Interagency Council for Genetic Services
Resource Allocation Plan
2002-2003

The Resource Allocation Plan is prepared by the Interagency Council for Genetics Services in compliance with Section 5, Chapter 134, Human Resources Code (Sec 134.0041) 71st Legislature - Regular Session.

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I. Background

Genetic disorders are those conditions resulting in abnormalities of structure and/or function, associated with changes in genetic material (DNA) that can be passed on from parent to child. Birth defects (congenital anomalies) are abnormalities of structure, function or metabolism which are present at birth, and which often result in physical or mental disability, or death. In more than half of birth defects cases, genetic abnormalities are the cause or contributing factor.

Individually, genetic conditions are rare. However, the aggregate of genetic conditions and birth defects is significant as indicated by the following statistics:

- Birth defects are the leading cause of infant mortality in the United States, directly causing over 20% of all infant deaths[1]
- Children with birth defects account for 25-30% of all pediatric hospital admissions[2]
- Birth defects are the fifth leading cause of premature deaths among all persons less than 65 years of age[3]

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[1]Centers for Disease Control (1988a) Administrative Document: 1988 State Health Profile. CDC, Atlanta, p. 17.

[2]Hall J.G., E.K. Powers, and R.T. McIlavaine (1978) The frequency and financial burden of genetic disease in a pediatric hospital. Am. J. Med. Genet., 1:417-436.

[3]Centers for Disease Control (1990) Years of potential life lost before ages 65 and 85 - United States, 1987 and 1988. MMWR, 39:20-22.

- Birth defects are the seventh leading cause of premature death among all Texans[4]
- It is estimated that nearly 10,300 children are born with serious birth defects in Texas every year[5]
- The percent of live births in Texas resulting in serious birth defects is 3%[6]
- Congenital abnormalities directly cause 25% of all infant deaths in Texas and Sudden Infant Death Syndrome (SIDS) claims another 10%[7]
- Birth defects are the third leading cause of death among children aged 1-14 in Texas[8]

Health care costs for children with birth defects exceed $1 billion annually in the U.S.; yet mortality, disability and costs associated with genetic conditions and birth defects can be decreased through prevention, as in the case of folic acid-preventable anencephaly and spina bifida, as well as early detection and intervention.

Understanding risks as provided by genetic services can be expected to prevent adverse pregnancy outcomes. Thus, the cost of providing genetic services can be more than offset by the prevention of only a few pregnancies where outcomes, because of genetic disorders, would require lifetime care. Through preventive measures, proper diagnosis, appropriate referral, treatment and early intervention, in many cases long-term disabilities and premature death can be prevented. This allows affected children to lead more productive lives, thereby lowering the costs associated with genetic conditions and birth defects.

In Texas, multiple organizations, both public and private, deliver genetic services. These entities are located throughout Texas and operate with highly competent staff and state-of-the-art facilities and equipment. Coordination of these activities and services is essential to provide optimal genetic services and potentially reduce infant morbidity and mortality. Coordination also facilitates early identification of individuals with genetic conditions allowing for early intervention.

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[4]Texas Vital Statistics 1998 Annual Report

[5]Texas resident live births from the Bureau of Vital Statistics

[6]Ibid.

[7]Texas Vital Statistics 1998 Annual Report

[8]Ibid.

II. Clinical Genetic Services

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 which is in a different city from the primary facility and 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.

Support for genetic services is derived from a variety of sources. These include third party payers, Medicaid, and Title V, Maternal and Child Health federal block grant. Title V services are reserved for some Medicaid ineligible clients or services not provided through Medicaid. In addition, TDH provides Title V contract funds to some genetics providers for education and outreach services.

A. University model

Medical schools and universities throughout the State and one site in Louisiana provide comprehensive genetic services. Generally they operate as tertiary referral centers as well as research facilities. Faculty and staff from several departments provide genetic services. All programs are supported by in-house laboratories and serve both clinical and research missions.

University settings are:

The University of Texas Southwestern Medical Center – Dallas
Baylor College of Medicine
The University of Texas Health Science Center at Houston
The University of Texas Medical Branch at Galveston
The University of Texas Health Science Center at San Antonio
Texas Tech University Health Science Center at Lubbock
Texas Tech University Health Science Center at Amarillo
Louisiana State University Medical Center

All universities listed except the University of Texas Southwestern Medical Center and Louisiana State University Medical Center received some fiscal support from the TDH federal Maternal & Child Health block grant (Title V). Formal contracts with these universities are renewed annually. All universities are under contract with Texas Department of Health for Medicaid reimbursement of genetic services.

