

The logo for the Texas Sunset Advisory Commission is a semi-circle with a thick black border. Inside the semi-circle, the words "Texas", "Sunset", "Advisory", and "Commission" are stacked vertically in a bold, white, sans-serif font.

**Texas
Sunset
Advisory
Commission**

STAFF EVALUATION

*Interagency Council
for Genetic Services*

A Staff Report
to the
Sunset Advisory Commission

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Interagency Council for Genetic Services

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Background and Focus

Creation and Powers

The Interagency Council for Genetic Services (IACGS) was created by S.B. 257 during the 70th legislative session. Genetic services have been of interest across the nation for many years. More than 5,000 genetic disorders have been identified which affect approximately three percent of the general population. Examples of some of the more prevalent disorders include Down's syndrome, PKU, spina bifida, congenital heart disease, sickle cell anemia, and cystic fibrosis. Many genetic disorders are preventable through a variety of genetic services, such as genetic screening of potential parents, prenatal services or newborn screening. The prevention and/or identification of one severe case of genetic disease through a genetic study can potentially save the state \$1.53 million in long-term care costs. The cost savings that could be realized through an efficient system of genetic service delivery as well as the decrease in human suffering, has made the need to evaluate and coordinate the genetic services delivery structure a topic of continuing interest in Texas.

The genetic services system in the state that has developed since the mid-70's has three distinct components: state agencies, medical schools, and private providers. Efforts to ensure that the state has a cost-effective, coordinated service delivery structure have been sporadic. In 1983 the Community Health Foundation was engaged by a number of state agencies to conduct a review of genetic services provided through TDH and TDMHMR to identify strengths and weaknesses, to assess costs incurred in carrying out genetic activities and to recommend methods of improving program performance and productivity. Many of the recommendations that came from this report, the Campbell Report, highlighted a need for greater coordination among genetic service providers.

In 1985, the Texas Genetics Network (TEXGENE) was established. This was an informal group composed of genetic service providers, agency representatives, consumers and professionals. At the same time, federal funds through the Bureau of Maternal and Child Health, Health and Human Services Administration became available to coordinate the provision of genetic services through regional networks. At this time, Texas was the only state that was not in a regional network, although federal officials indicated that Texas was large enough to qualify as a separate region.

In 1987, TEXGENE attempted to secure one of these federal grants but was unable to do so. Federal officials at the time perceived Texas as having a fragmented service delivery structure split between the Texas Department of Mental Health and Mental Retardation, the Texas Department of Health and private providers.

The apparent lack of coordination in the past, led to the creation of the IACGS. The legislature directed the council to:

1. survey current resources for genetic services in the state;
2. initiate a scientific evaluation of the current and future needs for the services;
3. 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;

4. promote a common statewide data base to study the epidemiology of genetic disorders;
5. assist in coordinating statewide genetic services for all state residents;
6. increase the flow of information among separate providers and appropriation authorities; and
7. develop guidelines to monitor the provision of genetic services, including laboratory testing.

These activities were intended to provide a formal method for coordinating services and comparing costs in order to determine the most efficient and cost-effective method for delivering genetic services and ensuring that a comprehensive network of genetic services is available for all state residents.

Policy-making Structure

The Interagency Council for Genetic Services consists of seven members. Three of the members are representatives from each of the following state agencies, the Texas Department of Health, the Texas Department of Mental Health and Mental Retardation, and the Texas Department of Human Services. Each of these members are appointed by the commissioner of their respective agencies. The remainder of the council membership consists of one representative from the University of Texas system who is appointed by the Chancellor of the University of Texas system; one representative from the public and private entities that contracts with the Texas Department of Health, who is elected from their membership; and two members that are consumers, family members of genetic service consumers or representatives of consumer groups, appointed by the governor.

The representative from the public/private entities and the two consumer members serve two-year terms and may be reappointed or reelected. The state agency representatives and the University system representative serve at the pleasure of their appointing body. The council is mandated to meet at least quarterly.

