

**Interagency Council for Genetic Services  
Resource Allocation Plan  
2006-2007**

The Resource Allocation is prepared by the  
Interagency Council for Genetic Services  
in compliance with Section 5, Chapter 135,  
Human Resources Code (Sec. 134.0041)  
71<sup>st</sup> Legislature – Regular Session

Questions regarding this plan may be directed to:

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## Table of Contents

Executive Summary.....	3
I. Introduction.....	6
II. Genetic Services Capacity: TexGene Survey and Analysis .....	9
III. Current Service System Resources.....	16
PRIVATE RESOURCES for HEALTH CARE.....	16
PUBLIC RESOURCES for HEALTH CARE .....	17
Texas Health and Human Services Commission (HHSC).....	17
1. Medicaid .....	17
2. Children’s Health Insurance Program (CHIP) .....	19
Department of State Health Services (DSHS) .....	19
1. Title V – Genetic Services.....	19
2. Newborn Screening .....	21
3. Services Program for Children with Special Health Care Needs .....	23
4. Newborn Hearing Screening .....	25
Department of Assistive and Rehabilitation Services (DARS).....	26
1. Early Childhood Intervention .....	26
2. Rehabilitation Services .....	27
3. Deaf and Hard of Hearing Services.....	28
4. Services for the Blind .....	29
Department of Aging and Disabilities Services (DADS).....	30
1. Mental Retardation Services.....	30
2. Children’s Services.....	30
IV. Gaps and Barriers .....	32
Gaps in Services .....	32
Barriers to Service Delivery.....	33
V. Priorities.....	34
Education, services prior to conception.....	34
Prenatal care .....	34
Capacity.....	34
Funding.....	35
Services.....	35
VI. Recommendations .....	36

## **Executive Summary**

### **Interagency Council for Genetic Services Resource Allocation Plan 2006-2007**

This plan examines funding for genetic services in Texas, describes the current status of the provision of genetic services in the state, and provides recommendations for future planning. The plan specifically addresses needs related to genetic disorders, birth defects, and prematurity.

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. Prematurity refers to an infant born before 37 weeks gestation and low birth weight refers to a birth weight of less than 2500 grams (5.5 pounds). While we do not know the causes for all premature births or low birth weights, risk factors include, but are not limited to, previous preterm births, multiple gestation, certain medical conditions, poverty, use of teratogens, late or no prenatal care, domestic violence, and certain birth defects in the baby. Premature infants are at risk for serious and costly health problems.

In 2001, there were 365,092 live births in Texas. Of these, 12,806 (4%) infants were born with birth defects. The number of low birth weights (<2500 grams) for 2001 was 27,585 (7.6%); the number of very low birth weights for the same period (<1500) was 4,808 (1%). Between 1994 and 2001, the number of births increased 14%; during the same period, the number of infants receiving genetic services decreased 35%. The Interagency Council for Genetic Services (IACGS) estimates that at least 7% of pregnant women are in need of genetic services but only 2.2% received prenatal services from a TexGene services provider during 2001, a 4.1% decrease from the previous year.

Based on the contents of this document and the activities undertaken in developing this plan, the Interagency Council for Genetic Services presents the following recommendations:

1. Revision of Section 5, Chapter 134, Human Resources Code. A revision of the code is needed to reflect the new health and human services agencies with IACGS representation and to enable the IACGS to continue data collection:
  - \* The IACGS recommends that the Department of State Health Services and the Department of Aging and Disabilities replace the Texas Department of Health and the Texas Department of Mental Health and Mental Retardation.
  - \* The IACGS requests provision of an ongoing source of funding for data collection (which does not take away current service dollars).
2. Development of strategies for increasing genetic services to rural and underserved (including areas in large population centers) areas of the state. Difficulties include the limited

of genetic services providers overall as well as the general lack of all types of health care services in various areas of the state. Many areas of the state do not have public transit systems. Even in areas with extensive public transportation, the difficulties a patient may experience, such as multiple bus transfers, waiting time in poor weather, her medical condition, and lack of childcare, are enormous barriers. To address the issue of unserved or underserved areas of the state, the IACGS proposes several specific strategies:

- \* Development of telemedicine in underserved areas. Resources required may include appropriate facilities, new equipment, and technical assistance in identification of potential partners and in contract negotiation. To ensure success, coordination of appointments for patients will be required as well as patient education regarding telemedicine.
- \* Identification and utilization of successful models that educate medical students and local health care providers and allow for their participation in genetic services clinics.
- \* Licensure of genetic counselors and the development of supports to supplement the work of clinical geneticists in unserved or underserved areas.

3. Coordinated and expanded education. A number of constituencies could benefit from education regarding prematurity, birth defects, and genetic disorders. Women of childbearing age and pregnant mothers and their partners need education regarding the dangers of teratogens, the potential impact of lifestyle decisions on their future children, family risks for genetic disorders, and the importance of early prenatal care and testing. Childcare workers and school personnel need education on the availability of genetic services and needs of children with genetic disorders. Health care providers need education regarding genetic services and on how to refer individuals/families to genetic service providers. Several strategies are proposed:

- \* Increased education of obstetrical, family planning, school nurses, and primary care providers regarding Texas Teratogen Information Services.
- \* Development or purchase and distribution of relevant educational materials.
- \* Establishment of an ad hoc group sponsored by the IACGS to assess and address educational needs relating to genetics for medical and other health care students and to provide recommendations to medical school curriculum committees.
- \* Development of strategies by the IACGS to increase the impact of their respective entities' educational initiatives.

4. Strategies to address language and cultural barriers.

- \* Development of recruitment strategies to attract diversity in genetics training programs.
- \* Provision of information and training in cultural competency for practitioners, including but not limited to the following:
  - Development and distribution of appropriate counseling tools and aids for special populations.
  - Training in understanding the impact of family and cultural beliefs of patients/families on acceptance of genetic counseling and in crafting appropriate counseling techniques to address the patient's beliefs and practices.

5. Legislative or executive assistance in addressing the trend to transfer the costs of providing genetic services to the clinical geneticists or their employer. With regard to Medicaid and

CHIP, it is recommended that contract provisions for HMOs be written to require prompt and sufficient payment for appropriate claims and that the provisions be enforced.

6. Restoration of Title V funding to at least FY97 levels. In FY97, the former Texas Department of Health awarded \$1,834,134 in Title V funds to contractors; this included over \$1.3 million in direct patient services and \$498,276 in education and population-based services. Currently, only \$1.2 million is available for contracting. The restoration of Title V funding will support implementation of many of the above recommendations, allow for expanded prenatal care, and increase the overall number of individuals and families served, thereby addressing many of the needs and priorities identified by genetic services providers and by the IACGS.

**Interagency Council for Genetic Services  
Resource Allocation Plan  
2005-2006**

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) 71<sup>st</sup> Legislature - Regular Session.

Questions regarding this plan may be directed to:

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**I. Introduction**

The Texas Legislature established the Interagency Council for Genetic Services (IACGS) in 1987. Representatives from three state agencies (Texas Department of Health (TDH), Texas Department of Mental Health and Mental Retardation, and Texas Department of Insurance), the University of Texas health science centers, a representative selected by (TDH) genetics services contractors from their membership, and two consumers representatives make up the IACGS. H.B. 2292, enacted during the 78th Legislature, realigned the mandates and activities of the 12 existing health and human services agencies into four new departments. This consolidation impacted two (formerly Texas Department of Health and Texas Department of Mental Health and Mental Retardation) of the three state agencies with representation to the IAC.

According to Section 134.004 of the Human Resources Code the IACGS is entrusted with the following responsibilities:

1. Survey current resources for human genetics 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 human genetic services and methods of service delivery
4. Promote a common statewide data base to study the epidemiology of human genetic disorders;
5. Assist in coordinating statewide human genetic services for all state residents;
6. Increase the flow of information among separate providers and appropriation authorities;
7. Develop guidelines to monitor the provision of human genetic services, including laboratory testing;
8. Identify state entities that serve persons with are affected by or at risk of having children who are affected by environmental genetic disorders and coordinate activities with those agencies; and

9. Work in coordination with the state agencies named in Section 134.001 when then the agency initiates, considers, or proposes a rule relating to human genetics or human genetic services.