B. Private practice

Genetic services provided by this model follow private medical practice models. The range of services available in any practice will vary, but may include diagnosis, treatment, and counseling of patients, and prenatal diagnostic services including amniocentesis, chorionic villus sampling (CVS), targeted ultrasound and laboratory services. Private office practices may be primarily supported by private payment, insurance payment and payment from public sources when services are provided to eligible patients. Some private practices are components of large medical groups or commercial laboratories. All private providers are under contract with TDH for Medicaid reimbursement of genetic services. Several private providers also receive fiscal support from the Title V block grant.

Private practice providers are:

Genetic Institute of Austin
Center for Genetic Services-Corpus Christi (with satellite clinics in Brownsville, McAllen, Laredo, Harlingen and Austin)
Southwest Genetics, PA-San Antonio
Cook's Children's Hospital -Ft. Worth (with satellite clinics in Abilene, Amarillo, College Station, Denton, Harlingen, Lewisville, McAllen, Midland, San Angelo, Waco and Wichita Falls)
Genetic and Developmental Center of the Southwest - Ft. Worth (with satellite clinics in Arlington, Bedford, Denton, Granbury, and North Richland Hills)
Laboratory for Genetic Services – Houston (with satellite clinic in Dallas)
Texas Health Care Network (Dallas)
Center for Medical Genetics - Houston

C. State-operated clinic facilities

Currently, a single TDH provider maintains a genetics clinic in El Paso. Texas supported genetics clinics through the TDH Bureau of Women and Children, Genetic Screening and Counseling Service (GSCS) until 1996. The program was headquartered in Denton and from that location professional staff traveled to the various clinic locations. GSCS also operated laboratory and other support facilities in Denton. Funding for the GSCS program was primarily provided from State appropriation and fee generation.

Clinic locations were:

Abilene	Amarillo	Austin	Beaumont
Brownsville	College Station	Corpus Christi	Dallas
Denton	El Paso	Fort Worth	Harlingen
Laredo	Lubbock	Lufkin	McAllen
Midland	San Angelo	San Antonio	Texarkana
Tyler	Victoria	Waco	Wichita Falls

TDH/GSCS was under contract with Texas Department of Health for Medicaid reimbursement for genetic services. Texas Department of Health/GSCS ceased operation on December 31, 1995 with the intention that these clinical genetic services be provided by university and private practitioners under contract with TDH and one single TDH genetics provider with other roles within TDH.

D. Other related programs

There are other programs that are an integral part of genetic services in Texas. These include the Chronically Ill and Disabled Children's Services (CIDC) program and the Newborn Screening program. CIDC provides funding for certain individuals (age 0-21) who are not Medicaid eligible, but are affected with genetic disorders. The Newborn Screening program screens all newborns in Texas (approximately 668,000 screening tests for 334,000 newborns per year) for the following five diseases: phenylketonuria, congenital hypothyroidism, galactosemia, sickle cell/hemoglobinopathies, and congenital adrenal hyperplasia.

There are five community-based, private sickle cell agencies in the State that provide diagnosis and counseling for carriers of sickle cell disease and work closely with other genetic service programs. (NOTE: some Title V funding is provided to sickle cell agencies in Houston and Dallas).

These programs are:

Sickle Cell Anemia Foundation of Dallas*
Sickle Cell Association of the Texas Gulf Coast - Houston*
Sickle Cell Anemia Association - San Antonio
Sickle Cell Association of Texas - Fort Worth
Central Texas Sickle Cell Anemia Association - Waco

(* Under contract with Texas Department of Health)

III. Laboratory Services

Laboratories which provide genetic testing have been divided into three categories; cytogenetic, biochemical, and DNA. Several laboratories provide more than one type of service and are therefore listed in each appropriate category. Numerous out-of-state private laboratories also provide services to Texans.

A. Cytogenetic Laboratories

University laboratories:

Baylor College of Medicine/Kleberg Cytogenetics Laboratory - Houston
Scott & White Cytogenetics Laboratory - Temple
Texas Tech University Health Sciences Center Cytogenetics Laboratory - Lubbock
UTMB Pediatric Cytogenetics Laboratory - Galveston
UTMD Anderson Clinical Cytogenetics Laboratories - Houston
UTHSC Clinical Cytogenetics Laboratory - San Antonio
UT Southwestern Medical Center Cytogenetics Laboratory - Dallas

Private laboratories:

Applied Genetics - Austin
Center for Genetics Services Cytogenetics Laboratory - Corpus Christi
Dynacare Hermann Cytogenetics Laboratory - Houston
Laboratories for Genetic Services, Inc. - Houston
Santa Rosa NW Hospital Cytogenetics Laboratory - San Antonio
Southwest Genetics, P.A. - San Antonio

State-operated laboratory:

Texas Department of Health Genetics Laboratory - Denton

B. Biochemical Genetics Laboratories

University laboratories:

Baylor College of Medicine Department of Molecular and Human Genetics
Biochemical Genetics Laboratory - Houston
UTHSC Hermann Hospital Pathology Laboratory - Houston
UTMB Developmental Nutrition and Metabolism Laboratory - Galveston
University of Texas Southwestern Medical Center - Dallas

Private laboratories:

Baylor University Medical Center Institute of Metabolic Disease - Dallas

State-operated laboratory:

Texas Department of Health Genetics Laboratory - Denton

C. DNA Laboratories

University laboratories:

Baylor College of Medicine DNA Diagnostic Laboratory - Houston
UT MD Anderson Molecular Diagnostic Laboratory - Houston
University of North Texas Health Science Center - Ft. Worth

Private laboratories:

Applied Genetics - Austin & San Antonio
GeneScreen - Dallas
Identigene - Houston

IV. Impact of Policy on Genetic Services in Texas

A. Improving Genetic Referrals

The Genetic Screening and Case Management Division of TDH is attempting to increase the rate of genetic services utilization among women and children in Texas. The progress made on this activity includes:

- Conducting a literature review and compiling a list of effective genetic education programs; and,
- Sharing the list of effective programs with genetic providers and TEXGENE to select the most viable programs for potential implementation.
- Increased education and contact with Texas Department of Mental Health and Mental Retardation (MHMR) service providers and families.

Three universities receiving Title V funding are currently working with TDH on the following projects:

- Baylor College of Medicine in Houston - a private entity: this project includes a one-day genetics training program for health care professionals to recognize genetic diseases in all age groups.
- The University of Texas Health Science Center at Houston - a public entity: this project offers a one-day training to non-geneticist professionals (nurses, counselors, and educators) helping them recognize genetic diseases in school age children; provides one-on-one training for physicians to increase their awareness about genetic conditions so that appropriate referrals for genetic services can be made.
- University of Texas Health Science Center at San Antonio - a public entity: provides one-on-one training for physicians to increase their awareness about genetic conditions so that appropriate referrals for genetic services can be made.

B. Health Insurance

In FY 98, there were approximately 1.4 million or 25.4% of the total children without health insurance.

1. Medicaid

In FY 99, 1,521,177 children were potentially eligible for Medicaid. Of those, 678,434 (44.6%) received a service paid by the Medicaid program. Medicaid covers genetic services.

2. Children's Health Insurance Program (CHIP)

CHIP is a state-designated program targeted to children ages 0 through 18 years of age at or below 200 percent of the Federal Poverty Level (FPL) who are not otherwise eligible for Medicaid. Texas also covers legal immigrant children who are ineligible for CHIP under federal law because of their immigration status. Because these children are not eligible for the federal CHIP match, their coverage is financed solely with state revenue.

It is anticipated that enrollment in the program will steadily increase over an 18-month period, with full enrollment in CHIP estimated to be 428,000 children. In addition, it is estimated that 60,000 children will enroll in the Medicaid program as a result of the CHIP screening and referral process.

A schedule of genetic benefits is included in the CHIP package.

3. Medicaid Managed Care

Texas continues to roll out Medicaid managed care. As of March 1, 2000, there are over 500,000 participants in managed care with approximately 63.5 percent in health maintenance organizations and 36.5 percent in the primary care case management model. Texas currently provides services under the Medicaid managed care program in the following service areas:

- Travis (9 county area)
- Bexar (7 county area)
- Tarrant (6 county area)
- Lubbock (9 county area)
- Harris (6 county area)
- Southeast Region (5 county area)
- Dallas (7 county area)
- El Paso (3 county area)

The 76th Texas Legislature imposed a moratorium on further expansion of Medicaid Managed Care pending a full evaluation and report to the 77th Texas

Legislature in January, 2001. The purpose of the evaluation is to review issues such as access, cost-savings and administrative complexity. This legislatively-mandated evaluation is in addition to ongoing quality evaluations required by the Waiver.

Genetic services are available on Primary Care Physician (PCP) referral and approval of the Health Maintenance Organization (HMO).

C. Neural Tube Defects (NTD) Project

In the fall of 1992, the Centers for Disease Control and Prevention (CDC) and TDH started the Texas Neural Tube Defects Project (TNTDP) for the 14 counties along the Texas-Mexico border. The TNTDP comprises three components: a surveillance initiative, a folic acid intervention (recurrence prevention), and a case-control study, with the following objectives:

? To determine the birth prevalence of neural tube defect (NTD)-affected pregnancies among residents of the 14 border counties through active surveillance.
? To decrease the risk of recurrent NTD-affected pregnancies in high-risk mothers by providing them with education and folic acid.
? To identify risk factors for NTD occurrence, particularly on the border, through a case-control study.