Funding and Organization

Currently, the IACGS does not receive any direct state appropriations. The cost of clerical and advisory support staff is shared by the agencies represented on the council. The council's state agency representatives worked together to secure \$10,000 from their respective agencies to fund a study of the costs of genetic services based on calendar year 1987 data. Additionally, the council was recently awarded the long sought federal grant in the amount of \$245,049, to carry out a number of duties :

1. coordinate and share resources among service providers ;
2. collect data on genetic services;
3. assure quality laboratory standards; and
4. increase professional and public awareness of genetically related diseases.

These funds will be used to pay for various expenses associated with continuing the mandated activities of the council, and to hire three staff people for the Genetics Coordinating Office. The council will not have any employees until the staff people

authorized under the new federal grant are hired. Exhibit A depicts the organizational structure of the council and related advisory committees.

TEXGENE has assisted the council since the council's creation. This group of genetic service providers and other professionals serves as an advisory committee to the council.

Focus of Review

The review of the Interagency Council for Genetic Services focused on two primary areas. First, consideration was given to the need to continue the council. This assessment concluded that :

- Although in operation only a short period of time, the council has been active in working to accomplish the specific objectives set out for it in S.B. 257 of the 70th Legislature in 1987.
- Useful dialogue is occurring as a result of the council's operation between the many facets of the genetic services delivery system.
- The existence and work of the council was instrumental in obtaining a \$245,000 federal grant for staff support for the council and coordination of the state's genetic services efforts.

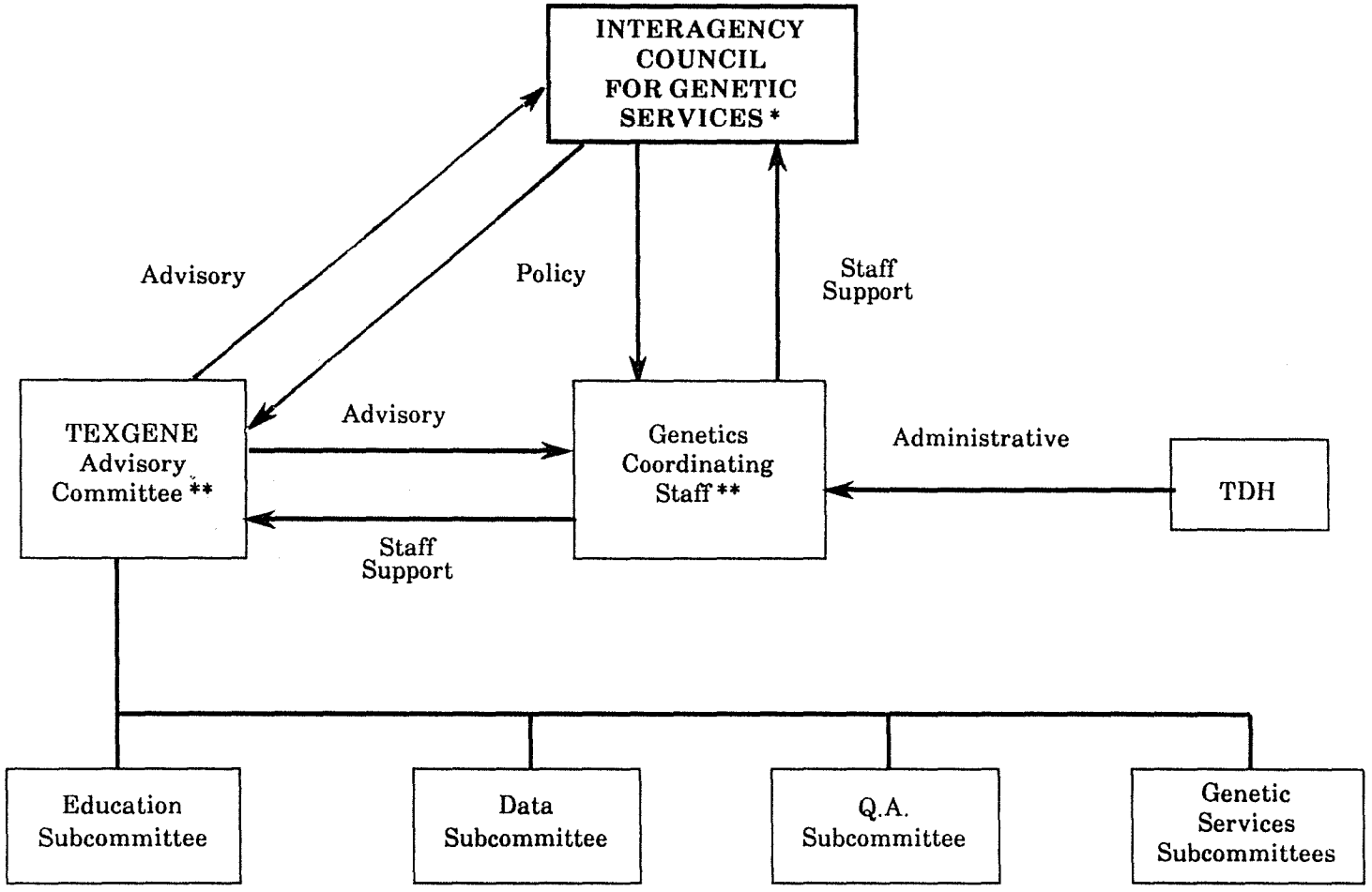
Second, the review examined whether or not the council should be given additional duties and powers to enable it to better carry out its coordination duties. As part of this area of inquiry the review concluded that the council's statute and operations need adjustment to:

- require the council to study and determine the most cost-effective method or methods for the state's delivery of genetic services ;
- require the council to develop a biennial resource allocation plan to guide agencies and decision makers on the distribution of funds for genetic services ;
- effect better coordination between the council and agencies serving persons with environmental genetic disorders ; and
- encourage the council to obtain broad based information through health insurance companies or other sources regarding genetic services provided or not provided by the private sector.

Overall, the review concluded the council should be continued for a six-year period to carry out its original duties as well as those identified above. A shorter time frame for sunset review would give the legislature an opportunity to assess the effort of the council.

The recommendations contained in the report would not result in increased state expenditures on behalf of the council.

Exhibit A
Interagency Council for Genetic Services Structure



* Funding provided for travel to council members through the federal grant.

** Funding provided for genetics coordinating staff and activities of advisory committee and subcommittees through the federal grant.

Findings and Recommendations

ISSUE 1: The council should determine the most cost-effective method for delivering the state's genetic services.

BACKGROUND

Currently, genetic services are provided through a variety of service delivery structures, including both public and private. State and federal funds are used to subsidize a number of different genetic service programs. There are two state agencies that receive funding earmarked for genetic services. These are the Texas Department of Mental Health and Mental Retardation and the Texas Department of Health.

The Texas Department of Mental Health and Mental Retardation operates the Genetic Screening and Counseling Services (GSCS) program. These services are provided through 25 regional clinics throughout the state and include testing, diagnosis, prognosis, counseling, psychosocial support, medical intervention, linkage to other services and public education. Exhibit B demonstrates the level and source of funding in fiscal years 1988 and 1989, as well as funding recommended by the Legislative Budget Board through fiscal year 1991.

The Texas Department of Health has several service delivery structures through which it administers genetic services. The department contracts with several universities and private foundations to provide genetic screening and counseling. The department also operates the Newborn Screening Program and the Chronically Ill and Disabled Children's program. Together, these programs screen all newborns for five genetic disorders, including sickle cell anemia, PKU, galactosemia, hypothyroidism and congenital adrenal hyperplasia. Exhibit B shows the level and sources of funding in fiscal years 1988 - 1991.

The state also provides genetic services through two other avenues. The Medicaid program operated by the Department of Human Services expends funds on an approximate 90/10, federal/state match basis for allowable genetic health services. The amount expended for genetic screening and counseling services by the Medicaid program in fiscal year 1988 totaled \$172,140. These funds are not specifically earmarked by the legislature for genetic services but are used to provide such services along with the many other health services available through the state's Medicaid program. The state's medical schools are also involved in the provision of genetic services. For example, the University of Texas, through four of its medical schools, provided genetic counseling to almost 1,500 prenatal patients in 1987. Funds for these services are not earmarked but are included in the school's overall appropriations.