Based on the above mandate, the ICGS has developed and now presents its Resource Allocation Plan addressing three overlapping areas of concern relevant to its mandate: genetic disorders, birth defects, and prematurity. 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. Prematurity refers to an infant born before 37 weeks gestation and low birth weight refers to a birth weight of less than 2500 grams (5.5 pounds). While we do not know the causes for all premature births or low birth weights, risk factors include, but are not limited to, previous preterm births, multiple gestation, certain medical conditions, poverty, use of teratogens, late or no prenatal care, domestic violence, and certain birth defects in the baby. Premature infants are at risk for serious and costly health problems.

Individually, one's risk for a genetic disorder, a birth defect or a premature birth is low but in the aggregate, genetic conditions, birth defects, and prematurity are significant to Texas as indicated by the following statistics:

- \* For the three years 1999 – 2001, the Texas Birth Defect Registry reports that the number of infants and fetuses with any monitored birth defect was 37,728, a prevalence of 350.12 per 10,000 live births. <sup>1</sup>
- \* Congenital malformations (birth defects) were responsible for 26% of all infant deaths under 28 days of age and for 22% of all infant deaths under the age of one in Texas. <sup>2</sup>
- \* In Texas, congenital malformations (birth defects) and homicide tied for the third leading cause of death for male children aged 1-14 and was the third leading cause of death for female children aged 1-14 during 2002. <sup>3</sup>
- \* According to the Center of Disease Control and Prevention, birth defects are the leading cause of infant mortality in the United States and account for more than 20% of infant deaths. <sup>4</sup>

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<sup>1</sup> Texas Department of State Health Services, Texas Birth Defects Registry, "Report of Defects Among 1999-2001 Deliveries" Data Tables, 20 August, 23 August 2004, [http://www.tdh.state.tx.us/tbdmd/Data/all\\_tables\\_99-01.pdf](http://www.tdh.state.tx.us/tbdmd/Data/all_tables_99-01.pdf)

<sup>2</sup> Texas Vital Statistics 2002 Annual Report, Table 32 and Table 31, 10 March 2004, 29 July 2004  
<<http://www.tdh.state.tx.us/chs/vstat/latest/t32.HTM>, <<http://www.tdh.state.tx.us/chs/vstat/latest/t31.HTM>>.

<sup>3</sup> 2002 Annual Report, Table 17, <http://www.tdh.state.tx.us/chs/vstat/latest/t17.HTM>

- \* In 2001, 10,953 infants (approximately 3% infants are born with a genetic disorder or birth defect) in Texas needed genetic services but only 1,251 received services from a TexGene provider (9702 infants needing genetic services did not receive them). While the number of births increased by 14% since 1994, the number of infants receiving genetic services decreased by 35%.
- \* Approximately 7% of pregnant women need prenatal genetic services. In 2001, 2.2% or roughly one-third received such services from a TexGene provider. There has been a steady decline in access to prenatal genetic services in recent years; 4.8% of pregnant women received prenatal genetic services in 1998, 4.5% in 1999 and 4.1% in 2000.<sup>5</sup>
- \* The March of Dimes reports that nationally, prematurity has increased 29% since 1981 and it now accounts for 12% of all live births.<sup>6</sup>
- \* The March of Dimes also reports the cost of hospital stays for premature babies nationwide as averaging \$75,000. If this national estimate of cost is comparable to hospital costs in Texas, then 49,290 premature babies born in Texas in 2002 would represent \$3,696,750,000 in hospital costs.<sup>7</sup>

Health care for children with genetic disorders and/or birth defects and for babies born prematurely are very costly as noted in this introduction and as will be documented in succeeding sections of this plan. Yet, mortality, disabilities, and associated costs can be decreased through prevention (such as folic acid preventable anencephaly and spina bifida), detection, and treatment. It is important that individuals and families with risk factors be educated and counseled so that adverse pregnancy outcomes can be prevented. The cost of providing pre-conceptual genetic services can more than offset the future costs if even a few pregnancies in which outcomes would require a lifetime of care were prevented. And early diagnosis and treatment of disorders and conditions can help children lead more productive lives, thereby lowering the costs associated with birth defects, genetic conditions, and prematurity.

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<sup>4</sup> Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, 5 August 2004, 18 August 2004, <<http://www.cdc.gov/ncbddd/bd/rate.htm>>.

<sup>5</sup> Research and Public Health Assessment, "TexGene Services Survey Results and Analysis", August 2004.

<sup>6</sup> March of Dimes, "Prematurity: the answers can't come soon enough", March 2004, 18 August 2004, <[http://www.marchofdimes.com/prematurity/5413\\_11560.asp](http://www.marchofdimes.com/prematurity/5413_11560.asp)>.

<sup>7</sup> March 2004, 18 August 2004, <[http://www.marchofdimes.com/prematurity/5414\\_10719.asp](http://www.marchofdimes.com/prematurity/5414_10719.asp)>.



## II. Genetic Services Capacity: TexGene Survey and Analysis

Since 1994, a collaborative group of service providers known as TexGene with funding from the U.S. Department of Health and Human Services, Health Resources and Services Administration, has conducted periodic surveys of genetic services providers in Texas. The data gathered by these surveys include numbers served, services delivered, reason for referral to genetic services, patient demographics, and type of payor. Information and data from their work has been incorporated into the biannual Resource Allocation Plans. The last survey was conducted in 2001, the final funding year for TexGene. The information gathered and analyzed at that time is reflected in this section, which examines the genetic services system and the need for such services.

The TexGene surveys did not include all genetic service providers in the state as some chose not to participate; however, the number of providers taking part in the surveys has remained stable over the years while some practitioners have moved away from a genetics specialty practice to research or another related specialty. Some genetic services are also offered at private physician offices and these are not reflected in the information contained in the tables below.

**Table A: Genetic Services to Infants by TexGene Clinic Providers by Region, 1994-2001**

Region	# Live Births 1994	3% of Live Births 1994	Infants Served 1994 by TexGene Providers	% Infants Served 1994 by TexGene Providers	# Live Births 2001	3% of Live Births 2001	Infants Served in 2001 by TexGene Providers	% Infants Served 2001 by TexGene Providers	% Change 1994-2001 Births	% Change 1994-2001 Served
01	11,894	357	114	1.0%	12,076	362	30	0.2%	2%	-74%
02	7,261	218	54	0.7%	7,275	218	15	0.2%	0%	-72%
03	78,919	2,368	183	0.2%	99,605	2,988	321	0.3%	26%	75%
04	12,891	387	33	0.3%	13,844	415	39	0.3%	7%	18%
05	9,807	294	51	0.5%	9,729	292	57	0.6%	-1%	12%
06	75,325	2,260	435	0.6%	85,546	2,566	225	0.3%	14%	-48%
07	31,283	938	192	0.6%	39,099	1,173	120	0.3%	25%	-38%
08	33,323	1,000	240	0.7%	35,144	1,054	12	0.0%	5%	-95%
09	8,244	247	69	0.8%	7,930	238	6	0.1%	-4%	-91%
10	15,983	479	96	0.6%	14,553	437	9	0.1%	-9%	-91%
11	36,158	1,085	339	0.9%	40,291	1,209	189	0.5%	11%	-44%
Unknown Region			123				228			
<b>Texas</b>	<b>321,088</b>	<b>9,633</b>	<b>1,929</b>	<b>0.6%</b>	<b>365,092</b>	<b>10,953</b>	<b>1,251</b>	<b>0.3%</b>	<b>14%</b>	<b>-35%</b>

**Table A** compares the number of infants served by TexGene in 1994 and 2001. While the overall number of infants increased by 14%, the number of infants who were provided genetic services decreased, both as an absolute number served (1,929 in 1994 vs. 1,251 in 2001) and as a percentage of the population served. An estimated 3% of infants are born with a birth defect or genetic disorder: this translates to 9,633 infants in 1994 and 10,953 infants in 2001. The percentage of infants who were provided genetic services in the TexGene survey of genetic

providers decreased from just over one half of one percent in 1994 to less than one half of one percent in 2001 statewide (from 0.6% to 0.3%).

The largely rural Regions of 2, 5, and 9, and Region 10 (El Paso) showed no increase or a small decrease in the number of births, while Regions 3, 6, and 7 reported increases in births from 14-26%. These increases did not result in increased genetic services to infants in these regions but rather a decrease. Only Region 3 showed a large percentage increase in infants who received genetic services. As stated above, the TexGene survey did not involved all providers so survey results do not capture the full number of infants who may have received genetic services.

