that a higher percentage of African-Americans (25.7 percent) and Hispanics (27.7 percent) than whites (8.1 percent) were living at or below poverty.

Among the 50 states and the District of Columbia, Texas has the highest percentage of the population without health insurance. Only one state in this country has a higher percentage of children without health insurance. Of the approximately 4.8 million Texans without health insurance, it is estimated that 1.4 million are below the age of 18. Minority populations make up the largest percent
of Texas’ uninsured with 52.7 percent Hispanic, 15.2 percent African-American, and 32.1 percent White or Other. (7)

F. Vital Statistics
Texas residents had more babies in 2000 (363,325) than in any other year since births were first recorded in Texas in 1903. The percentage of women receiving prenatal care in the first trimester was 78.8, a decrease compared to 1999. The percentage of infants with low birth weight (less than 2,500 grams) remained at 7.4 from 1999 to 2000.

Overall life expectancy for an infant born in Texas in 2000 was 76.7 years. A male infant born in 2000 could expect to live 73.8 years while a female infant could expect to live 79.5 years. Female infants had a higher life expectancy than male infants regardless of racial/ethnic group.

The number of deaths to Texas residents in 2000 was 149,763. This was a 2.1 percent increase over the previous year. Of this, the total number of infant deaths decreased from 2,160 in 1999 to 2,064 in 2000. The infant mortality rate also dropped, from 6.2 in 1999 to 5.7 in 2000.

Heart disease claimed 42,968 lives and continued to be the leading cause of death, followed by cancer with 33,298 deaths. Cerebrovascular disease ranked third with 10,721 deaths, and accidents ranked fourth with 7,602 deaths. The fifth leading cause of death was chronic lower respiratory diseases, which accounted for 7,284 deaths. These five leading causes were responsible for 68 percent of Texas resident deaths in 2000.

Completing the ten leading causes of death were: diabetes mellitus, 5,195 deaths; pneumonia and influenza, 3,708 deaths; Alzheimer’s disease, 3,171 deaths; suicide, 2,093 deaths; and chronic liver disease and cirrhosis, with 2,092 deaths. The ten leading causes together accounted for 78.9 percent of deaths to Texas residents. (8)

G. Concluding Remarks
Texas is a diverse state in geography, income and the ethnicity of its residents. Genetic disorders know no barriers and cross all socio-economic and ethnic lines. The geography of the state presents a unique problem in availability of services for children with genetic disorders. The Texgene data collection reports from 1992, 1994, 1997, 1998 and 1999 showed that many residents in rural areas who need genetic services do not receive them. There is also a lack of service providers in remote areas of the state. In order for the Texas State Genetics Plan to be useful it must address these issues.
III. State of the State Report on Genetic Health Care Registries/Monitoring Systems in Texas

A. Birth Registration

A birth certificate must be filed with the appropriate local registrar within five days from the date of birth. There are provisions for how to register births that are reported within 5 days, those reported between 5 days and 1 year, those reported between 1 and 4 years and those reported after 4 years. The birth certificate is an individual’s basic claim and proof of citizenship, identification and relationship to his or her parents. It serves as the primary document for individuals to enter school, play little league sports, obtain a social security number and account, a driver’s license, a marriage license, a passport, and lastly to prove citizenship and have the right to work in this country.

In addition to being the primary document of identification for an individual, a birth certificate contains a wealth of medical data. These data are collected for all births and are analyzed for specific geographic areas and periods of time. The resulting statistics contain essential public health information that serve to describe the health status and needs of all people of the area. For example, adequacy of prenatal care can be examined using birth certificate data. Pregnancy outcome can be assessed through statistics on birth weight and length of gestation. Abnormal conditions of mothers and babies can be identified and investigated. Complete and accurate birth certificate medical data are important keys to improving the health of a population. (9)

B. Newborn Hearing Screening Program

The Texas legislature mandated that by April 1, 2001, in counties with a population of more than 50,000, all hospitals offering obstetrical services and all birthing centers with greater than 100 births per year must screen newborns for hearing. Newborn hearing screening data is now being transmitted electronically for 91% of newborns in mandated birthing facilities in Texas.

Approximately two confirmed cases of hearing deficit are diagnosed per day in Texas through the newborn hearing screening program. Follow up appointments for infants with abnormal screens are made before they are discharged from the hospital. Links between the Genetic Screening and Case Management and the Newborn Screening program do not exist. (10)

C. Newborn Screening

The Texas Newborn Screening Program (NBS) tests for five disorders which, if not treated very early in life, can cause severe mental retardation, illness or death. The two inborn errors of metabolism, phenylketonuria (PKU) and galactosemia, are treated by diet; congenital hypothyroidism and congenital adrenal hyperplasia (CAH) are treated by medication; and sickle cell disease complications may be
reduced through a program of medical supervision and antibiotics administered at an early age.

The program is cost effective, saving more than 150 newborns from mental retardation each year, while lowering chances of morbidity and mortality of all affected.

All babies born in Texas are mandated by law to have two screening tests. In 2000, the live births in Texas totaled 363,325. The Texas Department of Health laboratory processed 2500-3000 screens daily. This includes the initial tests, the second screening and repeats which are requested because of abnormal initial results.

Administratively the Newborn Screening program is contained under the Bureau of Laboratories and the Bureau of Children’s Health. The blood spot testing is conducted under the Bureau of Labs and positive results are reported to the Genetics Services and Case Management Division in the Bureau of Children’s Health. In the Genetics Division the staff maintains an active follow-up system on all abnormal reports. Health care providers are contacted by mail or telephone with instructions for further testing. Public health nurses and social workers are often utilized to help locate families and assist with follow-up procedures.

State program funding may be available to all children with the above disorders. Blood monitoring for phenylalanine and tyrosine, thyroid studies, and confirmatory sickle hemoglobin DNA are provided free of charge to children identified through the screening program. Testing continues to be provided free of charge for all the conditions to children as they mature into adulthood.

The major thrust of the sickle hemoglobinopathy screening program is reduction of morbidity and mortality attributed to these conditions. Notices are sent to the submitter of the specimen when a trait is identified. Follow-up and counseling are done at the physician’s discretion.

A survey conducted by the Texas Department of Health examined the rates of occurrence of the disorders screened at birth. Within the Texas population of live births between the years 1992-1998, in a typical year, there were approximately 23 new cases of PKU, 7 new cases of galactosemia, 137 cases of congenital hypothyroidism, 34 cases of congenital adrenal hyperplasia, and 128 new cases of sickle hemoglobinopathies. See Figure 2.

**D. Immunization Registry**

Texas’ immunization registry is called ImmTrac. This statewide registry is a free, public health service provided by the Texas Department of Health (Health and Safety Code, Chapter 161.007).
ImmTrac contains immunization histories of children younger than 18 years of age and for whom consent has been obtained. Information contained in the immunization registry is confidential and may be disclosed only with written consent. Following consent, immunization records from the registry may be released to a physician, a public health district, local health department, or a school or childcare facility in which the child is enrolled.

As a central repository, the registry is a valuable resource for health care providers, parents, schools, and child care facilities. Providers can access immunization histories of their patients ensuring appropriate, timely immunizations and preventing over- or under-immunizations of children and unnecessary costs to families or third-party payors. Parents can receive complete immunization records for their children, regardless of the number of different providers who administered the vaccines. Schools and childcare facilities can have a single source of immunization records for all of their enrollees. Recall and reminder information and recommendations for dealing with complex immunization scheduling requirements are also available from ImmTrac.

The Texas immunization registry, ImmTrac, also provides a toll free number, 1-800-252-9152, and web site, www.ImmunizeTexas.com, that can be contacted for more information. (11)

**E. Birth Defects Registry and Research Center**

In 1993, the Texas legislature passed Senate Bill 89, which directed the Texas Department of Health to develop and maintain a statewide birth defects registry. The Texas Birth Defects Monitoring Division was created to set up and maintain the registry and to investigate clusters of birth defects throughout the state. At that time, the Legislature provided funding for a pilot project that included counties in the lower Rio Grande Valley and most of the Texas Gulf Coast area. In January 1998, the Texas Birth Defects Monitoring Division was expanded to begin collecting data on all births in the State. Budgetary challenges at TDH in 2001 required the Registry to cease operations in NE Texas and sections of the Panhandle; however, recent funding from a Center for Disease Control (CDC) Preventive Health Block Grant at TDH restored birth defects surveillance to the entire state.

The mission of the Birth Defects Monitoring Division is to protect and promote the health of the people of the State, by identifying and describing the pattern of birth defects and collaborating with others in finding causes of birth defects, working towards prevention, and linking families with services. (12)

According to the 1996-97 data report of the Texas Birth Defects Registry, the three most commonly observed birth defects were cardiovascular anomalies (patent ductus arteriosis, atrial septal defects, and ventricular septal defects), followed by two genitourinary anomalies (hypospadias/epispadias and obstructive genitourinary defect). Texas Birth Defects Registry staff detects approximately
11,000 pregnancies annually that are affected by one or more major malformations. Interesting age patterns were exemplified for gastroshisis (an abdominal wall defect) and Down syndrome, in which highest rates were observed for the youngest and oldest mothers, respectively. Racial/ethnic patterns were demonstrated as well. For example, pyloric stenosis was highest among non-Hispanic white mothers. African Americans experienced the highest rates of microcephaly, yet there were no cases of hypoplastic left heart syndrome in this ethnic group. Hispanics demonstrated the highest rates for two cardiovascular defects (ventricular septal defects, patent ductus arteriosis), ear anomalies (anotia/microtia), and spina bifida. Females were more likely to be born with ventricular septal defect and congenital hip dislocation, but pyloric stenosis and cleft lip were more common among males.

In 1996, the CDC funded Texas Birth Defects Research Center was established at TDH, under the auspices of the Texas Birth Defects Monitoring Division. It is one of eight collaborating research centers in the United States. The main purpose is to find preventable causes of birth defects. This is accomplished by participation in the multi-center National Birth Defects Prevention Study, as well as the epidemiologic studies within the state of Texas. These studies utilize information collected through telephone interviews from both mothers of cases from the Texas Birth Defects Registry, as well as mothers of children without birth defects. The 6-year Cooperative Agreement ends August 31, 2002, but TDH is competing for a 5-year grant renewal from CDC.

**F. Cancer Registry**

The Texas Cancer Registry (TCR) is a population-based registry, the goal of which is to collect timely, complete and accurate data on all cancer cases diagnosed in the state. The Cancer Registry Division of the Texas Department of Health is responsible for maintaining and administering the TCR. The Cancer Registry’s primary functions include maintaining a statewide cancer incidence reporting system; monitoring data accuracy, reliability and completeness through systematic quality assurance procedures; analyzing cancer incidence and mortality data; disseminating cancer information and facilitating studies related to cancer prevention and control. Cancer Registry data are used to identify populations at increased risk of cancer, investigate public concerns of suspected excesses of cancer due to environmental or other factors, and monitor trends in cancer incidence and mortality so that appropriate and timely interventions are undertaken.

The Texas Cancer Incidence Reporting Act makes cancer incidence reporting to the TCR mandatory for health care facilities, clinical laboratories and in certain instances, physicians and dentists. Rules have been adopted which specify how the data should be reported. The TCR has developed and distributes free software, SANDCRAB (Statewide Algorithm aNd Database for Cancer Registration and ABatement) Lite, for Windows, to meet the reporting requirements of this act. SANDCRAB is very user friendly and was designed to
be used by institutions to report cancer incidence data electronically to the TCR.

(13)

G. Chronic Disease
The Bureau of Chronic Disease and Tobacco Prevention provides chronic disease
prevention information, education, resources, and assistance to the people of
Texas to make healthy life choices, reduce the human and economic impact of
poor health, reduce the incidence of premature death and disability, and promote
healthy communities. The programs with a genetics component that are housed
under the Bureau of Chronic Disease and Tobacco Prevention include:
Alzheimer’s Disease, Cardiovascular Health and Wellness, Comprehensive
Cancer Control Program, Prostate Cancer Education Program, Texas Diabetes
Council, and Osteoporosis.