There have been three teams along the border performing all the tasks required for this project. These teams were based in Harlingen, Laredo, and El Paso. To ensure that sufficient data were available, data collection for the study was extended two years past its initial completion data, with additional support from CDC and TDH. These data collection efforts formally concluded on August 31, 2000.

The TNTDP has already had a major impact on the health and well-being of children along the Texas border. From 1993-1999 more than 400 women with at least one prior NTD-affected pregnancy were given folic acid. During this period, there were 169 subsequent pregnancies. If none of these women had taken folic acid, it is likely five to seven would have had another baby with an NTD. However, none of the women in the project taking folic acid had a second baby with an NTD. (One of the women in the project did have a second baby with an NTD, but she had not taken folic acid as recommended.) From these data, it appears that Hispanic women who have had one baby affected by a neural tube defect can significantly increase their chances of later having a healthy baby by taking folic acid.

D. Policy Issues

There is a need for accountability within government agencies creating policy affecting human

genetics and more effective policy-making and funding processes to ensure that Texas reaps the benefits of genetic knowledge yet protects and promotes the health of its people.

The Interagency Council for Genetic Services (IAC) recognizes the need to consider expanding the definition of genetic services and to broaden its scope in terms of constituent members. As the mapping of the human genome continues, there is growing potential to understand, prevent and treat genetic conditions. There is improved knowledge of genetic mechanisms and risk factors for genetic disease, increased diagnostic capabilities and improved therapeutic and preventive methodology. However, with these benefits come concerns for access to care, availability of adequately trained genetic professionals, ethical issues, confidentiality and other issues of great public significance.

With the expansion of the Children's Health Insurance Program and Medicaid genetic services, the IAC is concerned that Texans without access to these insurance programs or private insurance will be unable to access genetic services. Alternative funding resources such as Title V should be expanded to cover genetic services for patients without access to public health insurance programs or private insurance.

V. Program Capacity[9]

1998 Survey of Genetics Providers in Texas

This survey was conducted in order to determine the numbers and types of clinical genetic services utilized in Texas. It represents the fourth survey conducted by TEXGENE. The following process was utilized:

1. The survey form from 1997 was modified slightly by the TEXGENE Data Committee to include more information on payers.
2. Definitions of service types remained the same.
3. Data were collected on genetic services provided at each participating center for the period between 1/1/98-4/30/98.
4. Data entry and analysis were conducted at TDH in conjunction with the TEXGENE Data Committee.

Sixteen providers of pediatric genetic services in Texas participated in the survey. One center, University of Texas – Southwestern, reported only prenatal data. Thirteen providers of prenatal genetic services participated. However, many prenatal genetic services are provided by private practice physicians. Since this survey did not capture data from those services, prenatal services are under-represented. Utilization rates were calculated by comparing TEXGENE 1998 survey data to live birth

[9]Genetics in Texas: A Review of Current Programs and Recommendations for Future Action 1998.

data and Medicaid paid delivery data from 1997 (most recent data available). It is important to note that for those counties with low numbers of live births, the rates are imprecise estimates. Due to small numbers, these estimates may fluctuate considerably among counties and between years. We estimate that 3% of live born infants have a congenital anomaly or genetic disorder recognizable at birth.

Review of pediatric genetic services data indicate that an estimated 0.51% of all live born infants received genetics evaluation at one of the participating centers prior to their first birthday. This represents no significant improvement in genetic services provided to infants from 1994. Of the 1,719 infants less than one year of age receiving genetic services, 64% of the services were paid with public funds (mostly Medicaid) and 36% were paid with private funds or were uncompensated.

Table A summarizes genetic services provided to infants by public health region. As can be seen, most of the public health regions showed an increase in the number of services provided to infants in 1998. However, public health regions 1, 5, and 6 showed a decrease in the number of services provided to infants from 1997 to 1998. When data are compared between 1994 and 1998, all but four public health regions showed a decrease in services.

Table A Genetic Services to Infants by Region, 1994-1998

Region	# Births 1998	3% of Live Births	Infants Served in 1994	Infants Served in 1997	Infants Served in 1998	% Infants Served in 1994	% Infants Served in 1997	% Infants Served in 1998	% Change 94-98	% Change 97-98
1	11,961	359	114	87	57	0.96	0.71	0.48	-50.0	-34.5
2	7,325	220	54	3	24	0.75	0.04	0.33	-55.6	700.0
3	85,469	2,564	183	12	396	0.23	0.01	0.46	116.4	3200.0
4	13,351	401	33	9	36	0.26	0.07	0.27	9.1	300.0
5	9,914	297	51	45	39	0.50	0.46	0.39	-23.5	-13.3
6	78,734	2362	435	570	297	0.57	0.74	0.38	-31.7	-47.9
7	33,522	1,006	192	48	78	0.62	0.15	0.23	-59.4	62.5
8	33,735	1,012	240	123	222	0.72	0.37	0.66	-7.5	80.5
9	8,331	250	69	3	84	0.82	0.04	1.01	21.7	2700.0
10	14,792	444	96	21	24	0.59	0.14	0.16	-75.0	14.3
11	36,871	1,106	339	245	387	0.93	0.65	1.05	14.2	58.0
Total	**334,005**	**10,020**	**1,929**	**1,581**	**1,719**	**0.60**	**0.48**	**0.51**	**-10.9**	**8.7**