However, the survey does describes a gap between the number of infants who would benefit by genetic counseling and those who receive it, which has grown from 7,704 infants in 1994 to 9,702 in 2001.

**Table B: Genetic Services to Infants by TexGene Providers  
By Region and for Counties with 3,500 or more live births, 2000 – 2001**

Region/ County	1999 Live Births	2000 Live Births	% Served in 2000 of 1999 Live Births	% Served in 2001 of 2000 Live Births
Region 1	12,192	12,261	0.4%	0.2%
Lubbock	3,784	3,855	0.6%	0.4%
Region 2	7,486	7,405	0.3%	0.2%
Region 3	92,058	96,682	0.2%	0.3%
Collin	8,034	8,675	0.3%	0.3%
Dallas	40,677	42,444	0.2%	0.4%
Denton	6,792	7,434	0.4%	0.3%
Tarrant	24,427	25,428	0.3%	0.2%
Region 4	13,736	14,082	0.2%	0.3%
Region 5	9,882	10,254	0.6%	0.6%
Region 6	82,173	85,231	0.7%	0.3%
Brazoria	3,853	3,988	0.7%	0.4%
Ft. Bend	4,873	5,240	0.7%	0.3%
Galveston	3,706	3,805	1.0%	0.8%
Harris	61,067	63,325	0.7%	0.2%
Montgomery	4,393	4,663	0.8%	0.2%
Region 7	35,825	38,696	0.1%	0.3%
Bell	5,002	5,388	0.1%	0.1%
Travis	13,270	14,473	0.1%	0.7%
Williamson	3,931	4,446	0.0%	0.1%
Region 8	34,787	35,280	0.9%	0.0%
Bexar	23,597	24,033	1.0%	0.0%
Region 9	8,208	8,225	0.5%	0.1%
Region 10	14,310	14,664	0.3%	0.1%
El Paso	13,960	14,285	0.3%	0.1%
Region 11	38,500	40,545	0.8%	0.5%
Cameron	8,021	8,314	1.6%	1.2%
Hidalgo	14,087	15,359	0.7%	0.4%
Nueces	5,261	5,248	0.6%	0.0%
Webb	5,448	5,777	0.6%	0.4%
Texas	349,157	363,325	0.5%	0.3%

Note: Percent served is the annualized number of infants served divided by the total live births from the previous year.

**Table B** documents genetic service provision by TexGene providers in counties with greater than 3,500 live births for 2000 and 2001. In 2001, 0.3% of infants were served, a decrease from the 0.5% served in 2000. Public Health Regions 3, 4 and 7 were the only regions to increase the percentage of infants served between 2000 and 2001. All regions with exception of region 2

showed an increase in the number of live births between 1999 and 2000. Region 7 had the largest percent increase of all of the public health regions.

**Table C: Percent of Prenatal Patients Receiving Genetic Services from TexGene Providers, by Region 1997-2001**

Region/County	1997	1998	1999	2000	2001
Region 1	4.6%	1.3%	0.9%	0.6%	0.2%
Lubbock	4.7%	3.0%	2.3%	1.0%	0.3%
Region 2	0.1%	0.5%	4.0%	4.1%	0.1%
Region 3	1.7%	3.1%	3.3%	3.0%	0.0%
Collin	1.0%	2.9%	1.9%	1.3%	0.0%
Dallas	2.8%	5.1%	1.6%	1.4%	0.0%
Denton	2.9%	2.3%	2.0%	2.6%	0.0%
Tarrant	0.2%	0.6%	7.0%	6.3%	0.0%
Region 4	0.5%	2.5%	1.8%	0.8%	1.3%
Region 5	2.9%	4.4%	3.0%	4.8%	6.2%
Region 6	4.7%	5.5%	6.0%	6.0%	4.0%
Brazoria	3.4%	4.8%	5.3%	7.0%	<b>8.6%</b>
Ft. Bend	<b>7.1%</b>	<b>7.0%</b>	4.9%	6.6%	2.0%
Galveston	3.8%	6.7%	<b>8.9%</b>	<b>9.1%</b>	<b>14.4%</b>
Harris	4.9%	5.7%	6.3%	6.1%	3.2%
Montgomery	2.2%	2.7%	2.6%	2.8%	3.0%
Region 7	3.6%	5.2%	5.1%	3.2%	1.1%
Bell	0.1%	0.3%	0.2%	0.6%	0.0%
Travis	<b>7.1%</b>	<b>10.7%</b>	<b>9.4%</b>	5.7%	2.8%
Williamson	-	-	-	3.9%	0.0%
Region 8	<b>7.2%</b>	<b>9.1%</b>	6.4%	5.7%	3.0%
Bexar	<b>8.9%</b>	<b>10.7%</b>	<b>7.3%</b>	6.9%	3.4%
Region 9	0.1%	0.2%	0.4%	0.6%	0.1%
Region 10	0.0%	0.1%	0.1%	0.0%	0.0%
El Paso	0.0%	0.0%	0.0%	0.0%	0.0%
Region 11	5.3%	6.0%	6.0%	5.1%	2.8%
Cameron	<b>9.1%</b>	<b>8.6%</b>	<b>7.9%</b>	1.6%	5.0%
Hidalgo	3.1%	5.6%	5.8%	5.1%	2.3%
Nueces	6.8%	6.1%	6.9%	3.6%	1.6%
Webb	3.4%	5.3%	3.5%	4.3%	2.7%

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

**Table C** documents the percent of prenatal patients who received genetics services from TexGene providers based on the number of live births for each year from 1997 through 2001. TexGene has historically estimated that a minimum of 7% of pregnant women should receive genetic services. Based on birth rates, 2.2% of all women statewide who had live births received prenatal genetic services at a TexGene provider in 2001, a drop from 4.1% in 2000.

An estimated 9% of women who give birth in Texas are 35 years of age or more (AMA). Of these women, half or 4.5% will accept prenatal genetic counseling if offered. An additional 2.5% of pregnant women should be referred to genetics services because of high maternal serum alpha fetoprotein. This does not take into account women with other indicators for referral.

Roughly a third (2.2%) of the estimated 7% of women needing prenatal genetic services are receiving them. In 2001, 8.4% of women aged 35 or above who had live births received prenatal genetic services at a reporting center, a drop from 19% in 2000. On the positive side, Table C also indicates that some urban areas meet or exceed the 2001 statewide average of 2.2%. Brazoria and Galveston counties exceed the benchmark of 7%. Bexar, Cameron, Harris, Hidalgo, Montgomery, Travis and Webb counties and Public Health Regions 5, 6, 8 and 11 exceed the state average. By contrast, many rural areas in regions 1, 2 and 9 appear to be underserved by TexGene providers. In Region 10, there were no prenatal clients served by a TexGene provider during the survey periods.

**Table D: Utilization of Prenatal Genetic Services by Medicaid-funded Women, All Women and Advanced Maternal Age Women (AMA), by Regions and Counties of over 3500 Live Births.**