Alzheimer’s Disease (AD)

Alzheimer’s is a disease of the brain that causes a steady decline in memory,
thinking and behavior, severe enough to interfere with everyday life. Alzheimer’s
disease is a terminal illness. Currently, there are approximately 4 million
Americans who have Alzheimer’s disease and as the population ages, the number
is expected to reach 14 million by 2050. An estimated 280,000 Texans have
Alzheimer’s disease.

The role genes play in Alzheimer’s disease is not fully understood. The more
researchers learn about Alzheimer’s disease, the more they become aware of the
important function genes play in its development. Recent excitement has centered
on the discovery of the relationship between the apolipoprotein E (apoE) gene and
AD.

The Alzheimer’s Disease Program was established by legislative mandate in 1987
to provide information and support to Alzheimer’s patients, their families, and
long term care providers. House Bill 1066 established the Texas Council on
Alzheimer’s Disease and Related Disorders to serve as the state’s advocate for
persons with Alzheimer’s disease and those who care for them. The Council
functions to:

- Recommend needed action for the benefit of persons with AD and
  related disorders and their caregivers.
- Disseminate information on services and related activities for persons
  with AD to the medical and academic communities, caregivers,
  associations, and the general public.
- Coordinate services and activities of state agencies, associations, and
  other service providers.
- Encourage statewide coordinated research. (14)
Cardiovascular Health and Wellness

Cardiovascular disease (CVD) refers to a group of diseases that target the heart and blood vessels and is the result of complex interactions between multiple inherited traits and environmental issues including diet, body weight, blood pressure, and lifestyle habits. Common forms include heart disease, stroke, and congestive heart failure.

In Texas, heart disease claimed 42,968 (28.7%) of all deaths in 2000 and continues to be the leading cause of death in the state. Stroke ranked third in cause of death with 10,721 or 7.2% of all deaths in the state. Together, these two diseases cost the state more than $9 billion dollars per year, which totals over $500 per Texan.

The Cardiovascular Health and Wellness Program provides technical assistance, training and consultation on the development of policy and environmental change strategies. This is done with the objective of increasing access and availability to participate in physical activity and good nutrition as part of a healthy lifestyle for all Texans. Targeted sites include worksites, schools, food establishments, communities and health care settings. The program has developed an extensive resource list of educational materials promoting cardiovascular health issues. It also supports community-based, wellness mini-grants. These grant are awarded to communities for projects such as: development of walking trails and playgrounds; identification of mileage through trail markers; financial support to schools for opening their recreational facilities to the community; and offering incentives to food establishments that promote low fat food choices. (15)

Comprehensive Cancer Control Program

Cancer accounts for one of every four deaths annually in this country. It is the second leading cause of all deaths in Texas. Total number of cancer related deaths was 33,298 or 22.2% of all deaths in 2000. The devastation caused by this disease occurs at many levels - not only for those who are diagnosed, but loved ones, employers and others. Total estimated direct medical costs due to cancer in 1998 were $4.8 billion, and indirect costs from lost productivity were $9.1 billion – for a total of about $13.9 billion attributable to cancer in Texas that year.

Predictive gene tests are already available for some two dozen disorders. Genes have also been found for several types of cancer, and tests for rare cancers are already in clinical use. More recently, scientists have identified gene mutations that are linked to an inherited tendency toward developing common cancers, including colon cancer and breast cancer. All cancer has a genetic component.

The Texas Department of Health (TDH) received a grant from the Center for Disease Control and Prevention in 1998, to develop a Comprehensive Cancer Control Program. TDH was one of six sites in the nation funded for this program.
that provides leadership for and coordination of statewide cancer control efforts. TDH and the Texas Cancer Council (TCC), collaboratively administer this project. A major influence in Texas receiving this grant was that Texas had a Texas Cancer Plan (1998), which was developed by the TCC with input from all the major cancer stakeholders across the state. The Texas Cancer Plan establishes an overall approach to directing cancer control efforts with the following four goals:

1. Primary prevention
2. Early detection and treatment
3. Professional education

The goals of the Texas Comprehensive Cancer Control Program are to:

- Improve and expand the collaborative efforts already in place among the different stakeholders working on cancer control in Texas;
- Increase the use of the Texas Cancer Plan as the statewide document directing cancer control efforts;
- Develop a data-driven and science-based process for prioritizing the elements of the Texas Cancer Plan; and
- Disseminate the information available to local communities and provide technical assistance to communities working on local cancer control efforts.

These efforts will ultimately decrease cancer-related morbidity and mortality in the state of Texas. The Texas Cancer Council staff and the TDH Program staff formed the Texas Comprehensive Cancer Control Coalition, with representatives from major institutions working on cancer control in Texas. The Coalition provides the infrastructure for implementing this grant and its goals. (16)

Prostate Cancer Education Program

Each year about 12,000 men in Texas will be diagnosed with prostate cancer, making it the most common form of cancer in Texas men. Prostate cancer is the second leading cause of cancer death in Texas men, surpassed only by lung cancer. An estimated 1,717 Texas men died of this disease in 2000. According to health officials, although the disease is both deadly and common, many Texans remain unaware of prostate cancer.

In 1995, the Texas Legislature passed Senate Bill 1685, which created the Prostate Cancer Advisory Committee. Its mission is to help the Texas Department of Health and its partner organizations educate and raise public awareness about the disease. Committee members gather information, receive and evaluate presentations pertinent to prostate cancer and formulate and review
strategies that will help Texans deal effectively with prostate cancer in our state. (17)

Texas Diabetes Council

In 2001, there were 911,039 people in Texas diagnosed with diabetes. An additional 450,504 people in the state were suffering from diabetes but undiagnosed. These two groups represent over 10% of the state’s population. The estimated direct and indirect cost of diabetes in Texas was $9.2 billion in 1997.

Diabetes is the sixth leading cause of death in Texas. The disease was believed to have contributed to 13,553 deaths in 1998. However, it is believed that this number is actually much higher, due to the fact that death certificates often report complications of diabetes as the cause of death and not the diabetes itself.

As in other chronic diseases, diabetes has both genetic and environmental components. In type 2 diabetes, there is a genetic component that is subject to major influences from the environment. For the overwhelming majority of persons with typical type 2 diabetes, a single gene variant is not responsible. Instead, the genetic component of the disease is the result of multiple genes acting together. Scientists have identified some gene variants that contribute to type 2 diabetes, but have not found the variants that contribute to most cases. As medical research in this area advances, these genes will be identified. This information will help in the development of new medications and therapies.

The Texas Diabetes Council was established by the Texas legislature in 1983, it was mandated to develop and implement a state plan for diabetes treatment, education and training. Specific activities mandated by state legislature include:

- Public and professional education about all types of diabetes, its complications, and quality self-care management techniques;
- The development of programs for the prevention of non-insulin dependent diabetes mellitus (Type 2 diabetes) and its complications;
- The development of programs for the early detection and diagnosis of diabetes and;
- The development of accessible, high-quality diabetes treatment services and programs for patients with diabetes to improve glucose control or working toward normalizing blood glucose. (18)

Programs include:

- **Community Based Programs**
  The Texas Diabetes Program contracts with 15 organizations, serving 35 counties in Texas, to provide programs for promoting wellness, physical activity, weight and blood pressure control, and smoking
cessation classes for persons with diabetes. All of these community-based organizations target racial and ethnic minorities with health disparities. (19)

- **Texas Diabetes Institute (TDI)**
  TDI is housed in a state-of-the-art 153,000 square foot facility in San Antonio, Texas. It features classrooms and an auditorium, a teaching kitchen, patient library, fitness center, and video teleconferencing capabilities. In addition to the educational spaces, it has research laboratories, hyperbaric chambers, a renal dialysis clinic, a pharmacy, and clinics for each medical specialty. (20)

- **Diabetes Eye Program**
  The program’s mission is to prevent blindness by early identification of diabetic eye disease in high-risk public health clients. (21)

- **CATCH Texas**
  The Coordinated Approach to Child Health (CATCH) program is designed as a cardiovascular and diabetes education program for elementary school students. It is a coordinated effort between school classroom, cafeteria, and physical education programs. (22)

- **Walk Texas!**
  This is a community-based program whose mission is to promote the health of Texans by increasing awareness and opportunities for individuals to engage in regular physical activity, including walking. (23)

- **Texas Diabetes Prevention and Control Initiative**
  This initiative’s mission is to increase awareness of the importance of prevention, diagnosis and proper management of Type 2 Diabetes among Texas residents. This is done through diabetes prevention activities, early diagnosis and treatment referrals, and an awareness campaign. (24)

- **Texas Diabetes Pilot Medicaid Managed Care Project**
  This pilot project consists of continuous, comprehensive patient care, focusing on preventive services such as structured outpatient diabetes education, nutrition counseling, and care coordination for Medicaid recipients who have diabetes-related conditions, with an emphasis on community outreach. (25)
Osteoporosis Awareness and Education Program

Each year, osteoporosis and its associated health problems cost Texans about $977 million. Approximately 1.9 million Texans have osteoporosis or low bone mass and experience 72,000 associated fractures each year. While bone mass begins to deteriorate through normal aging beginning in a person’s fourth decade of life, there is no age at which it is too late to prevent fractures by taking steps to prevent bone loss.

As with many medical conditions, genetics and non-genetic factors interact with each other to exacerbate osteoporosis. There is not enough information at this point to speculate on the weight that genetic and non-genetic factors play in this disease. However, with more molecular information concerning the genetic aspects of osteoporosis becoming available almost daily, there is increasing likelihood for the design of new drugs to treat, reverse, or prevent the devastating effects of osteoporosis and also for new tests for identifying those at risk for the disorder.

The Osteoporosis Awareness and Education Program was established in 1995 by legislative mandate to perform three main functions: educate the public on the causes and risk factors for developing osteoporosis; publicize the value of early detection and prevention; and identify the most cost-effective options for available treatment. (26)

H. Texas Department of Health Genetics Work Group

The TDH Genetics workgroup consists of a representation of multiple programs in TDH that may relate to genetics. The areas include Newborn Screening Program (laboratory and follow-up), Genetics, Children with Special Health Care Needs Program, Newborn Hearing Screening Program, Birth Defects Monitoring Division, CCP Program (Medicaid), Office of General Counsel, Division of Public Health Automation, Bureau of Laboratories and Bureau of Chronic Diseases. The workgroup is sponsored by both the Associateship for Family Heath and the Associateship for Disease Control and Prevention.

The workgroup has been instrumental in the following activities:
A departmental survey on genetics involvement; automation recommendation (NBS/ NB Hearing Screening); recommendations/prioritization for modernization of NBS laboratory methods; summary on expansion of NBS Program to include additional disorders; summary documents on 30 conditions detected by tandem mass spectrometry; review of state genetic privacy issues and statutes; NBS birth prevalence data and summary document; TDH proposed components for a genetics state plan ; a “genetics and public health” teleconference; a legal opinion on retaining blood spots for research; a grant application to develop a data integration plan for newborn databases which was approved but not funded; meeting with representatives from March of Dimes about NBS for additional
disorders, including three recommended by national MOD for all states by 2005: MSUD, biotinidase deficiency, homocystinuria; convening of a NBS ad hoc task force regarding MS/MS and newborn screening in Texas.

The work group current activities are to enhance internal and external communication about genetics between TDH and its customers/ stakeholders (data, research findings, etc.); build partnerships with outside organizations and local health departments; develop a system to retain NBS blood spots for longer periods; look for ways to fund integration of newborn data bases; and review newborn screening rules.

I. Concluding Remarks

The state of Texas is doing much work in the area of genetic disorders with the numerous programs described in this section. However, the data collected on participants currently is not integrated into a common database. A successful State Genetics Plan will address the need for data integration for genetics services.

IV. Genetic Health Care Delivery Systems and Resources in Texas

A. Introduction

Medical genetic services are provided to Texans by three program models: university, private practice, and state operated clinic facilities. These models provide services to adult, pediatric and /or obstetrical patients. The following is a brief description of each model. Each model may have satellite clinics, which are defined as a clinic in a different city from the primary facility which has permanently assigned employees, but does not provide urgent care. Examples of urgent care in clinical genetics include treatment of life-threatening metabolic disorders, evaluation of the infant with severe congenital anomalies, and management of the high-risk pregnant woman late in pregnancy. Maps with the locations of clinical genetics providers are shown in Figures 3, 4 and 5.