Genetic service provision to infants in counties with greater than 3,500 live births is shown in Table B. This table compares genetic services provided in densely populated counties to those provided in the regions as a whole. In some instances, urban areas within the regions received significantly more genetic services. Overall, rural areas are still under served. This represents a continuation of a problem identified in previous surveys.

Table B Genetic Services to Infants

		1997 Live Births	% Served in 1998
Region 1	Lubbock	3,653	0.41
Region 3	Collin	6,814	0.13*
	Dallas	38,682	0.21*
	Denton	5,914	0.15*
	Tarrant	22,605	1.15
Region 6	Brazoria	3,548	0.85
	Ft. Bend	4,450	0.40
	Galveston	3,565	0.93
	Harris	59,167	0.33
	Montgomery	3,860	0.31
Region 7	Bell	5,103	0.06
	Travis	11,934	0.20
Region 8	Bexar	22,952	0.68
Region 10	El Paso	14,473	0.17
Region 11	Cameron	7,639	1.18
	Hidalgo	13,074	1.28
	Nueces	5,397	1.06
	Webb	5,143	0.82

*Potter County had 2,025 live births and 1.3% were served. Regions 2, 4, 5 & 9 do not have any counties with greater than 3,500 births.

Statewide, 4.8% of all women who had live births in 1998 received prenatal genetic services at a genetics center, representing a slight increase over 1997. 20.86% of women aged 35 or above who had live births in 1998 received prenatal genetic services at a center, again showing a small increase over 1997. We estimate 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). Statewide, 4.8% of pregnant women with live births received genetic services, a little more than half of the 7% goal.

Review of Table C suggests that some urban areas meet or exceed the statewide average. Bexar, Cameron, Ft. Bend, and Travis counties exceed the goal of 7%. Dallas, Galveston, Harris, Hidalgo, Nueces and Webb counties, and Public Health Regions 6, 7, 8 and 11 exceed the state average. Many rural areas appear to be under served.

Table C Prenatal Genetic Services

REGION	1997	1998
Lubbock	4.67%	2.96%
Potter	**12.45%**	0.00%
Collin	0.98%	2.91%
Dallas	2.76%	5.10%
Denton	2.87%	2.33%
Tarrant	0.20%	0.57%
Brazoria	3.36%	4.82%
Ft. Bend	**7.13%**	**7.01%**
Galveston	3.82%	6.65%
Harris	4.88%	5.66%
Montgomery	2.15%	2.72%
Bell	0.08%	0.29%
Travis	**7.13%**	**10.73%**
Bexar	**8.87%**	**10.73%**
El Paso	0.04%	0.00%
Cameron	**9.11%**	**8.56%**
Hidalgo	3.13%	5.62%
Nueces	6.84%	6.11%
Webb	3.37%	5.25%

Note: Figures in **bold** exceed the desired goal of 7%.

Forty-seven percent of infants born in Texas in 1997 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. We asked the following questions:

(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?

Medicaid records for FY 97 were searched for the following information:

(1) total number of Medicaid paid deliveries 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 1998, based on survey data collected between 1/98 and 4/98, compared to all women who had Medicaid paid deliveries in 1997, and
(2) an annualized estimate of prenatal patients aged 35 or above with Medicaid who used genetic services in FY 98, based on survey data collected between 1/98 and 4/98, compared to women aged 35 or above who had Medicaid paid deliveries in FY 96.

Table D indicates that statewide, among women who had Medicaid paid deliveries in 1998, 4.1% received genetic services at a reporting genetics center. Among women aged 35 or above whose deliveries were paid by Medicaid in 1998, 26.1% received genetic services at a genetics center. The percentages of Medicaid eligible pregnant women served in 1998 represent significant increases over 1994 but relatively little change from 1997.

Utilization of prenatal genetic services by Medicaid funded women in regions and urban counties in 1994, 1997, and 1998 are shown in Table D. Despite the increased number of reporting genetic centers and a statewide increase in reported prenatal service provision, Public Health Regions 1, 5, 6, and 7 reported decreased utilization of genetic services by Medicaid funded women between 1997 and 1998. Public Health Regions 3, 4, 8, and 11 showed an increase in the utilization of genetic services by Medicaid funded women. Public Health Regions 2, 9 ,and 10 reported no Medicaid services in 1997 or 1998. Overall, low population regions and counties did not have increased services, and some high population counties appeared to have decreased services in 1998 compared to 1997.