Region/ County	Medicaid Paid Deliveries 2001	Total Live Births 2001	Medicaid Paid Deliveries for AMA Women 2001	TexGene Prenatal Patients 2001	TexGene Prenatal Patients with Public Health Insurance 2001	TexGene AMA Prenatal Patients 2001	TexGene AMA Prenatal Patients with Public Health Insurance 2001	% Medicaid Women Served 1994 by TexGene	% Medicaid Women Served 1999 by TexGene	% Medicaid Women Served 2001 by TexGene	% AMA Medicaid Women Served 1994 by TexGene	% AMA Medicaid Women Served 1999 by TexGene	% AMA Medicaid Women Served 2001 by TexGene
<i>Region 1</i>	6,886	12,076	165	24	21	3	0	5%	1%	0%	42%	5%	0%
Lubbock	2,115	3,826	21	12	12	0	0	8%	5%	1%	48%	13%	0%
<i>Region 2</i>	3,865	7,275	142	6	6	3	3	0%	2%	0%	2%	23%	2%
<i>Region 3</i>	38,080	99,605	972	6	0	6	0	0%	1%	0%	0%	7%	0%
Dallas	20,118	42,902	386	3	0	3	0	0%	0%	0%	0%	3%	0%
Denton	1,593	7,899	43	0	0	0	0	1%	1%	0%	0%	29%	0%
Tarrant	9,843	26,367	358	0	0	0	0	0%	6%	0%	0%	23%	0%
<i>Region 4</i>	7,858	13,844	253	180	54	51	12	0%	2%	1%	0%	12%	5%
<i>Region 5</i>	5,622	9,729	220	600	447	180	96	2%	4%	8%	17%	24%	44%
<i>Region 6</i>	37,855	85,546	1,069	3,393	1,797	1,545	636	1%	9%	5%	7%	60%	59%
Brazoria	1,522	4,146	49	357	222	129	51	2%	10%	15%	26%	77%	104%
Fort Bend	1,157	5,289	47	108	36	66	15	2%	3%	3%	19%	39%	32%
Galveston	1,839	3,720	61	534	291	204	72	7%	12%	16%	15%	75%	118%
Harris	29,553	63,411	804	2,037	1,020	1,026	432	1%	9%	3%	6%	64%	54%
<i>Region 7</i>	14,605	39,099	365	447	375	171	132	1%	3%	3%	14%	17%	36%
Bell	1,314	5,328	14	0	0	0	0	3%	0%	0%	44%	0%	0%
Travis	5,843	14,599	138	405	354	153	126	3%	7%	6%	42%	24%	91%
<i>Region 8</i>	18,185	35,144	799	1,071	354	522	105	0%	4%	2%	0%	28%	13%
Bexar	11,899	23,742	497	798	210	441	69	0%	5%	2%	0%	30%	14%
<i>Region 9</i>	5,052	7,930	154	6	0	3	0	0%	0%	0%	5%	0%	0%
<i>Region 10</i>	8,801	14,553	368	0	0	0	0	0%	0%	0%	0%	0%	0%
El Paso	8,554	14,189	355	0	0	0	0	0%	0%	0%	0%	0%	0%
<i>Region 11</i>	28,870	40,291	1,063	1,110	792	381	261	2%	7%	3%	9%	31%	25%
Cameron	6,409	8,381	262	417	312	156	126	5%	9%	5%	50%	46%	48%
Hidalgo	11,520	15,083	451	351	270	117	81	1%	7%	2%	60%	35%	18%
Nueces	3,039	5,186	128	81	51	12	9	3%	7%	2%	16%	24%	7%
Webb	3,958	5,936	62	162	90	66	30	0%	3%	2%	0%	15%	48%
<i>Texas</i>	175,715	365,092	9,246	7,920	3,918	3,216	1,275	1%	4%	2%	6%	29%	14%

According to **Table D**, there were 175,715 deliveries in FY01 paid by Medicaid or roughly 48% of all births for the year. In 1994, Medicaid paid for 46% of the 321,088 births for the year. The percentage of Medicaid-paid deliveries for the last decade has remained stable, at just under 50%, while the number of total births and number of Medicaid-paid births increased apace. The percentage of Medicaid births that received TexGene genetics services has ranged from 1% in 1996 to 4% in 1999, and decreasing to 2% in 2001.

Mothers of advanced maternal age (AMA) (over the age of 35) are at increased risk of premature delivery (as are mothers under the age of 18) as well as for delivering infants with Down Syndrome. The number of total AMA mothers increased from 28,692 in 1994 (8.9% of all births) to 37,971 in 2001 (10.4% of all births). For 2002, the latest year available from TDH Bureau of Vital Statistics, the number of AMA births increased to 39,082 (10.5% of all births). The rate of increase in AMA births is slowing; a conservative estimate of the percentage of AMA mothers for 2005 would be 10.6% of all births in Texas, where births may exceed 400,000. In 2001, the percent of AMA mothers delivering premature babies was 12.3 compared to 10.3% for all mother. The percentage of Medicaid births to AMA mothers who received TexGene services is higher than the general prenatal population, ranging from 6% in 1994, to 29% in 1999, and then dropping to 14% in 2001.<sup>8</sup>

In this section, we noted that the number of births in Texas rose between 1994 and 2001. This upward trend continued in FY2002 with 7277 more births than in FY2001. The percent of low birth weight births in Texas has also continued to grow from 7.4% in 2000 and 7.6% in 2001 to 7.7% or 28,649 births in 2002.<sup>9</sup> The number of birth defects recorded in 1999 was 11,914. In 2000, the number jumped by more than a thousand to 13,008 and then dropped to 12,806 in 2001.<sup>10</sup> With regard to providing prevention and intervention service to this population, most measures indicated that genetic services providers lost ground. Throughout the reported periods, the numbers served and the percent of those in need of services who actually received services has continued to decrease.

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<sup>8</sup> Research and Public Health Assessment.

<sup>9</sup> Texas Health Data Births To Texas Residents.

<sup>10</sup> "Report of Defects Among 1999-2001 Deliveries".

### **III. Current Service System Resources**

In the previous section, the gap between numbers served and the availability of services was described. This section will address the service system resources for genetics services.

Throughout Texas, both private and public entities deliver genetic services, including university medical schools, hospitals, specialty practices, and private physicians. A variety of financial resources including private insurance, Medicaid, CHIP, Title V Maternal and Child Health federal block grant, state general revenue, and university operating funds support the services. In addition to providing, and paying for, genetic evaluation and counseling, these entities and these payment resources enable some individuals with chronic conditions resulting from their genetic disorder or birth defect to have ongoing care and services. While a number of potential resources exist for individuals needing diagnostic genetic services or treatment for their genetic disorders or birth defects, a significant number of Texans are without private or public funding resources and many go without needed services.

National sources report that Texas has the highest rate of uninsured individuals in the United States and that 1/10 of our nation's population without insurance resides in Texas. In 2002 (the last year for which full year data is available), 5.5 million Texans or 25.81% of the total population of our state was uninsured. The rates of the uninsured are even higher for Hispanic and African American Texans. It was estimated that 22.36% of all children under the age of 18 and 24.83% of all Texas women went without adequate or with no health insurance coverage.<sup>11</sup>

#### **PRIVATE RESOURCES for HEALTH CARE**

Despite the importance of private health insurance to individuals of employment age, the majority of uninsured Texans are adults under the age of 65. While most individuals ages 18-65 who have health insurance access it through their place of employment, almost two-thirds of those who are uninsured and not retired hold a job. These uninsured adults either work in jobs that do not offer health insurance or are unable to afford the coverage offered. At 52.6%, the portion of Texans covered by employer-based health insurance is lower than the national average of 61.3%. Nationally, although nearly 71% of the non-elderly received their health care coverage through private insurance, only 36% of the cost of health care was paid by private insurance. Out-of-pocket payments accounted for 16%.

One of the limitations of private insurance is that it tends to cover healthy individuals. Some of the sickest and most expensive individuals are unable to work, have met their lifetime benefit, have pre-existing conditions for which treatment is excluded for up to 12 months, or cannot afford the premiums.<sup>12</sup> Costs for their care are often transferred to the public sector and supported by the federal, state, or local governments.

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<sup>11</sup> Texas Department of Health, Texas Title V Block Grant FY05 Application and FY03 Annual Report, 15 July 2004, page 9 (printed online version).

<sup>12</sup> Health and Human Services Commission, Texas Medicaid in Perspective, Fifth Edition, June 2004, 27 August 2004, <<http://www.hhsc.state.tx.us/Medicaid/reports/PB5/PinkBookTOC.html>>, 2-5 and 2-6.



The array of services for diagnosis and treatment of genetic conditions and birth defects available to individuals with private insurance will vary from one insurance company to another. Some insurers may limit access to specialty care, based on their provider base or cost.

In 1999, TexGene service providers reported that 47% of services paid for by private insurance.<sup>13</sup> By 2001, the portion paid by private payors had dropped to 36%.<sup>14</sup>

## **PUBLIC RESOURCES for HEALTH CARE**

### **Texas Health and Human Services Commission (HHSC)**

As result of H.B. 2292, HHSC provides leadership to and has oversight responsibilities for four state health and human services agencies. In addition, the commission directly administers the Texas Medicaid Program and Children's Health Insurance Program (CHIP).