Over the years, two distinct types of service delivery structures have evolved. One, used extensively by the MHMR program, involves the use of satellite clinics and traveling teams of medical geneticists and other professionals. An appointment schedule is developed for each team and the teams travel as needed to see and counsel patients. The other service delivery approach, used by the Health Department's contractors, medical schools and physicians participating in the Medicaid program, does not have this traveling or circuit element except in limited circumstances. Persons in need of genetic services simply contact the nearest provider and services are developed to meet their situation.

Exhibit B
Genetic Services Funding

Funding for the TDMHMR , Genetic Screening and Counseling Services Program

	<u>1988</u>	<u>1989</u>	<u>1990*</u>	<u>1991*</u>
Method of Finance:				
General Revenue:	\$ 1,899,335	\$ 2,063,655	\$ 2,063,655	\$ 2,063,655
Other Funds:	446,308	591,123	591,123	591,123
Interagency Contracts:	<u>275,015</u>	<u>300,000</u>	<u>300,000</u>	<u>300,000</u>
TOTAL	\$ 2,620,658	\$ 2,954,778	\$ 2,954,778	\$ 2,954,778

Funding for the TDH genetics related activities**

	<u>1988</u>	<u>1989</u>	<u>1990*</u>	<u>1991*</u>
Method of Finance:				
General Revenue:	\$ 1,622,411	\$ 1,778,738	\$ 1,778,738	\$ 1,778,738
Federal Funds:	<u>421,549</u>	<u>881,984</u>	<u>841,295</u>	<u>721,549</u>
TOTAL	\$ 2,043,960	\$ 2,660,722	\$ 2,620,033	\$ 2,500,287

*LBB recommendations

**Activities include Newborn Screening and laboratory services (which accounted for 85 percent of TDH's genetics funding in fiscal year 1988), follow-up services through the Chronically Ill and Disabled Children's (CIDC) services, Maternal and Child Health genetics contracts, and the federal Sickle Cell grant program.

The review of the current approaches to the provision of genetic services indicated the following:

- ▶ Concerns about the cost-effectiveness of the different delivery structures of genetic services have been raised by the legislature since 1981.
- ▶ Efforts in 1983 to evaluate and provide definitive guidance for needed change criticized the current structures but resulted in little structural change.
- ▶ Although one purpose of the development of the current interagency council was to “permit the evaluation of cost-effectiveness of ... different genetic services and methods of service delivery” material gathered to date sheds little light on the issue of cost-effectiveness between different delivery systems.
- ▶ The membership of the council provides the needed broad based perspective to examine the service delivery structures in detail and make recommendations concerning changes needed to maximize the use of the state’s resources in providing genetic services.
- ▶ The council recently received a federal grant which will provide staff support that can be used to conduct the needed study.

PROBLEM

State resources available to provide genetic services are spent in many settings through two distinct service delivery structures. One structure provides services through a satellite clinic structure and requires medical geneticist teams to travel throughout the state. The other structure does not use this traveling component as extensively and patients use provider services in their area. The two approaches present distinct cost and service policy concerns which have not been fully evaluated.

RECOMMENDATION

The council’s statute should be amended to:

- require the council and its support staff to conduct a study to determine the most cost-effective service delivery method or methods for the state to deliver genetic services;
- require the study to include an examination of the costs, benefits and disadvantages of the methods used by the Genetic Screening and Counseling Services program of the Department of Mental Health and Mental Retardation, the state’s medical schools, the Department of Health, the Department of Human Services and other agencies or providers the council deems appropriate;

- require the council to propose any necessary changes in the state's approach to the delivery of genetic services. These changes should address the need to:
 - modify the state's approach to the delivery of genetic services;
 - reallocate staff and service dollars between agencies and service providers to maximize the limited resources the state can devote to genetic services; and
 - make any other adjustments the council determines appropriate.
- require the council to finish its study by April 1, 1990 so that it can be included in the deliberations occurring prior to and during the 72nd Legislative Session.