Utilization of Prenatal Genetic Services by Medicaid Funded Women

Table D

Region/ County	Medicaid Paid Deliveries 1996	% Medicaid Women Served 1994	% Medicaid Women Served 1997, est.	% Medicaid Women Served 1998, est.	% Medicaid AMA Women Served 1994	% Medicaid AMA Women Served 1997, est.	% Medicaid AMA Women Served 1998, est.
Region 1	6,744	5.14	1.82	1.65	42.47	19.91	15.64
Lubbock	2,100	8.21	5.43	3.43	48.00	54.55	36.36
Potter	1,495	2.21	0.20	0.00	47.73	5.88	0.00
Region 2	3,878	0.32	0.00	0.23	2.40	0.00	0.00
Region 3**	32,242	0.08	0.98	2.62	0.26	11.01	31.51
Dallas*	17,406	0.00	1.62	4.36	0.00	18.85	51.54
Denton	1,134	1.16	1.06	0.53	0.00	0.00	12.77
Tarrant	7,833	0.00	0.08	0.08	0.00	0.00	0.86
Region 4	7,237	0.09	0.54	1.49	0.00	9.09	10.39
Region 5	3,799	1.89	5.61	4.82	17.09	60.43	23.74
Region 6	35,168	1.42	4.86	4.22	7.32	28.15	22.52
Brazoria	1,471	2.28	4.08	5.10	25.86	33.87	14.52
Fort Bend	1,236	1.91	4.61	3.40	18.75	23.08	27.69
Galveston	668	7.43	8.08	9.43	15.38	41.86	27.91
Harris	28,481	1.20	5.03	4.17	6.44	28.77	21.93
Region 7	9,291	1.17	2.87	0.65	13.93	27.00	3.00
Bell	1,184	3.47	0.00	0.00	43.90	0.00	0.00
Travis	1,829	2.63	10.83	1.80	42.11	90.36	10.84
Region 8	17,477	0.21	5.06	7.07	0.36	35.10	39.15
Bexar	11,481	0.16	6.45	8.41	0.00	45.18	46.70
Region 9	5,043	0.43	0.00	0.18	5.36	0.00	0.00
Region 10	8,886	0.07	0.03	0.00	0.00	0.00	0.00
El Paso	8,695	0.07	0.03	0.00	0.00	0.00	0.00
Region 11	25,055	2.24	5.88	6.44	8.54	27.78	34.89
Cameron	5,486	4.95	10.23	9.19	16.56	65.71	50.48
Hidalgo	9,921	0.86	3.39	6.30	4.84	15.54	33.68
Nueces	2,920	3.32	8.42	6.16	15.45	16.67	33.68
Webb	3,416	0.00	2.72	5.53	0.00	12.18	28.93
TEXAS	154,820	1.13	3.43	4.14	6.29	22.48	26.09

* Does not include data from UT Southwestern Medical Center at Dallas in 1994, 1997, 1998.

**May represent better reporting.

Note: 1998 Medicaid Paid Deliveries were unavailable: 1997 deliveries were used as estimates of 1998.