#### **1. Medicaid**

Medicaid is an entitlement program, jointly funded by the federal and state governments. The federal government funds approximately two-thirds of the cost of Medicaid in Texas. Medicaid pays for basic health care services, including physician services, inpatient services, outpatient services, pharmacy, laboratory and x-ray services, and long-term care services.<sup>15</sup>

The state Medicaid Program covers three primary categories of individuals:

- \* Families and children
  - o Serves pregnant women and children
  - o Eligibility based on income level, age, and pregnancy status
  - o Accounts for 62% of the caseload
  - o Includes Medically Needy Program
  
- \* Case Assistance Recipients
  - o Serves recipients of Temporary Assistance to Needy Families (TANF) and Supplemental Security Income (SSI)
  - o Accounts for 28% of the caseload
  
- \* Aged and Disabled –
  - o Based on income, age, and physical or mental disability

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<sup>13</sup> The University of Texas Health Science Center at San Antonio, Department of Pediatrics and the Texas Department of Health, The Texas State Genetics Plan, 2002, Appendices and Tables, Appendix G: TexGene Data Collection Report from 1999 (no page number).

<sup>14</sup> Texas Department of State Health Services, Research and Public Health Assessment.

<sup>15</sup> Texas Medicaid in Perspective, 1-1.

- May receive services in a nursing facility, intermediate care facility for people with mental retardation, state school, state hospital, or under a Medicaid waiver program
- Accounts for 10% of the caseload

Medicaid services are delivered through two models:

- \* Traditional fee-for services model – no primary care providers or medical home is assigned in this model. Services are delivered by Medicaid enrolled providers and paid at established fee-for service rates. There are some services limitations, such as no more than three prescriptions per month for individuals 21 years of age or older and a 30 day limitation on inpatient stays with a 60-day break between hospitalizations.
- \* Managed care model
  - Primary Care Case Management (PCCM) – participants are assigned a primary care provider (PCP) who serves as their medical home. The PCP must approve services before Medicaid will pay for them and assists with coordination of services. Providers receive the fee-for service reimbursement (non-capitated).
  - Health Maintenance Organization (HMO) – Organizations licensed by the Texas Department of Insurance manage and deliver health care services under a risk-based arrangement. These organizations received a capitation payment for each individual enrolled. HMOs provide each participant with a PCP who must approve services and assist with their coordination. HMOs may offer value-added services to their enrollees.<sup>16</sup>

In traditional Medicaid or in the PCCM model, Medicaid eligible individuals may seek or be referred (by the PCP) to a clinical geneticist who is board eligible or certified by the American Board of Medical Geneticists and enrolled as a provider in the state Medicaid Program. Genetic evaluation services may include a health history, detailed family genetic history, medical genetics physical examination and psychosocial genetic assessment. Other services offered and reimbursed by Medicaid include medical genetic counseling and prenatal counseling, as well as genetic diagnostic and laboratory procedures and genetic ultrasound testing procedures.<sup>17</sup> Other physician and laboratory services may be ordered if necessary to appropriately diagnose and treat; some services may require prior approval. Under an HMO model, the PCP requests prior approval for genetic services. Because of the limited number of clinical geneticists in Texas or because long distance travel is a barrier, a patient may need to see an out-of-network provider. Some of these providers have reported difficulties to the IACGS in getting payment from the HMOs, either having the claim rejected or being paid as little as 7% of the Medicaid fee-for-services reimbursement. Others have reported providing services to HMO patients as charity cases because the cost to appeal rejected claims is higher than the reimbursement or because the patient experienced transportation barriers and was not able to travel to the approved provider of their plan.

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<sup>16</sup> Texas Medicaid in Perspective, 4-1, 4-2, 4-4, 6-2 and 6-6.

<sup>17</sup> Texas Medicaid & Healthcare Partnership, 2004 Texas Medicaid Provider Procedures Manual, 31 October 2004, 21: 2 - 4.

## **2. Children’s Health Insurance Program (CHIP)**

CHIP is designed to provide health care for children whose families who earn too much money to qualify for Medicaid health care but cannot afford to buy private insurance. Federal moneys cover approximately 72% of its cost with the state providing the balance.

To be eligible for CHIP a child must be a Texas resident, a US citizen or legal permanent resident, under the age of 19, otherwise uninsured, and living in a family whose income meets CHIP requirements.

Most families pay monthly premiums and co-payments for services. Services covered include hospital care, surgery, x-rays, physical/speech/occupational therapies prescription drugs, emergency services, transplants, and regular health check-ups and immunizations.<sup>18</sup> During the last legislative session, some services such as vision, dental, and hospice care were eliminated for the package of benefits and a 90-day waiting period between eligibility determination and coverage was instituted, among other changes.<sup>19</sup> Services are offered through private health maintenance organizations.<sup>20</sup> As with Medicaid, clinical geneticists report difficulties in getting reimbursed for services delivered.

## **Department of State Health Services (DSHS)**

The Department of State Health Services is comprised of the mental health community services and the ten state hospitals, from the Texas Department of Mental Health and Mental Retardation, the Texas Department of Health, the Texas Commission on Alcohol and Drug Abuse, and the Texas Health Care Information Council. Individuals needing evaluation and treatment for genetic disorders, birth defects, and conditions resulting from prematurity may be eligible for services provided or funded by DSHS.

## **1. Title V – Genetic Services**

Title V of the Social Security Act provides support to the states to improve the health of all mothers and children consistent with applicable health status goals identified in *Healthy People 2010*. The federal government provides funds to the states in the form of a block grant with state match. The purpose of these funds is to provide and assure that mothers and children (especially those with low income and those with limited access to services) have access to quality maternal and child health services. Among its goals are the reduction in infant mortality and in incidence of preventable disease and handicapping conditions among children and the promotion of the

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<sup>18</sup> [Texas Medicaid in Perspective](#), 2-7 and 8.

<sup>19</sup> CHIP Policy Changes 78th Legislature, Regular Session, 2003, 11 September 2003, 27 August 2004, <[http://www.hhsc.state.tx.us/Consolidation/post78/CHIP\\_Policy\\_Changes.html](http://www.hhsc.state.tx.us/Consolidation/post78/CHIP_Policy_Changes.html) >.

<sup>20</sup> TexCare: Children’s Medicaid and CHIP, 27 August 2004, <http://www.texcarepartnership.com/CHIP-Contractors-Page.htm>.

health of mothers and infants by providing prenatal and postpartum care for low income, at risk women.<sup>21</sup>

In keeping with this federal mandate, the Texas Department of State Health Services contracts with university medical schools, physician groups affiliated with non-profit hospitals, and private physicians to provide clinical genetic services to Title V eligible individuals. To be eligible for Title V genetic services, an individual must meet the following criteria:

- \* A child ages 0 through 21, a female ages 22 to 45 needing preconception and prenatal services, or a male age 22 or over being evaluated as part of an evaluation of a child or pregnant woman, with a family income less than 185% of poverty; and
- \* A Texas resident;
- \* Otherwise uninsured for the same services provided; and
- \* Not eligible for Medicaid or CHIP.

In addition, pregnant women or other potentially fertile women age 45 and over, who would otherwise meet Title V eligibility requirements, are also regarded as potentially eligible for Title V genetic services.<sup>22</sup>

Contracted service providers offer an array of evaluation and counseling services, including physicals, laboratory tests, psychosocial genetic assessments, prenatal counseling (including risks for low birth weight and birth defects), and genetic counseling (including risk assessment for genetic disorders). The genetic services and procedures offered through these contracts are those offered through the Texas Medicaid Program.<sup>23</sup> In FY03, over 8200 new patients were provided genetic services by Title V contractors and a total of 9160 encounters (not including laboratory studies) with new and returning patients were documented.

Due to the lack of genetic services providers, the Department of State Health Services offers genetic services in the El Paso area. Clinics are held two-three days a month in coordination with the PHR9/10 office. During FY03, 190 individuals received genetic services through these clinics.