In addition to the above clinical services, genetics education and counseling are provided by many agencies. These include state agencies, educational institutions and professional service organizations. The role of each of these organizations will be discussed in this section of the Texas State Genetics Plan.

Finally, and of equal importance is the funding sources for services. As earlier reported, only one state has more residents than Texas without health insurance. Without adequate health insurance coverage many Texas residents will not have access to clinical or educational services. (27)
B. Texas Department of Health Genetic Service Providers

1. Children with Special Health Care Needs

Of approximately 6.3 million children in Texas under age 21, the Center for Medicare and Medicaid Service reports that more than 960,000 may have special health care needs that limit their activities and that require more than usual amounts of medical care and related services. They live with chronic health problems ranging from respiratory allergies and asthma to cancer, heart disease, seizure disorder, cerebral palsy, sickle cell anemia, diabetes, and spina bifida. Of these 960,000 children with special health care needs (CSHCN), approximately 31,000 require daily, ongoing medical treatments and monitoring, and of these, as many as 6,000 depend on the routine use of a medical device or the use of assistive technology and live with ongoing threats to their well-being.

Texas offers several resources that recognize the unique needs of CSHCN and their families. Of all these resources, Medicaid reaches the most CSHCN. In addition to receiving regular Medicaid benefits such as physician visits and hospitalization, Medicaid-eligible children under age 21 may receive any federally allowable service that is medically necessary and appropriate through Medicaid’s Texas Health Steps Comprehensive Care Program (CCP). Services available through CCP can be especially important to CSHCN and may include private duty nursing, durable medical equipment and supplies, physical and occupational therapy, speech-language services, artificial limbs and braces, and nutritional formulas.

Children who qualify for Medicaid are also eligible for TDH’s Program for Amplification for Children of Texas (PACT). PACT provides early diagnosis of hearing impairment and related remedial services for children who are Medicaid-eligible or who meet financial guidelines. Approximately 5,600 children received PACT services in FY 96.

In addition to CCP and PACT, the Medicaid umbrella for CSHCN program in Texas includes the Medically Dependent Children Waiver Program (MDCP). Currently limited to serving 600 children, MDCP provides caregiver relief, or respite care, to families with medically fragile children as a cost-effective alternative to their child’s institutional placement. Participants also receive Medicaid coverage. In FY 96, the program was transferred to TDH from the Texas Department of Human Services, it was returned to the Texas Department of Human Services in FY 00. At the time of the initial transfer, rules were revised to expand its service array to include respite options such as in-home nursing care, personal assistance services, host families, and camps.
TDH also supports respite services through several grant-funded projects around the state. In FY 96, these projects provided caregiver relief to more than 330 families with special needs children.

CSHCN program at TDH uses state and federal funds to pay for medical care and related services for children with special health care needs whose families’ incomes are too high to qualify for Medicaid but not sufficient to cover extraordinary medical costs. CSHCN Client Support Services program pays for physician services, hospitalization, durable medical equipment and supplies, physical and occupational therapy, speech-language pathology, and other services for over 10,000 Texas children who have a covered diagnosis and who meet financial guidelines. CSHCN program revised its rules to require that all new applicants and many current participants apply for Medicaid before becoming or remaining eligible for the program. As a result, over 1,100 special needs children gained valuable Medicaid coverage.

To help maintain its perspective on all of these programs, TDH relies on its 18-member CSHCN Advisory Committee for valuable commentary and advice. However, the needs of nearly one million special needs children and families in Texas and their families are greater than TDH alone, with its limited resources, can address. TDH collaborates with other agencies, parents, and advocates through the Children with Severe Disabilities Workgroup, the Statewide Respite Task Force, and the Texas Planning Council for Developmental Disabilities, and other groups that share a common interest in special needs children.

The following summarizes what services the CSHCN program will funds for eligible residents:

- Case management
- Family supports
- Meals, transportation and lodging
- Transportation of remains
- Medical services
- Physical Therapy/Occupational Therapy/Speech Therapy
- Home health
- Medications (through Medicaid Vendor Drug Program)
- Prosthetics and orthotics
- Expendable medical supplies
- Durable medical equipment (28)

2. Genetic Screening and Case Management

The Genetic Screening and Case Management Division of the Texas Department of Health strives to improve the health of children who have genetic disorders. It is their mission to decrease the morbidity and mortality of infants in Texas through customer-oriented, high quality
newborn screening follow-up, case management and outreach education. Since newborn screening began in Texas in 1965 there have been 6,379 infants positively diagnosed with a genetics disorder through this program.

The case management staff follows up results from newborn screening for genetic disorders by ensuring that all abnormal screens are retested and contacting physicians and/or parents when confirmation of diagnosis is made. The names of infants with confirmed diagnosis are kept in a registry. The doctor of record is contacted on a regular basis to update the registry information. If the doctor reports that they have lost the child to follow-up a TDH case manager attempts to contact the child’s parent or legal guardian.

The Medicaid case management program and the CSHCN case management programs are also housed in the genetic screening and case management division of TDH. It is possible that children who are positively identified through the newborn screening program may also be in one of these case management programs. Even though the case managers are all under the umbrella of genetic screening their data bases are not linked to one another. (29)

3. Family Planning

The mission of the TDH Family Planning Program is to assist low income Texans to achieve their family planning goals and improve their health, and to positively affect the outcome of clients’ future pregnancies.

Preventive medical and educational services are provided under the direction of licensed physicians by over 100 TDH-funded family planning agencies in approximately 400 clinic sites across the state. The Family Planning Division contracts with a variety of organizations, including local health departments, medical schools, hospitals, private non-profit agencies, and community and rural health centers. Several TDH Regional clinics also provide family planning services. Charges to clients are based on a sliding fee scale according to family income and size. No client is refused services due to his or her inability to pay.

One of the many programs that the TDH Family Planning Program covers is genetic assessment, counseling and referral. It also provides preconceptual counseling to support healthy outcomes of future pregnancies. (30)

4. Special Supplemental Nutrition Program for Women, Infants and Children (WIC)

The Texas Department of Health’s Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), is a nutrition program
that serves as an adjunct to good health care. Its purpose is twofold: to provide nutrition education and food assistance to women and young children who are most vulnerable to the effects of malnutrition, and to achieve optimal nutritional status for children prior to entry into school. Its target population is low income pregnant, breastfeeding, and postpartum women, infants, and children up to age 5 who are at risk for nutrition-related health problems.

All WIC applicants are screened for income-eligibility and nutrition-related health conditions, for example, a dietary assessment is done to identify dietary inadequacy; a simple blood test is performed to screen for iron-deficiency anemia; height and weight are measured to identify poor weight gain, insufficient growth, and obesity; and a health history is taken to identify other health conditions that could impact nutritional status. Special accommodations are made for the families of children with special health care needs, and also for women with special needs. Applicants determined eligible are provided nutrition counseling, nutrition classes, and foods such as iron-fortified cereals, fruit juice, eggs, and mild or cheese. WIC encourages all women to breastfeed, but those who do not choose to do so are given infant formulas. They also provide very specialized metabolic formulas for those whose genetic disorders require them. Some WIC clinics offer childhood vaccinations, and others will refer the family to the nearest vaccination provider.

Average monthly participation in the WIC program during FY 2001 was about 750,000. WIC services are available in every county in Texas. (31)

5. Texas Health Steps (THSteps)

The mission of THSteps is to expand recipient awareness of existing health services, to recruit and retain a qualified provider pool, to make comprehensive services available through public and private providers so that eligible young people in the THSteps recipient population can receive medical and dental care before health problems become chronic and irreversible.

THSteps Medical Case Management (MCM) is housed within the Bureau of Children’s Health and the Division of Genetic Screening and Case Management. THSteps pays for medical check-ups, dental check-ups, immunizations, vision and hearing screening. Transportation coverage to healthcare and case management appointments is allowed for case management of early childhood intervention and for high-risk pregnant woman and infants; however the case management is often provided by phone or home visits and transportation for the recipient is not involved. If health problems are discovered during these appointments and the child needs further care the treatment is paid for by Medicaid.
The Comprehensive Care Program (THSteps-CCP) of THSteps provides medically necessary, federally allowable services to children under age 21 if federal financial participation is available. Such services include, but are not limited to, private duty nursing, durable medical equipment and supplies, physical and occupational therapy, speech-language pathology, artificial limbs and braces, and nutritional formulas. (32)

C. Other Relevant Resources

1. Texas Cancer Genetics Consortium

The Texas Cancer Genetics Consortium is one of a group of eight major research centers selected by the National Cancer Institute to lead the nation in the study of genetics and cancer. This coalition of research centers is called the Cancer Genetics Network and the regional centers and their affiliated clinics invite volunteers who have had cancer (or whose family history places them at high risk), to join the network’s research efforts.

The Texas Consortium consists of the M.D. Anderson Cancer Center in Houston, Texas, The University of Texas Health Science Center in San Antonio, University of Texas Southwestern Medical Center in Dallas and the Baylor College of Medicine also in Houston. (33)

2. MD Anderson – Clinical and Research

Located in Houston, Texas, on the sprawling campus of the Texas Medical Center, M.D. Anderson is one of the world’s most respected centers devoted exclusively to cancer patient care, research, education and prevention.

M.D. Anderson was founded in 1944 with the unique goal of treating only cancer. Over the years, M.D. Anderson has developed an ambitious cancer research program, with services in gene therapy, molecular therapy, and blood stem cell and bone marrow transplantation procedures.

The institution offers hundreds of clinical trials for patients with every type of cancer, studies that hopefully will reveal new drugs and treatment regimens that help to prolong and improve patient’s quality of life. (33)

3. Texas Medical Schools – Clinical and Research

- Texas Tech University Health Sciences Center
- The University of Texas Health Science Center at Houston
- The University of Texas Medical Branch at Galveston
- The University of Texas Southwestern Medical Center at Dallas
• The University of North Texas Health Science Center at Fort Worth
• Baylor College of Medicine
• The University of Texas Health Science Center at San Antonio

4. Early Childhood Intervention Program
The Texas Interagency Council on Early Childhood Intervention (ECI) is the designated state agency responsible for serving Texas families with infants and toddlers, birth to age three, with disabilities or developmental delays. Federal legislation, the Individuals with Disabilities Education Act (IDEA), Part C, defines the services that must be provided and establishes minimum eligibility requirements to ensure that all eligible children are identified and served appropriately. ECI provided comprehensive early intervention services to 33,649 infants and toddlers in the state fiscal year 2001 (September 1, 2000 through August 31, 2001). State, federal and local funding supports the ECI service system. ECI’s total direct services budget in fiscal year 2001 was $82,507,925. (35)

5. Mental Health and Mental Retardation
The mission of the Texas Department of Mental Health and Mental Retardation is to improve the quality and efficiency of public and private services and supports for Texans with mental illnesses and with mental retardation so that they can increase their opportunities and abilities to lead lives of dignity and independence.

The department’s priority population for mental health services consist of (1) children and adolescents under the age of 18 with a diagnosis of mental illness who exhibit severe emotional or social disabilities which are life-threatening or require prolonged intervention and (2) adults who have severe and persistent mental illnesses such as schizophrenia, major depression, bipolar disorder, or other severely disabling mental disorders which require crisis resolution or ongoing and long-term support and treatment. Mental health services include assessment and coordination, training and supports, in-home and family support, treatment, and community and campus hospitals. The Texas mental health community and campus-based system served 151,700 Texans in fiscal year 1999, approximately 30 percent of the potential eligible population. Recent waiting list figures indicate that 5,501 persons are waiting for mental health services.

The department’s priority population for mental retardation services consists of persons with mental retardation, pervasive developmental disorders, or related conditions. Mental retardation services include assessment, vocational supports, training, in-home and family support, and community and campus residential support. The Texas Mental retardation
community and campus based system served 28,657 Texans in fiscal year 1999, approximately 30 percent of the potentially eligible population. Recent waiting list figures indicate that 17,147 persons are waiting for mental retardation services. (36)

6. Department of Human Services

The Texas Department of Human Services was established in 1939 as the Texas Department of Public Welfare (DPW). When created, DPW absorbed the responsibilities of three former agencies; they were the Old Age Relief Commission, the Texas Relief Commission, and the Child Welfare Division. The mission of the Texas Department of Human Services is to provide financial, health, and human services that promote the greatest possible independence and personal responsibility for all clients. It does this by sponsoring a number of projects and initiative that are designed to improve services to Texans in need.