This approach will provide a solid base for decision making regarding the need for any adjustments the state needs to make in its genetic services programs.

FISCAL IMPACT

No increase in expenditure is expected due to this recommendation. The council recently received a \$245,000 federal grant which should be used to accomplish the study.

ISSUE 2: The council should be required to develop a biennial resource allocation plan for the delivery of genetic services.

BACKGROUND

As mentioned previously, the state uses a variety of providers and structures to deliver genetic services. Due to the number of entities and individuals involved it is important that the state be able to effectively coordinate their activities to prevent duplication of effort and to maximize its investment in genetic services.

In situations similar to genetic services, the state has developed several inter-agency "councils" to ensure that coordination occurs. For example, this approach is found in the state's efforts to address problems associated with diabetes, cancer and developmentally delayed children. The Texas Diabetes Council, established in 1983, composed of eight public members and five state agency representatives, helps the state coordinate its resources to combat diabetes through many activities including the development and implementation of a state plan for diabetes control. The Texas Cancer Council, established in 1985 and composed of 16 members representing the public, the legislature, health service industries and state agencies, also provides coordination through planning and can award service grants to help combat cancer. The Interagency Council on Early Childhood Intervention Services, established in 1981, and composed of one lay member and four agency representatives, coordinates the delivery of ECI services through planning and the actual annual allocation of over \$12 million in grants and contracts to over 70 service providers.

The review of the Interagency Council for Genetics Services in relation to other coordinating councils indicated the following:

- ▶ The structure and composition of the council are appropriate and provide a broad based perspective on the delivery of genetic services in the state.
- ▶ The duties of the council are numerous and similar to those of other inter-agency councils in terms of information gathering and analysis.
- ▶ The powers of the council are limited, however, and do not contain the normal planning functions of other inter-agency councils.
- ▶ The ability of the council to control the allocation of funds to provide genetic services is non-existent.
- ▶ Funding for genetic services is tucked away in many locations and difficult to clearly extricate. This is true in medical schools and the Medicaid program operated by the Department of Human Services. Funds expended by the Department of Health and TDMHMR are more easily identifiable but isolating and pooling all state funds for council control would be mechanically difficult.

- ▶ Although it does not appear feasible to place the control of state expenditures for genetic services under the council, a mechanism is needed to better utilize the expertise of the council to advise on the allocation of these funds.

PROBLEM

Texas uses many providers to make genetic services available to its citizens. Although an inter-agency council has been established to help coordinate service delivery, it lacks the traditional powers to plan for the allocation of the available service resources.

RECOMMENDATION

The council's statute should be amended to:

- require the council to develop a biennial resource allocation plan for genetic services;
- require the council in its plan to clearly identify the level of financial support and service delivery structure for each component of the genetic services system that receives state funding or federal funding funneled through the state;
- require entities affected by the plan to cooperate with the council and supply information requested by the council;
- authorize the council to hold hearings to gather information needed to develop the plan;
- require the council to incorporate the findings of the April 1, 1990 cost-effectiveness study in its first biennial allocation plan;
- require that the plan be approved by a majority vote of the council;
- require any medical school or state agency affected by the recommendations of the plan to follow those recommendations or:
 - develop a written explanation and justification for each deviation from the plan; and
 - submit the written explanation and justification to the council, the Legislative Budget Board and the governor's budget office by November 1 of each even-numbered year.
- require the biennial resources allocation plans to be developed and published by June of each even-numbered year; the first plan is to be finished June 1,
- require the council to distribute the plan to all affected agencies and any other entity that the council deems appropriate.

This approach will enable the council to play a more effective role in the control of state expenditures for genetic services. The recommendations will not remove the ultimate control of the funds by the legislature, governor and components of the system but will place the council squarely in the middle of the process used to determine how the programs are structured and financially supported.

FISCAL IMPACT

No increased costs are expected to occur due to implementation of this recommendation as current resources are available to develop the plan. Future savings may result due to improved allocation of the state resources for genetic services.

ISSUE 3: The council should be required to coordinate with state entities that serve persons affected by environmental genetic disorders.