One of the difficulties experienced by Title V genetic services contractors is that the genetics services provided under Title V are limited to those approved by Medicaid for genetic services. Geneticists often need to order laboratory studies other than those listed in Section 21 of the Medicaid Provider Procedures Manual so that a definitive diagnosis can be obtained. Medicaid will pay for medically necessary studies for Medicaid eligible individuals; however, for a Title V client, studies that may be ordered are limited to the approved genetic services studies. There is no funding under Title V – Genetic Services to provide other diagnostic or treatment services to an individual with a genetic disorder or birth defect. A second difficulty for Title V genetic

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<sup>21</sup> Texas Department of Health, Associateship for Family Health Services, Fiscal Year 2005 Competitive Request for Proposals, Component II, Attachment F; Title V Fee-for-Service, 10 March 2004, F1.

<sup>22</sup> Texas Department of State Health Services, Fiscal Year 2005 Title V Genetic Services Procedures Manual, 1-1.

<sup>23</sup> 2004 Texas Medicaid Provider Procedures Manual, 21:2-4.

services contractors is the limited availability of Title V (approximately \$1.2 million per year). Over half of the Title V contractors reach their contract limit by late spring or very early summer and must either provide charity services to Title V eligible clients for the remainder of the fiscal year or decrease services to this population. With reimbursement issues resulting from Medicaid and CHIP HMO policies, their charity work has continued to increase over the last several years, making it difficult for them to admit new patients when Title V funding runs out toward the end of the fiscal year.

In addition to clinical services, DSHS supports one population-based contractor. The University of North Texas is funded to provide statewide teratogen information services. Teratogens are substances that can harm an unborn fetus; they may result in birth defects, premature delivery, low birth weight, mental retardation, and/or learning and behavioral problems. Examples include alcohol, smoking, prescription and over-the-counter drugs, street drugs, and some environmental agents. The Texas Teratogen Information Services provides up-to-date, authoritative information and counseling regarding the effects of drugs and chemicals on the human embryo and fetus. Services are provided to both the general public and to professional health care providers, with a major emphasis on women of childbearing age. Services are delivered through a toll-free phone line, public lectures and workshops, student education, literature, public service announcements and newspapers submissions. The contractor also sends information to a limited number of service providers such as obstetricians, crisis pregnancy centers, junior high and high school nurses and other school personnel, licensed midwives, and family planning programs. With additional funding, the Teratogen Information Services could conduct more mailings and follow-up to providers, increasing their knowledge and enabling them to pass on information to their patients and students.

## **2. Newborn Screening**

In 1965, the Texas Legislature established the Newborn Screening Program, assigning the Texas Department of Health the authority to implement the program. The Texas Newborn Screening Program, funded by Title V and Medicaid, tests for five disorders which, if not treated very early in life, result in severe mental retardation, illness, or death: phenylketonuria (PKU), galactosemia, congenital adrenal hyperplasia (CAH), congenital hypothyroidism, and sickling hemoglobinopathies (including sickle cell disease). The two inborn errors of metabolism, PKU and galactosemia, are treated by diet. The endocrine disorders, congenital hypothyroidism and CAH, are treated with medication (hormone replacement therapy). Complications resulting from hemoglobinopathies may be prevented through a program of medical supervision and antibiotics administered at an early age.

All babies born in Texas are required to have two panels of screening tests. In FY2003, the births in Texas totaled 381,088 (this is a preliminary number and is subject to change).<sup>24</sup> The Newborn Screening Laboratory received approximately 3,000 babies' specimens daily, totaling 734,946 specimens.<sup>25</sup>

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<sup>24</sup> Bureau of Vital Statistics, 27April 2004.

<sup>25</sup> "Texas Department of Health Laboratory, Biochemistry and Genetics Division, Newborn Screening Program Monthly Report of Laboratory Activities," 2003.

In FY2003, 9,885 babies were identified with presumptive positive screens. 426 of these babies were confirmed with a congenital disorder:

**Table E: Number and Percentage of Newborns and Others Screened, Confirmed and Treated<sup>26</sup>**

Total Births by Occurrence: 381,088\* Reporting Year: FY 03 (Sept 2002 thru Aug 2003)

Types of Screening Tests	Babies Receiving at Least One Screen		Number of Presumptive Positive Screens	Number of Confirmed Cases	Babies Needing Treatment who Received Treatment	
	No.	%			No.	%
<b>Phenylketonuria (Classical)</b>	364,212	95.57	344	7	7	100
<b>Congenital Hypothyroidism (Primary)</b>	364,212	95.57	7087	196	196	100
<b>Galactosemia (Classical)</b>	364,212	95.57	328	7	7	100
<b>Sickle Cell Disease</b>	364,212	95.57	202	202	202	100
<b>Other Screening (Specify) Congenital Adrenal Hyperplasia (Classical)</b>	364,212	95.57	1924	14	14	100

\* The FY2003 occurrence births number is a preliminary number and is subject to change.

During FY2003, NBS also continued the Maternal PKU Project, contacting the parents of all female patients of 15 years of age diagnosed with PKU to alert them to the dangers and appropriate treatment during pregnancy. Before newborn screening for PKU, women with PKU rarely reproduced as they were confined to institutions. After screening and early treatment, women with PKU began having children of their own. The women who had discontinued diet tended to have children with major birth defects called the Maternal PKU Syndrome. The problems included microcephaly, congenital heart defects, low birth weight and mental

<sup>26</sup> Title V Block Grant FY05 Application and FY03 Annual Report, 6-15.

retardation. There are women with PKU who are not on diet and at high risk for delivering infants with the Maternal PKU Syndrome. The difficulty is identifying these women and referring them to a PKU clinic for counseling. NBS identified 33 adolescents aged 15 years and mailed packets of information on the avoidable dangers of PKU and pregnancy including *The Young Woman with PKU, Lets Focus on PKU and Pregnancy for Adolescents with PKU ages 11-15 years old* and *The Young Woman with Mild Hyperphe*.<sup>27</sup>

### **3. Services Program for Children with Special Health Care Needs**

The Services Program for Children with Special Health Care Needs (CSHCN), now part of the Purchased Health Services Unit at the Texas Department of State Health Services, offers an array of services to children with extraordinary medical needs, disabilities, and chronic health conditions, including health care benefits, family support services, and related services not covered by Medicaid, CHIP, private insurance, or other “third party payor.” In addition, CSHCN contracts with agencies throughout the state to provide clinical and support services to children with special health care needs and their families. CSHCN also assists children and their families by supporting case management at TDH regional offices throughout Texas.<sup>28</sup>

To qualify for CSHCN health care benefits, individuals must meet the following criteria:

- \* Is younger than 21 years of age with a chronic physical or developmental condition
  - o That will last or is expected to last for at least 12 months; and
  - o That results or, if not treated, may result in limits to one or more major life activities; and
  - o That requires health and related services of a type or amount beyond those required by children generally; and
  - o That must have a physical (body, bodily tissue or organ) manifestation; and
  - o That may exist with accompanying developmental, mental, behavioral, or emotional conditions; but
  - o That is not solely a delay in intellectual development or solely a mental, behavioral, and/or emotional condition; or
  
- \* Is of any age with cystic fibrosis, and
  
- \* Is a Texas resident and has a family income of 200% of poverty or less.

CSHCN health benefits cover services such as diagnosis and evaluation, ambulance service, ambulatory surgery, primary and preventative care, speech and hearing services, vision care, dental care, mental health services, inpatient rehabilitation, specialty care, equipment & medical supplies, home health nursing, hospice care, hospital care, physical and occupational therapy,

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<sup>27</sup> Narrative Sections, 39.

<sup>28</sup> Children with Special Health Care Needs, 30 July 2004, 26 August 2004, < <http://www.tdh.state.tx.us/cshcn/>>.

pharmacy, orthotics and prosthetics, outpatient renal dialysis, family supports, and meals, lodging, and transportation when needed to obtain medical care.<sup>29</sup>

**Table F: CSHCN Program Health Care Benefits  
Active Clients for FY02 and FY03**

Fiscal Year	Active clients	Active clients with paid claims	Active clients with selected genetic disorders or congenital anomalies	Active clients with selected genetic disorders or congenital anomalies and paid claims
FY02	5,287	2,553	2073	936
FY03	2,867	1,653	2012	594

As illustrated in **Table F**, 5,287 children were actively enrolled in CSHCN in FY02; claims were paid for 2,553 of these individuals. Of those in active status, 2,073 had selected genetic disorders or congenital anomalies, including chromosomal anomalies. Claims were paid for the 936 individuals with these disorders at a cost of \$6,893,490 or approximately 40% of the total paid by CSHCN for FY02 claims. Two hereditary or congenital disorders, cystic fibrosis and hemophilia, accounted for nearly \$4 million in claims paid in FY02.