- Texas operates the nation’s largest electronic benefits transfer (EBT) system, delivering Temporary Assistance to Needy Families (TANF) and food stamp benefits to more than 1.4 million recipients (528,000 households) via a magnetic stripe debit card that can be used at more than 13,000 Texas retail outlets. EBT was implemented statewide in November 1995. Texas now uses electronic finger imaging technology to deter fraud and prevent duplicate participation in the Food Stamp and TANF programs.
- Fraud Investigation and Enforcement staff examine individuals or businesses suspected of illegally using DHS resources or services; actively seeks prosecution of flagrant violators; and returns money to the state treasury from the restitution of fraudulently obtained benefits.
- The State of Texas Assistance and Referrals System (STARS) allows people to self-screen for potential eligibility for programs provided by the Texas Department of Human Services and other Texas state agencies.
- The Texas Integrated Eligibility Redesign System (TIERS) project was created to implement several improvements in the delivery of social service programs administered by DHS. The project’s primary goals include replacing several outdated automation systems with one state-of-the-art integrated system and changing the agency’s business processes to improve accuracy and the delivery of services to millions of Texans.
- Texas Works helps people identify barriers to employment and find resources that will help them along the road to economic and social self-sufficiency. (37)

7. Texas Education Association

The Office for the Education of Special Populations is comprised of seven divisions: Special Education, Migrant Education, Student Support
Programs, Services for the Deaf, Parent Involvement and Community Empowerment, State/Federal Waivers, and Program Evaluation.

The office currently employs 100 staff members that administer an estimated 800 million dollars in state and federal funds. In addition, the Office is responsible for coordinating the Texas Consolidated State Plan, which allows the state and school districts to submit consolidated applications for most major federal education programs. This flexibility initiative, approved by Congress and included in a provision of the 1994 Improving American Schools Act, is intended to “improve teaching and learning by encouraging greater cross-program coordination, planning, and service delivery, as well as enhanced integration of federal education programs.” The estimated number of children served in the various program areas for 1999-2000 was 1,552,063. (38)

8. Department of Protective and Regulatory Services
The mission of the Texas Department of Protective and Regulatory Services (PRS) is to protect the unprotected – children, elderly, and people with disabilities – from abuse, neglect, and exploitation.

The agency provides child protective services, child-care licensing, adult protective services, and community based programs. PRS regulates child care; investigates allegations of abuse and neglect against children, the elderly, and people with disabilities; provides for foster care, adoption, and a variety of services for victims and their families; and supports contracted programs that make families safe and secure. The agency’s functions are divided into four main programs: Child Protective Services, Adult Protective Services, Child Care Licensing, and Prevention and Early Intervention. The programs serve different populations, but share many administrative and organizational functions. They also share a common goal: to provide the best possible services to their clients. (39)

9. Texas Natural Resource Conservation Commission
The Texas Natural Resource Conservation Commission strives to protect the state’s human and natural resources consistent with sustainable economic development. The goal is clean air, clean water, and the safe management of waste. (40)

10. Texas Department of Criminal Justice
The mission of the Texas Department of Criminal Justice (TDCJ) is to provide public safety, promote positive change in offender behavior, reintegrate offenders into society, and assist victims of crime.

The Health Services Division coordinates offender health care between TDCJ and health care providers. It is the responsibility of the Health Services Division Director to provide the agency with clinical expertise.
and guidance. The Division Director handles issues and inquiries requiring clinical investigation or consultation.

As of August 31, 2000 there were 669,675 offenders in the Texas Correctional system. (41)

D. Professional Service and Educational Organizations

1. Texas Genetics Society
The Texas Genetics Society was established in 1974 as a nonprofit association whose purpose is to foster the development of all aspects of genetics, to promote the exchange of research results and the teaching of genetics, and to provide a forum for discussion of matters of interest to all geneticists. Membership is open to all persons interested in genetics research, the training of geneticists, and the delivery of genetic services. (42)

2. Texas Association of Obstetricians and Gynecologists
The Texas Association of Obstetricians and Gynecologists (TAOG) works primarily in four areas:
• Serving as a strong advocate for quality health care for women.
• Maintaining the highest standards of clinical practice and continuing education for its members.
• Promoting patient education and stimulating patient understanding of and involvement in medical care.
• Increasing awareness among its members and the public of the changing issues facing women’s health care.

TAOG has a legislative arm with a legislative lobbyist and a political action committee. The also have an affiliated group, The Texas Coalition for Women’s Health, which consists of 6,000 patients of Ob./Gyn. doctors across the state of Texas. This group assists TAOG in legislative issues, and TAOG helps keep this group updated on women’s health care issues through two newsletters per year.

The Texas Association of Obstetricians and Gynecologists supports the above mentioned goals by sponsoring an annual educational meeting, a political action committee, and a biannual newsletter. Dues from members (approximately 1000) solely fund the association. (43)

3. Texas Perinatal Association
The Texas Perinatal Association is a non-for-profit, multidisciplinary organization whose purpose is to promote continuing improvement in the quality of health care for mothers and infants in the state of Texas. It is actively committed to achieving continuous improvement in the quality of
health care for mothers and infants in the State of Texas by: promoting networking of providers of perinatal health care; supporting education for providers and consumers of perinatal health care; improving availability, accessibility, and continuity of preventive and primary prenatal health care services; and prompting initiatives toward improving the care of mothers and infants.

The Texas Perinatal Association is funded through the proceeds from regional conferences and annual membership dues. They hold three conferences a year that promote low cost perinatal education in the more rural areas of Texas. The Texas Perinatal association participates in active lobbying for legislative issues that pertain to the health of mothers and babies. They also publish a newsletter three times per year that deals with various educational issues pertaining to the education of providers and consumers. (44)

4. March of Dimes

The mission of the March of Dimes Birth Defects Foundation is to improve the health of babies by preventing birth defects and infant mortality. The March of Dimes is known not only for its funded programs but also for its research to increase understanding of birth defects and causes of infant mortality, opening doors to new opportunities for prevention and treatment.

The national March of Dimes goals are to eliminate four major problems that threaten the health of American’s babies. These problems include: birth defects, infant mortality, low birth weight, and lack of prenatal care. The goals adopted by the March of Dimes include:

- Reduce birth defects by 10 percent.
- Reduce infant mortality to 7 per 1,000 live births.
- Reduce low birth weight to no more than 5 percent of all live births.
- Increase the number of women who get prenatal care in the first trimester to 90 percent.

To meet these goals the March of Dimes supports programs of Community Services, Research and Medical Support and Education.

In January 2001, the seven March of Dimes chapters in Texas merged to create a single Texas Chapter. This new chapter has division offices in 24 cities located in all regions of the state. As a result of this merger, grant proposals are no longer requested separately by each division office. Instead, there is one community grant program for the Texas Chapter in 2002. The March of Dimes Texas Chapter Community grants program is
designed to invest in priority projects that support three important foundation strategies:

- Access to and quality of health care for women and infants
- Availability of prevention services
- Folic Acid education

In 2001, the March of Dimes spent a total of $1,848,484.00 supporting research projects in the state of Texas. The specific programs funded can be found in Appendix I. (45)

5. Spina Bifida Association
Spina Bifida Association of Texas is divided into two chapters; they are the SB Association of Dallas and SB Association of Texas (Central and South Texas). The mission of both chapters is to promote the prevention of spina bifida and to enhance the lives of all affected. This is accomplished through many services, including; newsletters, peer counseling programs for families and others, 24-hour hotline, information and referral service, monthly meetings with speakers and experts in the field of spina bifida, scholarship funds, emergency funds, equipment funds, social activities, therapeutic camping program and public awareness. (46)

6. Texas Teratology Information Service
The Texas Teratology Information Service is housed at the University of North Texas in the Department of Biological Sciences. It is available for all residents of Texas, including health care professionals, the public, and students who need the most current information concerning fetal exposure to drugs, alcohol and other possible teratogens. The service receives partial funding from the Texas Department of Health and the North Texas Chapter of the March of Dimes.

The teratogen service has access to many current teratogen references, including TERIS and Reprotox, national teratogen computer database systems. Free teratogen counseling is provided to clients who live within driving distance of the University of North Texas. For those patients outside the area, a list of genetic resources in their area is provided if they need further assistance. (47)

7. Texas State Sickle Cell Disease Association
The Texas State Chapter of the Sickle Cell Disease Association functions to provide corporate infrastructure for the chapters that facilitate the delivery of programs and services for persons with abnormal hemoglobinopathies. Specific activities of the Texas State SCDAA include: coordination of the State Hemoglobinopathy Training Program;
liaison for funding distribution throughout the state; distribution of genetic counseling and screening availability information; coordination of speakers bureau; to seek grant sources to assist in the establishment of community support groups; and a referral service for health and social service organizations who treat sickle cell clients.

There are currently five local chapters of the SCDA in Texas. All but one is affiliated with the national organization. The Texas State Sickle Cell Association receives its funding through: grants, proposals for underwriting of programs, public and private contributions, collaborative partnerships and government entities. The priorities for funding are: 1) education outreach, awareness and training; 2) client camp for kids; 3) the design and marketing of sickle cell disease literature; and 4) transition program for adults based on the national model with input from the state chapters and the Texas Department of Health.

### 8. Genetic Alliance

The Genetic Alliance is an international coalition of individuals, professionals and genetic support organizations that are working together to promote healthy lives for everyone impacted by genetics. Founded in 1986, the organization works to create a world that celebrates the richness of diversity and recognizes everyone’s unique contribution to all aspects of life. The Alliance provides education, policy and information services in a supportive, non-directive and confidential manner. A prime objective of the Alliance services is to help people to understand genetics within the personal context of their lives and arrive at decisions consistent with their cultural, familial and personal values.

### 9. Texas Pediatric Society

The Texas Pediatric Society (TPS) is the Texas chapter of the American Academy of Pediatrics. The TPS is dedicated to the premise that the most important resource of the state of Texas is its children, and to this premise pledges its effort to promote their health and welfare. The goal of this Society is the attainment by all children in the state of their full potential for physical, emotional, and social health.

The PTS is a growing non-profit organization of 2,700 Texas pediatricians and 360 medical students. The activities of the Society are directed by a 16-member Executive Board, 19 working committees, and a 60 member council. The council consists of: elected officers and board members, chairs of the 19 working committees, chairpersons of department of pediatrics in the eight teaching institutions in Texas and directors of pediatric residency programs of Texas.

The activities of the PTS focus on legislation, health care reform and access to care for pediatric patients. TPS provides pediatric input
regarding important legislation affecting children through its Legislative Committee. Its work with statewide coalitions have resulted in new laws concerning child health insurance, assess to health care and tobacco use. The Society continues to support legislative initiatives concerning uninsured and under insured children, child safety, teenage pregnancy, maternal and child health, Medicaid expansion, and immunizations. In addition, the Society officers maintain contact with the American Academy of Pediatrics offices in Washington, DC, assisting when possible on national-level legislative efforts. (50)

E. Funding Sources

1. Title V – Genetics

The purpose of the Texas Title V Program is to address the overall intent of the Maternal and Child Health (MCH) Services Block Grant to improve the health of all women of childbearing age, infants, children, adolescents and children with special health care needs (CShCN). The state of Texas has responsibility to: a) provide and assure access to quality MCH services for mothers and children; b) provide and promote family-centered, community-based, coordinated systems of care for CShCN and their families; and c) facilitate the development of community-based systems of care for the MCH and CShCN populations.

The Texas Title V Program operates within the strategic plan framework articulated by Texas State Government, the Texas Health and Human Services commission (HHSC) and the Texas Department of Health. Texas’ priority goal for health and human services, as outlined by the Governor’s Office of Budget and Planning is as follows:

“To reduce dependence on public assistance through an efficient and effective system that promotes the health, responsibility, and self-sufficiency of individuals and families.”