BACKGROUND

The number of known genetic disorders reaches into the thousands and is increasing as medical technology improves. The results of these disorders can be devastating and can take many different forms ranging from blindness, skeletal disfigurations, mental retardation, and heart malfunctions to name a few.

The traditional aim of genetic counseling is to identify persons who have the likelihood of passing on a genetic disorder and educate them on their particular "genetic situation". A fairly recent development in the field of genetics, is the identification of "environmental" genetic disorders. These disorders are not the traditional heritable problems but can have the same results. An environmental genetic problem is caused by the exposure of a fetus to certain adverse environmental conditions. The classic example is the recently identified problem known as "fetal alcohol syndrome". This problem is due to excessive drinking of alcohol by the mother during pregnancy. Babies born under these circumstances often have the same problems of those born with inherited genetic disorders and the need for costly long-term care is similar.

Many state agencies including the Texas Commission on Alcohol and Drug Abuse and the Commission for the Blind, are concerned about and must deal with various aspects of environmental genetic disorders.

The review of the council's duties in the area of environmental genetic disorders indicated the following:

- ▶ One of the council's statutory requirements is to collect and analyze information regarding genetic disorders and services in the state.
- ▶ Although council members are acutely aware of environmental genetic disorders, there is no specific requirement that the council consider these disorders and coordinate with established state agencies to maximize all sources of knowledge and understanding with regard to these types of genetic disorders.

PROBLEM

The current statute which sets out the work parameters of the council does not provide any directive to include environmental genetic disorders in its deliberations. These disorders affect many Texans served by many state agencies.

RECOMMENDATION

The council's statute should be amended to:

- require the council to identify and coordinate with state entities that serve persons affected by or at-risk of having children with environmental genetic disorders.

This recommendation will not require the council to conduct any studies with regard to environmental genetic disorders, instead it will specify that the council's duties include coordination with agencies serving persons affected by or at-risk of having children with environmental disorders.

FISCAL IMPACT

No change in expenditure is expected from this coordination requirement.

ISSUE 4: The council should use the resources of its membership to gain a better understanding of the genetic services being provided through the private sector.

BACKGROUND

The provision of genetic services occurs in many settings. Information on the frequency, cost and types of services provided by public agencies and medical schools is being collected by the council. Genetic counseling and services provided outside these settings, however, are difficult to quantify since they are often provided as part of a person's treatment by a private physician or hospital. Information on this activity is important and is needed for the council to have a complete understanding of the incidence of genetic disease as well as the availability of genetic service resources.

The review of the situation regarding private provider genetic services indicated the following:

- ▶ The health care system in Texas and the nation is greatly supported through the insurance industry.
- ▶ Studies have shown that 30 to 40 percent of hospitalization in childhood is for genetic conditions.
- ▶ Although information and data related to specific patients is closely protected, aggregate data on costs of genetic related physician counseling and hospitalizations is likely available through private insurance companies.
- ▶ The membership of the council includes representatives of the Department of Health, the Department of Mental Health and Mental Retardation, the Department of Human Services, the Health Science Centers operated by the University of Texas and other members familiar with the health care industry. Each of these agencies has extensive dealings with health care providers and insurance companies that help pay for the care of their clients.
- ▶ Unless a concerted, informed approach is made to obtaining relevant insurance information on treatment of genetic disorders as well as screening and counseling activities, no incentive exists for the companies to provide it.

PROBLEM

Information regarding the provision of genetic services by private providers is difficult to obtain but is likely available through health insurance companies that pay for such services. This information is critical to allow the council to carry out its work. A concerted effort by the members of the council to use the knowledge and abilities of their respective agencies could help obtain this information.

RECOMMENDATION

As a management change, the council should consider:

- using the knowledge and abilities of the agencies and groups represented on the council to establish a means of obtaining broad based information from health insurance companies or other sources regarding the amount, types and costs of genetic services provided or not provided by private physicians and hospitals.

This approach will allow the existing relationships between the concerned agencies and the insurance companies or other sources to be used to help obtain information which is difficult to obtain but necessary for the council to carry out its work.

FISCAL IMPACT

No change in expenditure is expected from this management recommendation.