In FY03, a total of 2,867 were actively enrolled in the CSHCN health care benefits; of this total, 2,012 had selected genetics disorders or congenital anomalies. Of the 1,653 individuals with paid claims for services, 594 of these had selected genetic disorders or chromosomal anomalies. Claims paid for these 594 individuals totaled \$6,420,458 or 44% of total claims. Again, two of most costly conditions were cystic fibrosis and hemophilia, with payments to providers of nearly \$4.5 million.

In order to control costs, the Service Program of CSHCN utilizes a waiting list. When funding allows, individuals are moved from the waiting list to active services based on medical urgency and original date of the clients' latest uninterrupted sequence of eligibility. As of August 31, 2002, 1,288 individuals were on the waiting list and at the end of FY03, 1,301 were waiting for services. During FY03, approximately 150 individuals were removed from the waiting list and provided services. During FY04, 1344 were moved to active status from the waiting list.

**Table G: Waiting List Clients for CSHCN Program Health Care Benefits, FY02-03**

Fiscal Year	Waiting list clients as of the last day of the fiscal year (August 31)	Waiting list clients with genetic disorders or congenital anomalies moved to active status during fiscal year	Waiting list clients as of the last day of the fiscal year with genetic disorders or congenital anomalies
FY02	1288	0	491
FY03	1301	26	465

<sup>29</sup> 7 June 2004, 26 August 2004, < <http://www.tdh.state.tx.us/cshcn/benefits.htm> >.



While the program health care benefits for CSHCN are quite comprehensive, children with special health care needs and individuals with cystic fibrosis who are not eligible for Medicaid or CHIP may not be able to obtain health care services (if a waiting list is in effect) when they are needed, as noted in **Table G**.<sup>30</sup>

#### **4. Newborn Hearing Screening**

Between 1996 and 1999, the Audiology Services Program at the Texas Department of Health sponsored a pilot project called the “Sounds of Texas. This public-private partnership implemented newborn hearing screening for 80,000 newborns at 30 Texas hospitals. “Sounds of Texas” became a national model and provided the impetus for the passage of H.B. 714, mandating newborn hearing screening at Texas birth facilities and designating TDH as the oversight agency. This universal screening program is funded by Medicaid, Title V, and CSHCN.

The driving force behind the initial pilot project and the resulting mandated program was the need to screen babies for hearing loss at an early age. Historically, children with hearing impairment and deafness in Texas were not being identified until approximately 56 months of age. Recognizing a hearing loss and intervening during the baby’s first six months of life is critical to the development of the child’s language and learning abilities, helping such a child achieve his/her optimal academic, communication, and social functioning.<sup>31</sup>

In addition to preventing later language and learning problems, newborn hearing screening may, in some cases, save the infant’s and other family members’ lives. Texas newborns who fail their hearing screen have a 25-50% increased risk for Sudden Infant Death Syndrome (SIDS) when compared to those who pass their hearing screen at birth. An infant with Jervell and Lange-Neilsen Syndrome has usually inherited one of two gene mutations from both parents. Either of these mutations cause severe potassium channel malfunction in the heart and cochlea. It is very important that infant with such a mutation to receive immediate therapeutic intervention as the first symptom of heart malfunction is often cardiac arrest or sudden death and that family members be tested and treated if they possess the mutation. (Malfunction in the cochlea leads to profound congenital hearing loss.)<sup>32</sup>

The state’s universal newborn hearing screening, now known as the Texas Early Hearing Detection and Intervention (TEHDI) Program, oversees implementation at 196 birth facilities that screen over 300,000 babies each year for hearing loss. In comparison to the national average of 86%, Texas is screening 98.6% of newborns. Four (4) to 5% of those screened are referred

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<sup>30</sup> FY2002 & FY2003 CSHCN Served and Paid Amounts for Selected Diagnoses Report and FY2002 & FY2003 CSHCN Client Enrollment for Selected Diagnoses Report, 13 August 2004.

<sup>31</sup> “Sometimes Pilot Projects Work”, MONITOR, Vol. 9-2, 6-7.

<sup>32</sup> John Walker, M.D., Universal New born Screening: Saving Money, Saving Lives, (Austin: Armstrong Printing, 2003), 21-28.

for re-screening. Three (3) out of 1,000 are typically diagnosed with permanent hearing loss, or between 800-1000 (based on the birth rate) per year in Texas. Texas continues to receive recognition for its NBHS program and has received a rating of Excellent by the National Campaign for Hearing Health (NCHH) for the last two years.<sup>33</sup>

## **Department of Assistive and Rehabilitation Services (DARS)**

H.B.2292 transferred the duties of the Texas Interagency Council on Early Childhood Intervention, Texas Rehabilitation Commission, Texas Commission for the Blind, and the Texas Commission for the Deaf and Hard of Hearing to the new Department of Assistive and Rehabilitation Services. Individuals with certain genetics disorders or birth defects may be eligible for services provided by DAR's ECI, Rehabilitation Services, Deaf and Hard of Hearing Services, or Blind Services.

### **1. Early Childhood Intervention**

The Division of Early Childhood Intervention (ECI), now part of the Department of Assistive and Rehabilitative Services (DARS), is a statewide program for families with children, birth to three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. Services are provided by a variety of local agencies and organizations across Texas.

Services are funded by state and federal dollars through the Individuals with Disabilities Education Act (IDEA, PL 105-17). ECI provides evaluations to determine eligibility and need for services, at no cost to families.<sup>34</sup> Children are eligible for services if they meet one or more of the following criteria:

- \* A delay in one or more areas of development;
- \* Atypical development; and/or
- \* A medically diagnosed condition with a high probability for developmental delay.<sup>35</sup>

Families and professionals work as a team to plan appropriate services based on the unique needs of the child and family. As of January 1, 2004, a sliding fee scale was put in place for some ECI services. Most services are provided in the child and family's natural environment, such as at home or a childcare center.<sup>36</sup> Services include the following:

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<sup>33</sup> MONITOR, 6-7.

<sup>34</sup> Department of Assistive and Rehabilitation Services, Division for Early Childhood Intervention Services, 31 August 2004, <[http://www.eci.state.tx.us/about\\_eci/index.html](http://www.eci.state.tx.us/about_eci/index.html)>.

<sup>35</sup> Early Childhood Intervention: Help Starts Here, 2003 ECI Biennial Report, (Texas Interagency Council on Early Childhood Intervention), 9 .

<sup>36</sup> <[http://www.eci.state.tx.us/about\\_eci/index.html](http://www.eci.state.tx.us/about_eci/index.html)>.

- \* Assistive Technology: Services & Devices
- \* Audiology
- \* Developmental Services
- \* Early Identification, Screening & Assessment
- \* Family Counseling
- \* Family Education
- \* Medical Services (diagnostic or evaluation services used to determine eligibility)
- \* Nursing Services
- \* Nutrition Services
- \* Occupational Therapy
- \* Physical Therapy
- \* Psychological Services
- \* Service Coordination
- \* Social Work Services
- \* Speech-Language Therapy
- \* Vision Services<sup>37</sup>

**Table H: Number of Children Served by ECI and Average Cost Per Child, FY02-03<sup>38</sup>**

Year	Number Served – Comprehensive Services	Average Cost Per Child for Comprehensive Services	Additional Children Served with Follow Along Services
FY02	37,932	\$2,135	4,845
FY03	42,458	\$2,218	5,344

**Table H** indicates that ECI provided services to a total of 42,777 children in FY02 and 47,802 children in FY03. Services are delivered through contractors such as community and state mental health and mental retardation centers, regional education services center, local independent school district, private nonprofit organizations, university medical school, and county hospital districts. Most referrals to services come from medical and health service providers or from parents, family members or friends.<sup>39</sup>

## 2. Rehabilitation Services

- \* The Vocational Rehabilitation Program helps people who have physical or mental disabilities prepare for, find or keep employment. Disabilities covered include mental illness, hearing impairment, impaired functioning of arms or legs, back injury, alcoholism

<sup>37</sup> “Early Childhood Intervention: Help Starts Here, 2003 ECI Biennial Report”, 9.