The statewide benchmarks relevant to this goal are consistent with the requirements of Title V national outcome and performance measures. The relevant statewide benchmarks include: incidence of vaccine-preventable disease; infant mortality rate; teen pregnancy rate; low birth weight rate; number of persons enrolled in Medicaid; incidence of confirmed cases of abuse, neglect, or death of children, the elderly, persons with disabilities, or spouses.

The Vision, Mission and Philosophy of the Texas Department of Health further support and strengthen the Texas Title V Program. The mission of the Texas Department of Health is to protect and promote the health of the people of the state. In keeping with this mission, each program or activity conducted by TDH strives to obtain the most up-to-date information
possible about public health conditions, to direct its human and financial resources toward the areas where improvements in public health are needed, and to make every effort to ensure that the people of Texas receive the vital information and services needed to maintain and improve the health of the public.

As part of the Texas Department of Health, the Title V program is committed to the four TDH Board of Health strategic directions:

- Community-based solutions: a community orientation that creates a synergistic dynamic between the department and local organizations and individuals.

- Emphasis on prevention: a prevention strategy that can actually reduce major threats to the health status of our populations.

- Focus on outcomes: a moral determination to affect concrete outcomes in the health status of individuals throughout the state.

- TDH as a state leader: a leadership that transcends management. (51)

2. Medicaid Delivery Models

a. Fee-For-Service (FFS)-Traditional Medicaid

In a Fee-For-Service system, each client may choose any physician or health care specialist who is a Medicaid provider as and when needed. The State directly contracts with physicians and health care specialists who receive payment for services rendered. Medicaid pays geneticists (physicians) for evaluations including amniocentesis and chorionic villus sampling, genetic counseling, and ultrasounds; and labs for cytogenetic testing. See Appendix for full description of services covered by Medicaid and G-codes for service provision. (52)

b. Managed Care-Health Maintenance Organizations (HMO)

In Managed Care, each client has to choose a Primary Care Provider (PCP) who is responsible for administering the preventive and primary care of the client, including medical screens and immunizations. The client may only choose a PCP from the network of providers that the Managed Care plan has contracted with. When the client needs specialized or acute care, the PCP refers the client to other health care specialists who are part of the network for those services. The HMO receives a monthly capitation payment for each member enrolled based on a projection of what it may typically cost to treat that patient. (52)
c. Managed Care-Primary Care Case Management (PCCM)
In Manage Care, PCCM is a fee-for-service alternative to capitated HMOs. In it, each client has to choose a Primary Care Provider (PCP) who is then responsible for administering the preventive and primary care of the client, including medical screening and immunizations. When the client needs specialized or acute care, the PCP refers the client to other health care specialists for those services. The client may only choose a PCP from the network of physicians that the State has contracted with. (52)

Appendix A: How Medicaid Works in Texas
Appendix B: Differences between Managed Care-HMO (Commercial), Medicaid Managed Care and Fee-For-Services
Appendix C: Types of Medicaid Programs

3. Children’s Health Insurance Program (CHIP)
The Children’s Health Insurance Program (CHIP) is a national program designed for families who earn too much money to qualify for Medicaid, yet cannot afford commercial insurance. The State of Texas developed TexCare Partnership to raise awareness of new children’s health insurance options and to help Texas families obtain affordable coverage for their uninsured children, ages 0-19 years.

TexCare Partnership offers a comprehensive benefits package with a full range of coverage, including regular checkups, immunizations, prescription drugs, eyeglasses, lab tests, X-rays, hospital visits, dental care and mental health care – from a broad choice of doctors.

As of December 3, 2001 the estimated number of children enrolled in the CHIP program in Texas was 490,258. The number of families that had applied for CHIP coverage was 852,945. (53)

V. Gaps in Service Delivery–Present and Future

A. Assessment of Needs
Introduction
In November 2000, the Walter Richter Institute of Social Work Research (WRISWR) at Southwest Texas State University (SWT) was contracted by the Texas Department of Health (TDH), Genetics Division to conduct a three-part
research project. The overall goal of The Public Health Leadership in Genetics Project was to collect data that would aid in the development of a statewide plan for genetic services in Texas that represents the perspective of the various constituent groups directly affected by the genetic service delivery system. The Project involved data collection from three stakeholder groups: (1) state-level health and human services agencies and organizations, (2) individuals with genetic conditions and their families, and (3) physicians and allied-health practitioners from a variety of professional disciplines.

Also included in the assessment of needs are: the TEXGENE data collection report for 1999; the report of federal and state laws impacting the State Genetics Plan; and the report of database systems within specific Texas agencies, to determine the feasibility of integrating these systems. These reports, excluding the TEXGENE data collection report, were developed for the State planning grant. These studies were developed to ensure specific needs of Texas are incorporated into the state plan.

**B. Summary of Report Exploring Inter-Organizational Linkages to Enhance Coordinated Genetics Services in Texas (Full report found in Appendix D)**

**Introduction**
The Texas Department of Health (TDH) contracted the School of Social Work at Southwest Texas State University to assist in the development of a state-wide strategic plan for genetics services. The first of these three reports provides information about the external service environment. It identifies a limited number of potential partnering organizations/programs that could be targeted for future coordination, training, and collateral activity. The primary objective in undertaking this area of work was to suggest a list of agencies and programs which might be considered for establishing partnerships in the strategic planning process and ultimately in the provision of a more comprehensive system of coordinated services.

**Findings and Discussion**
Twenty programs were initially targeted for data collection. Of those, fifteen decided to participate and completed the survey for a return rate of 75%. Several items were not completed, although the methodology of the survey was designed to accommodate key informants’ needs in order to save time and to help facilitate the completion of the items. Some of this information was later collected in the telephone calls to the respondents. However, the lack of completion of some survey items may be associated with the fact that many of the participants reported little, if any, knowledge of genetic conditions or genetics services in Texas. In addition, researchers decided to include several advocacy programs in the study, and these did not all provide direct services. In addition, some programs rely
heavily on contracts with local providers for direct service delivery and appear to know little about contractor service data. Therefore, some questions in the survey did not apply to every program. However, within these limitations certain themes were evident.

Very few programs reported that they had an understanding of genetics services or the system of services in Texas. The majority of programs do not track or estimate the percentage of their consumers diagnosed with a genetic condition. Of the programs responding to this question (N=12) only two programs or 16.6% reported tracking clients with genetic conditions. When asked if the programs served consumers at-risk for genetic disorders, twelve programs answered this item (N=12). Of these, seventy-five percent (75%) reported either they “did not know” (N=5) or “no” (N=4). Of the respondents answering the item on familiarity with genetics services, the majority reported they were “not familiar at all with the provision of genetics services in the state” (58.3%), or were “minimally familiar” (33.3%), with only one (8.3%) reporting they were “somewhat familiar.” It appears from this study that within the programs participating, few human and social service programs are familiar with this consumer population, the services designed for them, or how to access these services. Interagency coordination and participation in this area is very minimal.

Consumers with genetic conditions represent a small fraction of social and human services’ total consumer population. Many of the social service programs focus on services to increase a specific populations’ functional level in society. Because of the infrequency of working with consumers with a genetic, unique service challenges, and significant service gaps/barriers are created at the local level. Since only two programs reported tracking clients who need genetics services, some of the reports of infrequency of working with this population are most likely impressionistic since data on this is not collected by most agencies. However, these impressions are likely to be accurate since key informants were chosen with a wide knowledge of the programs’ operations. Centralizing information about genetics services at the state level might fill some of these gaps. One option to explore would be a state genetic information and referral source operated by TDH or HHSC, or by educating state “Program Specialists” in different programs, who provide technical assistance at the local level. It is important to note that social workers at the local level are always in need of strong information and referral sources to help them guide their consumers through a web of services.

Eight programs out of 13 that responded, or 62%, reported that they do not utilize an interdisciplinary team that includes a professional trained in genetic assessment. None of the programs reported utilizing an internal agency genetics professional for staff training on genetic disorders. When asked where consumers are referred for service information related to genetic disorders, thirty-one (31%) or the responses were “I don’t know.” Area resource and referral agencies accounted for 23% of the responses, with 14% choosing “Personal Physician”,

34
9% Genetic Specialist, 9% Hospital/Clinic, and 14% designated as “other.” Multiple responses on this item were possible. Still, almost one-third of the respondents stated that they were unaware of where to refer consumers.

Consistent themes also emerged from questions concerning barriers in the provision of genetics services. The majority of responses to this question (45.5%) indicated “I don’t know.” Other responses included a lack of education regarding genetic disorders and/or treatment (18.2%), and lack of information regarding genetics services (18.2%). Only one program reported that frontline staff received training in genetic disorders, and only one program reported that supervisors received similar training. This indicated the need for enhanced training and knowledge about genetic conditions, systems of care, and resources.

In terms of programmatic efforts to regularly seek input from consumers, thirteen programs answered this item (N=13) and all but one (92.3%) state that their programs do use some form of methodology for seeking consumer input. Programs were asked to list methods used to seek consumer input. Five of the thirteen agencies (38.4%) listed multiple methods and responses ranged from one method to three methods. One program also reported that this was not applicable. A variety of methods were identified including: surveys (47%); review of grievances (17.6%); general consumer feedback requested (11.7%); committees (5%); service plan input (5%); focus groups (5%); toll free lines (5%); policy groups (5%); and not applicable (5%). From the above responses, it appears that programs are beginning to respond to the need for consumer input, with 92.3% listing some type of customer satisfaction work completed. This is expected since the Legislature now mandates consumer satisfaction tracking by state programs.

In terms of the family-centered nature of services, fourteen programs responded to this question. Of those, eight (N=8) or 57% reported that consumers were fully engaged in the child assessment process and the remaining six (43%) reported that this did not apply to their services. However, in terms of engaging consumers in team meetings, 42% reported engaging them fully, 29% reported engaging them moderately, and 29% reported not engaging them. This data appears to indicate the need to enhance family input into the service design, evaluation, and policy development processes. Only then, can services reflect the needs from family perspectives. This data, along with the preceding consumer satisfaction results, indicates the need for programs to continue developing ways for improving consumer-oriented models of care.

**Recommendations**

Creating a statewide coordinated effort between a fragmented, localized genetics services system, and a fragmented localized social service system will be challenging. However, it is important to highlight a number of overall and agency/program specific recommendations to facilitate a more enhanced system of services.
• Explore an on-going interagency task force for working on key issues of coordination and training regarding genetics services. This could be folded into on-going task forces or interagency cooperative initiatives already in existence. This proposed effort should be considered by the HHSC Commissioner in order to enhance participation across agencies and coordinated by the TDH Genetics Services Division.

• Staff responsible for developing the strategic plan should contact and include the Health and Human Services Commission (HHSC). HSC has numerous cross-cutting initiatives already underway that focus on enhancing coordination of services across several service populations as well as across several specific issues. Efforts should continue to build on these existing initiatives and avoid duplication.

• Explore creation of statewide or regional guides to genetics services to include information about genetic disorders, service availability, and directions for accessing genetics services. Make these available to targeted state level personnel in identified programs. Also, explore with state-level program personnel, if regional or frontline program staff would benefit most from such a guide. It would also be essential to provide the guide to local information and referral centers. Information already developed should be further disseminated across social service programs. A specific marketing plan for dissemination should be developed that would target human service agencies for this information.

• Staff at the agency and local program level are in need of more comprehensive information about genetics services and genetic conditions. A curriculum for training agency staff is also needed. The feasibility of efficient methods of disseminating this information should be studied including such methods as web-based courses, teleconferencing, CD-ROMs, and continuing education workshops.

• Efforts to expand the number of programs and agencies involved in the strategic planning process and in any future training and coordinating efforts should be expanded beyond those explored in this study. The limitations of this study in terms of time and fiscal resources were such that only a limited number of programs could be included. Other agencies and programs exist that might be important to include.

• Especially important are efforts to include advocacy groups in the planning and coordination efforts. Reaching out to statewide and population specific service advocacy groups should be a priority in order for any strategic plan to be supported at the state or community level by consumers. Advocacy groups beyond those specifically associated with genetic conditions should also be targeted.
• In addition, other stakeholders such as universities and medical schools have a potential interest in participation in strategic planning since they represent the front-end of the customer chain. These entities should also be invited to participate.