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

Table E

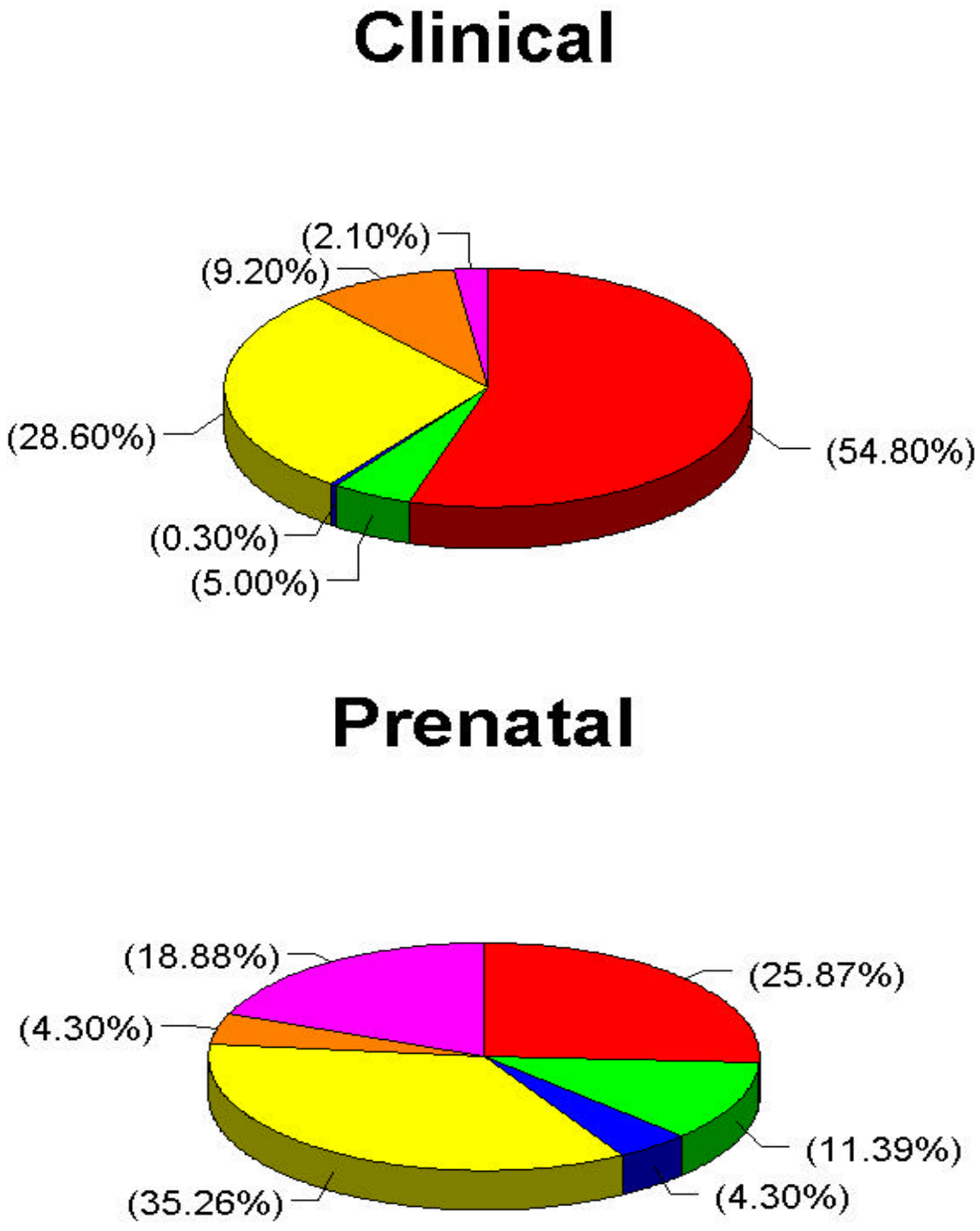
Statewide Utilization of Prenatal Genetic Services: 1994, 1997, and 1998			
	1994	1997	1998
All Prenatal Patients	2.5%	4.3%	4.8%
Medicaid Prenatal Patients	1.1%	3.4%	4.1%
All AMA Prenatal Patients	11.1%	21.4%	20.9%
AMA Medicaid Prenatal Patients	6.3%	22.5%	26.1%

Note: Does not include data from Cook's Children's Hospital and Scott & White for 1997; Scott & White for 1998.

Starting with the 1997 survey, providers were asked to specify payers for genetic services. Medicaid represented the major payer for prenatal as well as clinical genetic services in 1997. Title V provided only a small proportion (3%) of the funding for clinical (primarily pediatric) patients, and funded 11.2% of prenatal genetic services. Most recipients of the total Title V funding were prenatal clients in Austin (7.5%), Houston (20.2%), Corpus Christi (19.7%), and Galveston (16.3%)

In the 1998 survey, Medicaid continued to be the major payer for clinical services, but was outpaced by private payers for prenatal services. Title V provided 5% of the funding for clinical patients and 11% of prenatal genetic services. Figure 1 on Page 18 shows the percent of patient visits by payer type. Over 96% of prenatal patients whose genetic services were funded by Title V lived in 4 cities: 45.3% of all Title V funded prenatal genetics visits were in Houston; 24.4% in Corpus Christi , 17.5% in Dallas, and 9.1% in Galveston.

Figure 1 - Percent of Patient Visits by Payer Type



VI. Funding

E. Genetic Services

Funding to operate genetic service programs in Texas comes from multiple sources, i.e., Medicaid, Title V Social Security Act, Private, and other public funds. Title V provides funding for 12 genetic contractors (8 genetic service providers, two sickle cell agencies, and 2 population-based service providers [education and outreach services]), one TDH genetic clinic, and state support for the genetics laboratory.

In 1997, Title V funds dedicated to genetic services total approximately $1.9 million dollars. The TDH Genetics Laboratory annual budget for FY 97 was reported at $1 million dollars ($600,000 income; $300,000 Title V; $100,000 general revenue). In 1998, Title V funds dedicated to genetic services remained the same.