• Identify, catalogue, and target existing training curricula across agencies/programs that can add modules on genetic conditions and family-centered principals of service delivery in order to enhance the effectiveness of service providers.

• Promote the training of case managers and other front line staff in all agencies in advocacy techniques, understanding of current programmatic initiatives, and referrals in order to be more effective in securing and linking consumers to genetics services.

• Provide technical assistance to TDH contractors and genetic service providers towards enhancing methodologies for seeking consumer input into service design and delivery.

• Recommendations from this report and other pieces of overall grant report should be shared with stakeholders and potential stakeholders agencies by disseminating hard copies, posting on the TDH web site, and sharing with key advocacy groups.

C. Summary of Report on Consumer Needs for Genetics Services (Full report found in Appendix E)

Introduction
This report is an analysis of data collected from consumer focus groups gathered during Spring 2001. It was decided by representatives from the TDH Genetics Division and the Advisory Council of this project that conducting focus groups would be an efficient way to gather public input, and encourage consumers to become “stakeholders” in the development of a state plan for genetic services. Three focus groups were conducted with consumers or family members from several urban and semi-rural communities throughout Texas. The data collected from focus groups reflect rich descriptions about what it is like to receive a diagnosis of a genetic disorder, and how this news affects the quality of life experienced by individuals diagnosed with genetic conditions and the families that care for them. This report attempts to capture the richness of the commentary expressed during focus group sessions, and summarizes the distinct and commonly shared perspectives of consumers of genetic services.
Findings
Discussions about the current service structure for genetics were initiated by posing the first research question, “What is the current state of genetic services for families?” This question was developed to not only encourage participants to describe how current services are delivered, but to also provide participants a forum where they could discuss the merits and limitations of the current service structure. Participants grappled with the challenge of this question by sharing personal observations and experiences in acquiring genetic services, and eventually discussing specific strengths and shortcomings of current services.

The topics of inadequate funding for genetic services and genetic counseling, and a general scarcity of resources to educate, inform, and support families, dominated most discussions. Concern about these issues varied according to the group and region. Family members frequently discussed the amount of time, money, and emotional energy it took to address the needs of their children. Subsequently, their concerns focused on the need for medical, financial, psychological, and social supports. Service providers focused more heavily on how the current system of genetic services can complicate a family’s ability to acquire the services they need. Both consumers and service providers were concerned about the current distribution of services and resources to residents of Texas, especially residents in rural communities. There was also mutual concern about the overall need of educating health care professionals, insurance companies, and the general public more adequately about genetic disorders, genetic testing, and the care needs of children and adults affected by genetic disorders.

There were five major themes that emerged from the content analysis of the focus group transcriptions. These major themes were:

- Barriers to Service
- Psychological Issues
- Unmet Service Needs
- Educational/Information Issues
- Program Resources

Conclusions
Areas that need to be addressed when developing a state plan for genetic services in Texas should include:

- Increased funding and reimbursement to local genetic services programs in order to stabilize their efforts and allow for expansion of their services;
- Expanded efforts to encourage medical providers to identify and refer persons of all ages who are suspected of a genetic disorder for screening and testing;
• Developing measures to more adequately estimate the current need for genetic services in the state and to collect demographic data about genetic disorders in Texas;
• Expanded public education and information efforts about genetics, and genetic disorders, and how to prevent them;
• Supporting the expansion of genetic services in remote and rural sections of the state, especially in West and East Texas;
• More consideration of the time, financial, and emotional limits of families when developing genetic services program policies and plans;
• Supporting programs in providing effective counseling and patient education for families from various cultural and linguistic backgrounds; and
• Developing specialized case management services for families with children born with genetic disorders.

D. Summary of Report on Provider Needs for Genetic Services (Full report found in Appendix F)

Introduction
The Public Health Leadership in Genetics Project study results involving medical and allied health practitioners representing a variety of professional disciplines are explained in this report. A web-based survey was designed to obtain practitioners’ perceptions of the service delivery system and the types of knowledge needed in order to enhance the genetic service experience for individuals and families. A better understanding of providers’ perceptions of the genetic service system and knowledge needs can contribute to improvements in the service system by targeting areas for health promotion activities and education and training efforts to enhance practitioners’ knowledge.

Discussion
The demographic profile of respondents suggests that survey participants are predominantly white, non-Hispanic males practicing in regions of the state where the largest metropolitan areas are located. Since the majority of respondents have been in practice less than five years, the data also suggest relatively recent graduation from medical or professional education. Because recency of graduation is among the strongest predictors of genetics knowledge (Hofman et al., 1993; Geller et al., 1993; Acton et al., 2000), the current sample might be expected to be fairly knowledgeable concerning genetics. Although the majority of respondents indicate they have completed more than five years of academic training in genetics, most do not report genetic specialty as the focus of their professional practice. It may be that respondents considered genetics content in their medical or professional school as formal academic training and not specialized genetics training.
In terms of reported level of knowledge, respondents perceived practitioners as knowledgeable in aspects related to risk assessment. That is, they believe practitioners are knowledgeable in recognizing the needs for genetic services and knowing when to refer individuals for specialized services. It should be acknowledged that these are subjective, self-reported measures. Nevertheless, respondents perceive practitioners as less knowledgeable regarding the application of clinical information (i.e., genetic test results and putting family history information into hereditary patterns).

Knowledge about what services are available for persons with genetic conditions appeared to be a recurring need in responses to various survey items. This type of knowledge was among those about which practitioners were perceived as “Not Very or Not At All Knowledgeable.” Lack of knowledge regarding available services was reiterated in open-ended responses about types of knowledge perceived as important for practitioners to have, as well as barriers encountered in making referrals to genetic services. Open-ended comments suggest that while survey respondents believe themselves to be knowledgeable about available services, they may not feel that other practitioners share that knowledge.

Preferred sources of genetic information indicate that practitioners rely more on sources that are expedient, i.e., consultation with genetic specialists and the Internet and less on more traditional sources such as books, journals or professional associations. These preferences may reflect the general trend toward increased use of technology but may also imply that new information being generated needs to be made accessible more quickly than some mediums, such as publication in the professional literature allow.

The overwhelming majority of respondents indicating that at least some level of services are available in their regions is likely to be a function of the fact that their practice is located in regions with large metropolitan areas where teaching hospitals also tend to be located. However, open-ended responses conveyed a clear perception that the geographic distribution of genetic services and resources is uneven, leaving rural or less heavily populated areas of the state at a disadvantage. The lack of geographically accessible resources is perceived as presenting additional burdens to individuals and families in terms of cost, time and effort required to travel to obtain services.

Financial considerations in accessing services were also cited among open-ended responses. The lack of services available for poor, economically disadvantaged and uninsured families was specifically cited as a need. For individuals and families who are insured, exclusions and coverage limitations for genetic conditions were cited as barriers to accessing services. Thus, even if the types of services currently available in some areas were expanded into rural areas and these were marketed in such a way as to increase knowledge of their availability, financial limitations are likely to have the potential of continuing to function as barriers to services.
Recommendations
This exploratory study of medical and allied health practitioners was designed to capture perceptions of the genetic service delivery system as well as the types and levels of knowledge that practitioners possess. The study sought to contribute to improvement in the service system by providing a better understanding of providers’ perceptions regarding these issues and to identify areas for targeting health promotion and training efforts.

In keeping with the purpose of the survey and the findings discussed above, the following recommendations are offered:

- A state-wide referral system should be developed that would provide readily available information about services available by geographic area. A user-friendly web-based database could be accessible by providers and consumers alike.
- Clear, written educational materials should be developed to increase practitioners’ knowledge of when referrals to genetic service may be indicated as well as the implications and limitations of genetic services.
- A phone or fax-on-demand information service for providers should be developed that would offer up-to-date information regarding specific genetic conditions, information summaries, case studies, etc. for guiding clinical decisions.
- Well-articulated referral guidelines should be developed and made available in a variety of mediums (written, web-based, CD-ROM, etc.) to enhance appropriate referrals of individuals to genetic services.
- Computer- or web-based continuing education materials should be developed featuring specific educational topics or skills development training in such areas as taking genetic family histories, putting family history information into pedigrees, and communicating genetic information to patients and their families.

Implementation of these and additional educational strategies statewide can help the wider population of medical and health practitioners become more confident and effective in their use of the service delivery system, thereby contributing to the enhancement of the service experience for individuals and families affected by genetic conditions.

Finally, although not directly related to practitioners’ knowledge of genetic services, the fundamental issue of funding must be addressed. Funding for genetic services is needed not only to expand service availability to underserved areas, but to make services accessible to families who are uninsured, underinsured, or whose out-of-pocket medical expenses result in financial hardship. Furthermore, the lack of sufficient reimbursement for genetic services also places a burden on service providers as they seek to care for persons with suspected or diagnosed genetic conditions. Financial constraints on their ability
to respond to the needs of patients and the lack of financial incentives may discourage practitioners from entering this field of practice, placing an undue burden on the service delivery system at a time when growing awareness of genetic concerns and new developments in genetic research signal the potential for increased service demand. Increased funding support for genetic services and improved knowledge necessary for effective use of services available are critical elements in strengthening the statewide service system of genetic services to better meet the genetic service needs of children and families in Texas.

E. Summary of TEXGENE Data Collection Report from 1999 (Full report found in Appendix G)

Introduction
Clinical Genetics Services surveys were conducted in 1992, 1994, 1997, 1998 and 1999 by the Texas Genetics Network (TEXGENE). The first four reports were presented to the Interagency Council (IAC) for Genetic Services and to the Commissioner of the Texas Department of Health (TDH). These surveys and the present survey asked the following questions:

1. Who are the genetic service providers in Texas and under what models of service provision do these providers operate?
2. Who requires genetic services in Texas?
3. Where are the patients located?
4. How many patients are seen?
5. Where do genetic service providers operate, in relation to patient populations?
6. Are there medically indigent Texans who need genetic services? If so, how are such services provided?
7. What funding sources are available to pay for services?
8. How are genetic service providers funded?
9. Are there populations of patients which are unserved or underserved? If so, what are the reasons (no provider available, inadequate funding)?
10. Are there areas of service redundancy?

The results of these surveys were intended to guide implementation of genetic services in underserved and unserved areas of Texas, and to identify regions in which redundancy of genetic services existed. The Clinical Genetics Assessment of 1994 was conducted with the goal of determining how well the genetics provider community had succeeded in redistributing genetic services based on previous study recommendations. In 1996, genetics services in Texas underwent a change in funding. The TDH program, Genetic Screening and Counseling Services (GSCS), was eliminated and a portion of their funding was redistributed to contract providers. Only one TDH genetics provider remains and the effect of this redistribution led to a decrease in clinical genetic services in 1997. In order
to track and evaluate genetic services in Texas, TEXGENE instituted assessment on an annual basis, and surveys were conducted annually from 1997-2000.

The following information was reviewed in this report:

1. Survey of 1999 Clinical Genetic Service Providers in Texas
2. Survey of Medicaid funded genetic services in Texas

**1999 Survey of Genetics Providers in Texas**
This survey was conducted in order to determine the numbers and types of clinical genetic services provided in Texas. It represented the fifth survey conducted by TEXGENE. The following process was used:

1. Definitions of service types remained the same from prior surveys.
2. Data were collected on genetic services provided at each participating center for the period between 1/1/99 and 4/30/99.
3. Data were analyzed at TDH under the supervision of the TEXGENE Data Committee.

Review of pediatric genetic services data indicated that an estimated 0.62% of all live born infants received genetics evaluation at one of the participating centers prior to their first birthday. This represents an improvement (23.7% increase) in genetic services provided to infants since 1998 and was the same level of genetic services provided in 1994. Of the 2,127 infants less than one year of age receiving genetic services, 65% of the services were paid with public funds and 35% were paid with private funds or were uncompensated.

Most of the public health regions showed an increase in the number of services provided to infants in 1999. However, public health regions 4 and 9 showed either a decrease or no change in the number of infants receiving services from 1998 to 1999. When data from 1994 and 1999 were compared, seven Public Health Regions, region 1, 4, 5, 6, 7, 9 and 10 showed the same level or decrease in services to infants. However, the overall percent of infants served in 1999 (.62%) was comparable to the 1994 rate (.60%). Genetic service provision to infants in densely populated counties was compared to those provided in the regions as a whole. In general, counties in which genetics providers practiced had higher percentage of infants served.

In 1999, 4.5% of all women statewide who had live births received prenatal genetic services at a genetics center. This represented no substantial change from 1998. It was estimated that a minimum of 7% of pregnant women should receive genetic services. (An estimated 9% of women who give birth in Texas are 35 years of age or more. Of these women, half or 4.5% will accept prenatal diagnosis if offered. An additional 2.5% of pregnant women should be referred
because of high maternal serum alpha fetoprotein. This does not take into account women with other indicators for referral. Thus a little more that half of the estimated 7% of women needing prenatal genetic services were receiving them. 19.6% of women aged 35 or above who had live births received prenatal genetic services at a reporting center, again showing no appreciable change over past years.

Some urban areas met or exceeded the statewide average of 4.5%. Tarrant, Galveston, Travis, Bexar, and Cameron counties exceeded the goal of 7%. Tarrant, Harris, Brazoria, Ft. Bend, Galveston, Travis, Bexar, Cameron, Hidalgo, and Nueces, and Public Health Regions 6, 7, 8 and 11 exceeded the state average. Many rural areas in regions 1, 2, 4, 5 and 9 appeared to be underserved. All of region 10 was underserved.

Forty-seven percent of infants born in Texas in 1998 were delivered to women who were eligible for Medicaid funding (source: State Health Data and Policy analysis, Blue Ribbon Report). Therefore, Medicaid is a highly significant payer for genetic services to pregnant women and newborn infants. The following questions were asked:

1. Is utilization of genetic services by Medicaid eligible individuals’ uniform throughout the State of Texas?
2. If not, what counties have fewer than average genetic service clients in proportion to their Medicaid eligible population?

Information about Medicaid paid deliveries for 1999 was unavailable, so 1998 information was used as these data were not believed to have changed substantially. Medicaid records for 1998 were searched for the following information:

1. Total number of Medicaid paid deliveries for women aged 35 or above by county, and
2. number of Medicaid paid deliveries for women aged 35 or above by county.

The following ratios were computed for each county and for the state of Texas as a whole:

1. An annualized estimate of all prenatal patients with Medicaid who used genetic services in 1999, based on survey data collected between 1/99 and 4/99, compared to all women who had Medicaid paid deliveries in 1998, and
2. an annualized estimate of prenatal patients aged 35 or above with Medicaid who used genetic services in 1999, based on survey data collected between 1/99 and 4/99, compared to women aged 35 or above who had Medicaid paid deliveries in 1998.
Among women who had Medicaid paid deliveries in 1999, 4.4% received genetic services at a reporting genetics center. Among women aged 35 or above whose deliveries were paid by Medicaid in 1999, 29% received genetic services at a genetics center. The percentage of Medicaid eligible pregnant women served in 1999 represented an increase over all other years.

Utilization of prenatal genetic services by Medicaid funded women by public health regions and urban counties in 1994, 1997, 1998 and 1999 were also reported. Despite the increased number of reporting genetic centers and a statewide increase in reported prenatal service provision, Public Health Regions, 1, 3, 5, 8, and 11 reported decreased utilization of genetic services by Medicaid funded women (all ages) between 1998 and 1999. Utilization of prenatal genetic services by Medicaid funded AMA (Advanced Maternal Age, age 35 years or older) women between 1998 and 1999 overall showed significant increases; however only Public Health Regions 1, 3, 8 and 11 showed decreases in these services between 1998 and 1999.

Statewide rates of utilization of genetic services at a genetics center for all prenatal patients were compared with rates of utilization by Medicaid reporting patients in 1994, 1997, 1998 and 1999. In 1994, Medicaid funded patients were less likely to receive these services than patients with other funding. In 1997, these differences were no longer evident, and in 1998 and 1999 AMA Medicaid funded women received more services. In addition, reported utilization of prenatal genetic services by all pregnant women increased dramatically since 1994; some of this increase may be accounted for by the expanded number of centers reporting data in 1997 compared to 1994. There was little difference in prenatal services provided between 1997 and 1999 with the exception of services to AMA Medicaid prenatal patients, which showed a marked increase.

Starting with the 1997 survey, providers were asked to specify payers for genetic services. In 1999, Medicaid continued to be the major payer for clinical services (50.7%), but was outpaced by private payers for prenatal services. Title V provided 4.3% of the funding for clinical patients and 11.9% of prenatal genetic services which is comparable to 1997 and 1998. Over 98% of prenatal patients whose genetic services were funded by Title V lived in 5 cities: 54% were in Houston; 29% in Corpus Christi, 3% in Dallas, 8% in Galveston, and 4% in Austin.

Of the patients receiving clinical genetic services in Texas, 36% were non-Hispanic white, 38% Hispanic, and 11% African American. The overall distribution of these ethnic groups in Texas was 55%, 30% and 11% respectively. Based on the percentages of the population and the patients, Hispanic patients received proportionately more services than non-Hispanic white patients. Non-Hispanic white patients were markedly underserved in Public Health Region 8, while Hispanics were markedly underserved in Public Health Regions 2, 3 and 9.
Hispanic patients predominately utilized public and Title V funds, whereas Non-Hispanic white and Asian patients predominately utilized private health care insurance. African American patients utilized public and private health care insurance equally.

Summary of Findings
1. In 1999, 2,127 infants received genetic services; 10,000 were estimated to require services. This utilization represents a small increase compared with services in 1994, 1996, 1997 and 1998, but only 1/5 of the infants who required services per year were receiving them.

2. In 1999, approximately 5% of all pregnant women and 20% of AMA pregnant women received prenatal genetic services at genetic centers. This did not include prenatal genetic services provided by other physicians. Both clinical genetics and prenatal services showed no substantial increase in services over 1997 and 1998. Regions 9 and 10 had minimal services provided.

3. More than sixty percent of genetic services provided to infants were paid with public funds. Of these, the majority were paid by Medicaid. Medicaid was the largest single source of funds for infants receiving genetic services. Medicaid funds many children with special health care needs, which may account for the high proportion of services paid by Medicaid.

4. There was disparity in payer type by race/ethnicity. Hispanic patients primarily used public health care funding, Non-Hispanic white patients primarily utilized private health care funding and African American patients used public and private health care funding equally.

Recommendations for Genetic Service Provision in Texas
1. Since only 20% of infants estimated to need services were receiving them, provision of genetic services to infants and other non-pregnant patients is of particular concern throughout the state. The Texas Department of Health and the TEXGENE data collection committee should proceed with the development of a comprehensive planning process to address this important public health problem.

2. Utilization of prenatal genetic services in rural areas, and in El Paso, by genetics providers remains low. The Texas Department of Health and TEXGENE should undertake an analysis to determine the factors that underlie this observation. Where unavailability of qualified providers is a factor, TDH and TEXGENE should work with community leaders and providers to address the problem.
3. Additional educational programs should be focused at health care providers in order to achieve increased referrals for children less than 1 year of age.

4. Since Medicaid is such an important payer for genetic services to infants, this category of funding should be preserved.

5. Title V is an important payer for genetic services for Hispanic clients, particularly in Houston and Corpus Christi/Rio Grande Valley. Efforts should be made to expand and preserve this funding.

### F. Summary and Analysis of Laws Affecting Genetic Activities in Texas (Full report found in Appendix H)

**Introduction**

This report was prepared for the Texas State Genetics Planning grant by Joseph J. Wang, J.D., M.P.H., Assistant Professor of Law at the Health Law and Policy Institute, University of Houston Law Center. Mr. Wang was subcontracted by the Texas Department of Health to conduct a legal review of all current and proposed laws, regulations, and rulings that affect genetic activities in Texas. Specifically, this report provides a summary and analysis of health information privacy and genetic nondiscrimination laws both at the federal and state levels.

The following is an executive summary of Mr. Wang’s findings. The report can be read in its entirety in Appendix H.

1. A Texas State Genetics Plan calling for the sharing of information among governmental agencies, state programs, and third parties must be scrutinized by considering the various provisions in both federal and state law. The key preliminary questions are: is the genetic information protected health information; does the law apply to the particular entity in question; was consent or authorization given prior to access to, use or disclosure of protected health information; and are there exceptions to the rule?

2. Federal law under HIPAA prohibits the unauthorized use, disclosure, access, and retention of health records; imposes affirmative duties on the entities it regulates with respect to privacy and security; and authorizes governmental bodies to enforce its various provisions.

3. The federal GLBA requires “financial institutions” to provide consumers notice of the privacy policies regarding the use and disclosure of nonpublic personal information and to give consumers an opportunity to opt-out of the sharing of that information with affiliates and third parties. Because health entities could be regarded as “financial institutions: and
some medical records as nonpublic personal information, GLBA is an important law in protecting health information privacy.

4. The Texas Medical Practice Act addresses specifically the duties of physicians and hospitals in protecting the confidentiality of and limiting the access to patient medical records.

5. The recently enacted Texas Senate Bill 11 not only adopts in large part the HIPAA privacy standard into state law, but also provides privacy protections beyond that required under federal law by broadening its definition of “covered entities” that must comply, adding an opt-in requirement before marketing activities, and expanding the availability of possible legal and equitable remedies.

6. HIPAA protects individuals from genetic discrimination in health insurance by including genetic information as a health factor that may not be used to deny or limit coverage in the group health insurance market and by prohibiting the use of genetic information as a preexisting condition. HIPAA provides less protection in the individual health insurance market.

7. Forty-six states and the District of Columbia have enacted laws that protect individuals against genetic discrimination in health insurance. In almost all of these states, the laws apply in both the group and individual health insurance markets. Texas law only applies in the group market, leaving many individuals without genetic anti-discrimination protections.

8. Federal law does not address specifically genetic discrimination in employment. However, employees have been successful in challenging genetic testing in the workplace under the Americans with Disabilities Act. Also, federal law under a presidential executive order prohibits federal agencies from using genetic information in employment decisions.

9. Twenty-two states have statutes that provide protection against genetic discrimination in employment. Although a few of these states only prohibit employers from using genetic information for employment purposes, most states go further and prohibit them from requiring or even requesting it. In Texas, an employer cannot require genetic testing as a condition of employment.

10. The scope of anti-discrimination protection depends on the definition of “genetic information” in the law. If its definition is broader, the scope of protection is broader. Most states define genetic information broadly to include family history. Texas recently amended its definition of genetic information to include family health history. Consequently, the scope of genetic anti-discrimination protection in Texas is stronger than before the amendment.
11. Congress is now considering comprehensive legislation banning genetic discrimination in health insurance and employment. In the health insurance context, the ban would prohibit genetic discrimination in both the individual and group health insurance markets. In the employment context, the ban would apply to employers, employment agencies, labor organizations, and training programs and limit their use of and access to genetic information.

G. Summary of Report on the Feasibility of Integrating the Data Infrastructure of the Texas Genetics Surveillance Programs and associated Service Delivery Programs (Full report found in Appendix I)

Introduction
This study was conducted to answer a specific question: “Can the data systems of the various genetic surveillance systems and intervention systems be integrated?” In addition, several other possibilities are explored. If total integration is not feasible, can the surveillance systems be integrated and linked to the intervention systems? If integration is not a viable option, can all systems be linked to provide access to relevant data?

Included Programs
The programs included in this study fall into three categories; surveillance systems conducted within the Texas Department of Health, related delivery systems, and general service delivery systems. All of these service delivery systems agencies fall under the Texas Health and Human Services Commission umbrella.

A. Genetic Surveillance Systems
   1. Laboratory Information System for Case Management (LIMS)
   2. Newborn Hearing Screening (NBHS)
   3. Birth Defects Registry (BDR)

B. Genetics-Related Service Delivery Systems
   1. Children with Special Health Care Needs (CSHCN)
   2. Early Childhood Intervention (ECI)
   3. Medically Dependent Children Waiver Program (MDCP)
   4. Commission for Blind and Visually Impaired (CB)
   5. Commission for the Deaf and Hearing Impaired (CD)

C. General Service Delivery Systems
   1. Immunizations (IMM)
   2. Special Supplemental Nutrition Program for Women, Infants, and Children
Integration/Linkage
Integration is the combining of two or more program datasets, using a common data engine, common data entry screens, and maintained at one location by one entity. Linking is providing a method of either accessing all relevant data from one point or, at the least, being able to ascertain whether information on a specific individual is maintained by one of the participating programs.