Medicaid (state & federal) pays for individual professional claims for clinical services provided to Medicaid eligible individuals. Medicaid expenditures for genetic services had steadily increased from $2.958 million in 1994, to $3.607 million in 1995, $4.066 million in 1996, and $4.445 million for FY 1997. Since 1997, though, Medicaid expenditures for genetic services have steadily decreased to $4.238 million in 1998, $4.060 million in 1999, and $3.960 million in FY 2000. Managed Care dollars for genetic services are not captured in these figures.

F. Birth Defects Monitoring Division

The Texas Birth Defects Monitoring Division has asked for an exceptional item for the 2002-2003 year in the amount of approximately $900,000. The Division's budget for FY 2001 is $2.4 million, roughly 50% from general revenue and 50% from Title V. These funds support 61 personnel, 50 of whom are regional staff. Roughly 70% of the $900,000 of additional funding would go towards recurring-type expenses (re: regional data collection/coordination and a scheduled replacement of aging computer hardware). The remaining 30% goes towards non-recurring IT programming costs for that biennium.

VII. Allocation Plan

A. General

Council used previously developed and published philosophy[10] as guidance in preparing this plan.

1. The goal is that genetic services be comprehensive, integrated, and easily accessible. Case management should be an integral part of the provision of genetic services;

2. Quality service is to be assured. Standards are to be specified;

3. The preventive and cost-effective aspects of genetic services should be emphasized and analyzed;

4. To assist and enhance accountability and cost effectiveness the request for proposals (RFP) process will be used;

5. Where services are provided is an important consideration. Under served and high-risk populations to include, but not limited to, state school populations, community MHMR Centers and other community providers, geographically isolated areas, urban areas, and medically indigent must be specifically addressed;

6. Perceptions of the public should be addressed (e.g., not all genetic disorders are related to mental retardation);

7. Federal matching funds should be maximized;

8. Utilize public hearings held by Texas agencies in regions throughout the state as a forum for input from the public regarding genetic services; and

9. The plan should be dynamic (i.e., it should be subject to regular review and

[10] Evaluation of Cost-Effective and Functional Methods of Providing Genetic Services, March 30, 1990; Resource Allocation Plan for the 1992-1993 Biennium, June 1, 1990; Resource Allocation Plan for the 1994-1995 Biennium, May 31, 1992; Resource Allocation Plan for the 1996-1997 Biennium, May 31, 1994; Resource Allocation Plan for the 1998-1999 Biennium, May 31, 1996

modification).

B. Services

Services should be comprehensive, of high quality (quality assured), preventive, and cost effective.

C. Plan Development and Implementation

Mechanisms should include establishing standards, monitoring quality assurance, establishing funding level and competitive process and maximizing federal contribution (where appropriate Medicaid should be the first payor for indigent persons). Additionally, public hearings on genetic services should be held in conjunction with other Texas state public hearings, establishing future plans through a dynamic process of review, ongoing needs assessment, accountability (clients, costs, reporting procedures, services, audit and hearing authority), and ongoing interagency cooperation.

D. Population Targets

Population Targets should address equitable distribution of services, under served areas, medically indigent in all areas, state institutions (schools and hospitals), mentally retarded/developmentally delayed populations within the community, and all populations without regard to ethnic origins, age, race, or gender.

VIII. Summary

1. In 1998, 17% of Texas infants estimated to require genetic services actually received services. This low utilization represents a decrease compared with 1994, when 19% of infants received services.

2. In 1998, approximately 5% of all pregnant women and 21% of AMA pregnant women received prenatal genetic services at genetic centers. This does not include prenatal genetic services provided by other physicians. Both genetics and prenatal services show no substantial increase in services over 1997. Urban areas again had more services while rural counties were still less likely to receive services. Regions 9 and 10 had minimal services provided.

3. 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.

IX. Recommendations

1. Texas Department of Health, Texas Department of Insurance, Texas Department of Mental Health and Mental Retardation, Texas Department of Human Services, and TEXGENE undertake a comprehensive planning process to address the provision of genetic services to infants and other non-pregnant patients.

2. Where unavailability of qualified providers is a factor, TDH and TEXGENE should work with community leaders and providers to address the problem. Utilization of prenatal genetic services in rural areas, and in El Paso, remains low. Texas Department of Health and TEXGENE should undertake an analysis to determine the factors that underlie this observation.

3. Focus additional educational programs at payers in order to achieve increased referrals for children less than 1 year of age.

4. Continuation of commitment to expand the birth defects monitoring program statewide. Council recommends that the Texas Legislature fully fund the Texas Birth Defects Monitoring Division.

5. Expanding alternative funding resources such as Title V to cover genetic services for patients without access to public health insurance programs (i.e., Medicaid and Children's Health Insurance Program) or private insurance.