The following is a review of options considered and our opinion of their feasibility.

1. **Total integration of all programs in this study.** The feasibility of this happening is practically nil. As an example of the immediate decisions and/or difficulties faced would be bringing NBHS data collection under the auspices of the TDH, with a possible loss of statewide data by not being able to duplicate the contractor’s existing network. The amount of money, manpower, time and infrastructure needed to redesign and rewrite all systems into a single unit is tremendous, without even considering political and privacy issues. Physical access to the data, training and security are all major concerns. Agreement to a standard set of demographic variables would be mandatory.

2. **Integration of TDH surveillance programs and linkage with service providing programs.** Integration of the surveillance programs at TDH is possible, but only remotely. Again, money, time, and the inclusion of NBHS data “in-house” are major hurdles. If integration were to occur, linkage with the service delivery programs would be feasible through an intermediate database, a “Unified Locator Table” (ULT), linked to the other agencies. Data from each of the participating agencies and TDH would be downloaded to this ULT at predetermined times and, through a combination of programmatic and manual scrutiny, individuals from each agency would be matched. To make this possible, a standard set of demographic variables would have to be adopted. The question of who ‘owned’ or operated the ULT, and who was physically and financially responsible for its maintenance and security would need to be addressed.

3. **Linkage of all programs’ demographic information through an intermediate database.** As mentioned in the second scenario, a ULT could be constructed which contained only demographic information about an individual and references to whether data related to that individual was maintained at any of the participating programs. This is the simplest and most economical solution to implement, but it requires a standard set of demographic variables be adopted, and
forces the requesting individual go to the responsible program to obtain specific information. Timeliness obviously suffers, as well as having to deal with two separate entities to arrive at the answer to a single question. The question of who maintains and is responsible for the ULT remains.

4. **Centralized Data Warehouse.** Although not as simple, and somewhat more expensive than scenario #3, this solution would provide the most utility at the most reasonable (relative to the other scenarios) cost. Expanding on the concept of the ULT wit its standard set of demographic variables, a centralized data warehouse would also contain the actual data each program maintains on the client in question, translated from the originating system to the common system. Matching of individuals would occur as before, but now all relevant information would be available to the requestor at the time for the request. Instituting a centralized data warehouse is currently under consideration by the Associateship for Family Health at TDH.

**Conclusions**
A central data warehouse as a vehicle to collect and disseminate disparate information from multiple programs with the least intrusion on those programs is our recommendation. The chief benefit of this system is that it leaves the responsibility of collecting data in the hands of those programs tasked with doing so, without imposing the additional burden of having to put in place an infrastructure to disseminate that information further. No program need change their current system of data collection to match a norm, as the data is translated into the warehouse’s schema at the point of importation. With appropriate and agreed upon privacy, security and dissemination policies in place, the information can be released from a central point without further effort on the part of the program from which it originated.

**VI. The Texas State Genetics Plan**

A. **Infrastructure Building Services**

*Infrastructure building services should be designed to form the foundation upon which the other services are built.* (54)

1. **Assessment**

*Health of communities and populations at risk is assessed and monitored to identify genetic health and health care problems and priorities* (54).
• **Birth Defects Monitoring**
  - Obtain additional funding for the NTD Recurrence Prevention Project
  - Implement system to retain newborn screening blood spots for the purpose of epidemiological research
  - Link Birth Defects Registry with Cancer Registry and Newborn Screening to conduct research on co-morbidity and common risk factors
  - Conduct research on various outcomes of children born with birth defects
  - Assess referral component, with some ability to look at its usefulness
  - Compete successfully for next cycle of the CDC-funded Texas Birth Defects Center

• **Newborn Screening Program**
  Please see page 57.
  B. Population-Based Services
   2. Comprehensive Newborn Screening Systems

• **Clinical Services Survey (formerly TEXGENE data report)**
  - Continue annual data collection of genetic service provision in Texas
  - Revise data collection to determine the incidence and prevalence of genetic disorders and what impact they have on funding and policy
  - Survey genetic service providers to determine if other information would be useful in the data collection report
  - Publish data collection of genetic services report annually

• **Insurance Records/Public Health Records**
  - Conduct feasibility study to determine if information about genetic conditions can be collected from insurance and public health records; include risks and benefits.
  - Develop method of collecting genetic information across the life span

• **Newborn Hearing Screening Program**
  - Include all positive newborn hearing assessments in “health services record” database.
  - Link databases of all services received by children with hearing impairment that have been identified by newborn hearing screening program.
Establish data reporting system to assure children with hearing impairment are getting intervention services
Publish data collection report annually of children with hearing impairment

2. Information Systems Development

*Information systems should be developed with the following aims: integration of public health and personal health services data; linkage of clinically useful data to improve access to high quality services; and continuous quality improvement (54).*

- Develop “health services record” database for all children with abnormal newborn screens (ages 0 to 18 years).
- Store “health services record” in data warehouse that is compatible with other databases currently used at the Texas Department of Health.
- Run quarterly data analysis on children with disorders detected by abnormal newborn screen, run parallel analysis using both “health services record” and TDH database.
- Use data analysis to determine timeliness of treatment, quality of care, and caseload management.
- Integrate “health services record” database into current TDH database. This centralized integrated system would be housed at TDH in the Research and Public Health Assessment Division.
- Establish a mechanism for reviewing privacy, confidentiality and security practices and issues.

3. Applied Research

*The genetic service system should be current and grounded scientifically in both basic and applied research (54).*

- Maintain inventory of human genetic research being conducted within the state of Texas; registry to be housed at the Texas Department of Health.
- Encourage collaboration of public health genetics system research projects within the state where appropriate; recognizing legitimate public health policy uses of genetic information.
- Establish or collaborate with periodic state human genetic research conference.
- Investigate additional funding sources for research projects.

4. Policy Development

*Public policies should be formulated to prevent harmful uses of genetic information and to protect against discrimination (54).*
• Continue Interagency Council for Genetic Services oversight of all state agency policies dealing with genetic services.
• Expand the number of representatives on the Interagency Council for Genetic Services to achieve a more broadly-based representative body
• Obtain legislative mandate for funding the Interagency Council for Genetic Services
• Expand of services performed by the Interagency Council for Genetics Services to include:
  - Defining minimum standards for genetic centers
  - Developing quality assessment models
  - Generating quality assessment and care guidelines
  - Reviewing cost-consequence data
  - Reviewing published guidelines for care
  - Reviewing published guidelines for reimbursement
  - Developing position statement regarding standards of care for genetic services
  - Exploring methods of assessing quality
  - Insuring licensing of genetic counselors
  - Certifying care providing centers
  - Reviewing policies as developed regarding informed consent
  - Investigating retention of blood spots for future testing
  - Explore the expansion of the IAC scope of responsibilities to include monitoring of public policy concerning genetic information.

5. Legal Framework and Regulatory Infrastructure

Statutes and regulations should exist that protect the public interest while supporting the development and provision of comprehensive, quality genetic services (54).

• Promote legislation to protect confidential ‘health services records’ and the individuals right to privacy without unduly intervening with patients access to quality health care.
• Promote legislation to insure adequate appropriation and equitable distribution of funds for genetic services.
• Explore licensure for genetic counselors.

6. Assurance

Access to appropriate, beneficial, and cost-effective care should be assured for all populations, including health promotion and disease prevention services (54).
a. System of Integrated Genetic Services

*Genetic services should include integration of genetic medicine into public health programs and health systems (54).*

- Integrate genetic testing into health promotion programs and preventative care services.
- Facilitate communication between researchers and clinical service providers, in order to ensure clinical genetics practice is grounded in current research.
- Investigate use of telemedicine to bring genetic services to remote regions of the state.
- Implement recommendations of TEXGENE 1999 report (see summary page 43 and appendix for full report).

b. Funding for Genetic Services

*Genetic services should be available, accessible, and affordable to all individuals who need or desire them (54).*

- Advocate for state funding to permit development of genetic services programs in regions with few or no providers.
- Explore a legislative mandate regarding reimbursement for genetic services.
- Identify alternate sources of funding for those whose health care coverage does not cover genetic services.
- Explore alternative care delivery models for genetic services.
- Identify resources to permit assessment of genetics capabilities within chronic disease programs in TDH.
- Based on above, convene a planning group within TDH, in co-operation with IAC, to develop a 5 year plan for integration of genetic services within these programs.

c. Training and Education of Health Professionals

*A well-prepared community of health care and public health practitioners with genetics expertise should be available in numbers sufficient to meet the needs of the public. These practitioners should be capable of communicating the benefits, risks, limitations, and implications of genetic testing and accurately interpreting and appropriately utilizing genetic information in clinical and public health practice (54).*

- Identify methods of educational improvement for genetics.
- Create website creation for medical ethics CEUs in clinical genetics that includes ethics credits.
- Expand educational programs for genetics
- Assess genetic education requirement for Texas medical schools and develop recommendations for improvement.

d. Evaluation of the Genetic Services Systems

High quality, culturally competent genetic services should be available and accessible to all who need or desire them. Health outcomes should be improved by the use of genetic testing and interventions (54).

- Review TEXGENE data report (1999) to identify gaps in service availability within Texas (see summary page 43 and appendix for full report).
- Develop position statement regarding use of published clinical practice guidelines.
- Identify socio-cultural barriers to access to genetic services using existing data from Texas Communities, and elsewhere.
- Implement programs which address the identified socio-cultural barriers.
- Explore methods of assessing quality.
- Develop quality assessment models.
- Generate quality assessment guidelines.
- Analyze and report on cost-consequence data for areas without genetics service providers.

B. Population-Based Service

Population-based services are designed to serve the entire community and encompass both health promotion and disease prevention activities. These services are provided generally without regard for ability to pay, with the understanding that they benefit the population as a whole (54).

1. Public Education

The general public and key policy makers should be well informed about genetics, its impact on health, and the ethical, legal, and social issues that are important to the provision of genetic services and the use of genetic information (54).

- Disseminate Texas State Genetics Plan and subsequent materials.
- Disseminate handbook of available genetic services in Texas.
- Sponsor ‘genetic health summit’ for key policy makers.
- Create or collaborate on a website for genetics education of the public.
Recommend improvement to genetics education in public schools (K-16).
Initiate educational campaign to increase genetic health care services awareness among public, politicians, educators and health care providers

2. **Comprehensive Newborn Screening System**

*All newborns should be screened at birth for certain treatable and preventable heritable disorders (54).*

- Develop Newborn Screening Division within the Texas Department of Health under the Associate Commissioner for Family Health
- Expand number of genetic disorders screened for by use of tandem mass spectrometry
- Provide care coordinators to families with children who have abnormal newborn screens
- Implement “health services record” database for children with disorders diagnosed through newborn screening
- Maintain registry of abnormal newborn screens
- Maintain tracking system of children and adults in newborn screening registry
- Link databases of services received by children in newborn screening registry
- Obtain newborn screening results for people relocating to Texas
- Perform outcome studies of individuals identified by testing
- Publish annual outcomes report

C. **Enabling Services**

*These are services that allow, provide access to, or permit the derivation of benefits from the array of basic health and other health care services (54).*

- Recommend provision of care coordinators to families with children with genetic disorders, including those diagnosed by newborn screening.
- Recommend care coordinators who will begin genetic education at first home visit
- Recommend care coordinators who will assess need for referral to specialty care clinics
- Develop a data system, modeled after SDI program, that identifies which services (public and private) the child is qualified to receive.
- Implement referral component for Texas Birth Defects Registry.
D. Direct Health Services

*These are services that are delivered one-on-one between a health professional or social service professional and a patient* (54).

- Analyze service provision structure that would facilitate integration of adequate genetic services into primary and specialty care.
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36. Texas Department of Mental Health and Mental Retardation: *Compact with Texans*. Retrieved December 26, 2001 from www.mhmr.state.tx.us


* Inclusion of information about local, state and national programs was reviewed and approved by the appropriate agency before inclusion.