<sup>38</sup> Data and Analysis, 2 September 2004.

<sup>39</sup> “ECI Fact Sheet”, 2002, 2 September 2004.

or drug addiction, mental retardation, learning disability, traumatic brain injury, or other physical or mental disabilities that prevent the person from finding and keeping a job.<sup>40</sup>

- \* Independent Living Services assist people with disabilities confront barriers that severely limit their choices for quality of life. Services provided include counseling and guidance, training and tutorial services; adult basic education; rehabilitation facility training; telecommunications, sensory and other technological aids for people who are deaf; vehicle modification; assistive devices such as artificial limbs, braces, wheelchairs and hearing aids to stabilize or improve function; and other services as needed to achieve independent living objectives, such as transportation, interpreter services and maintenance.<sup>41</sup>
- \* Comprehensive Rehabilitation Services provides intensive rehabilitation to persons with a traumatic spinal cord injury or traumatic brain injury so that they can re-enter the community and live as independently as possible. Specific services are as follows:
  - Inpatient Comprehensive Medical Rehabilitation – Services includes a variety of intensive therapies, medical care and other services to help individuals live as independently as possible, which are provided on an inpatient basis at an accredited rehabilitation hospital.
  - Outpatient Services - Rehabilitation services for occupational therapy, physical therapy, speech therapy and cognitive therapy offered on an outpatient basis.
  - Post-Acute Traumatic Brain Injury Services - Services that help an individual deal with injury-related cognitive difficulties such as memory loss and/or inappropriate behaviors.<sup>42</sup>

### 3. Deaf and Hard of Hearing Services

Among services provided for individuals who are deaf or hard of hearing are the following:

- \* Information and referral
- \* Communication access services such as sign language or oral interpreters, and real-time captioning so that individuals can receive essential services and participate in the community
- \* Training, information, referral, and adaptive equipment demonstrations for individuals who are hard of hearing, late-deafened, or oral deaf<sup>43</sup>
- \* Financial assistance to purchase specialized equipment or services for access to the telephone systems<sup>44</sup>

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<sup>40</sup> Vocational Rehabilitation, 31 August 2004 <<http://www.dars.state.tx.us/services/VocatRehab.shtml>>.

<sup>41</sup> Independent Living Services and Centers, 31 August 2002, <<http://www.dars.state.tx.us/services/LivingServices.shtml>>.

<sup>42</sup> Comprehensive Rehabilitation Services, 31 August 2004, <<http://www.dars.state.tx.us/services/ComprehensiveRehab.shtml>>.

<sup>43</sup> Deaf and Hard of Hearing, 31 August 2004, <<http://www.dars.state.ts.us/services/deaf.shtml>>.

#### 4. Services for the Blind

- \* Blindness Education, Screening, and Treatment (BEST) Program assists uninsured adult Texas residents with the payment for urgently needed eye-medical treatment. The intent of the BEST Program is to prevent blindness, and the program serves qualified individuals with diabetic retinopathy, glaucoma, detached retina, or other eye disease determined to be an urgent medical necessity by the applicant's eye doctor and a state medical consultant.<sup>45</sup>
- \* Blind Children's Vocational Discovery and Development Program helps children with visual impairment between the ages of birth and 10 years and provides support to their families. Services include educational support, help coordinating medical services, information on resource, and assistance to children in developing confidence and competencies.<sup>46</sup>
- \* Vocational Rehabilitation for the Blind or Visually Impaired assists individuals who have a visual impairment that is a barrier to employment, who can benefit from vocational rehabilitation services in terms of an employment outcome and need vocational rehabilitation services to prepare for, get, or retain gainful employment. Services include evaluation; rehabilitation teaching; counseling, guidance, and referral; orientation and mobility services; physical and mental restoration; reader services; transportation; technological aids and devices; vocational training; and employment assistance.
  - o The Transition Program is for students 10 and older who are making the change from school to work, or from secondary school to college or vocational school and is designed to help the young adult who is blind or visually impaired gain the skills needed to be independent and successful for life.<sup>47</sup>
- \* Criss Cole Rehabilitation Center offers intensive vocational and independent living training to Texans who are blind. Located in Austin, the center provides intensive, comprehensive training in areas such as orientation and mobility, Braille, communication skills, home and personal management, technology and career guidance. A special training program is offered each summer to prepare consumers for post-secondary academic or vocational training.<sup>48</sup>

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<sup>44</sup> Specialized Telecommunications Assistance Program, 31 August 2004, <<http://www.dars.state.tx.us/services/SpecializedTelecomm.html> >.

<sup>45</sup> Blindness Education, Screening, and Treatment, 25 August 2004, <<http://www.dars.state.tx.us/services/BEST.shtml> >.

<sup>46</sup> Blind Children's Vocational Discovery and Development, 25 August 2004, <<http://www.dars.state.tx.us/services/BlindChildren.shtml> >.

<sup>47</sup> Vocational Rehabilitation for the Blind and Visually Impaired, 25 August 2004, <<http://www.dars.state.tx.us/services/VocationalRehab.shtml>>.

<sup>48</sup> Criss Cole Rehabilitation Center, 25 August 2004, <<http://www.dars.state.tx.us/services/CrissCole.shtml> >.

- \* Independent Living Rehabilitation Program helps people with vision problems gain the skills and confidence to live independently. Services include eye examinations; information and referral; counseling; orientation and mobility training; recreation and socialization; and independent living skills training. <sup>49</sup>

## **Department of Aging and Disability Services (DADS)**

The Department of Aging and Disability Services assumed responsibility for the 13 state school programs from Texas Department of Mental Health and Mental Retardation, community care nursing home services from the Department of Human Services, and the aging services programs from the Texas Department of Aging. Individuals with mental retardation and children with certain disabilities may be eligible for services from DADS.

### **1. Mental Retardation Services**

Services for individuals with mental retardation may be accessed through a community mental health/mental retardation center, at intermediate care facilities (ICF/MR), and a state-owned facility, or through a waiver program. Services available through local community MHMR centers may include service coordination, respite, vocational training and support, habilitation services, residential services, and In Home and Family Support Services, which enables the individual/family to select needed service from a established array up to \$3,600/yr. ICF/MRs and state facilities provide 24-hour care. Waiver services provide services and supports so that the individual can live on their own, with their family, or in another home-like setting in the community. Over 3600 individuals are enrolled in Home and Community-Based Services (HSC) or in Home and Community-Based Services–OBRA (HCS-O). <sup>50</sup>Both the waivers services and In Home and Family Support maintain waiting lists.

### **2. Children’s Services**

Services for children with disabilities that will enable them to remain in the own homes and communities include the following: 1) Community Living Assistance and Support Services, 2) Consolidated Waiver Program (Bexar County only), 3) Day Activity and Health Services, 4) In-home and Family Support, 5) Medically Dependent Children Program, and 6) Primary Home Care. In addition, permanency planning is available; this process is intended to help every child find a permanent community living arrangement, either with the child’s own family or with a surrogate family. <sup>51</sup>

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<sup>49</sup> Independent Living Rehabilitation Program, 25 August 2004, <<http://www.dars.state.tx.us/services/LivingRehab.shtml>>.

<sup>50</sup> Texas Department of Aging and Disability Services, “How DADS Can Help Persons with Mental Retardation”, 30 August 2004, 31 August 2004 <[http://www.dads.state.tx.us/services/dads\\_help/mental\\_retardation/index.html](http://www.dads.state.tx.us/services/dads_help/mental_retardation/index.html)>.

<sup>51</sup> “How DADS Can Help Children” 30 August 2004, 31 August 2004, <[http://dads.state.tx.us/services/dads\\_help/children.html](http://dads.state.tx.us/services/dads_help/children.html)>.

As documented by this section, the array of services provided by the state is comprehensive; however, the services are not universal. Many have stringent income and other eligibility requirements. In addition, those who do qualify must often wait for service provision due to funding limitations.

## **IV. Gaps and Barriers**

Past Resource Allocation Plans relied heavily on the work of TexGene, a collaborative group of service provider with funding from the federal government. Based on its surveys and data gathering activities, TexGene was able to develop recommendations and propose ideas and plans for the delivery of genetic services. Some IAC members also participated in the work of TexGene and supported coordination between the two groups. As a result, the IACGS was able to incorporate TexGene's data, analyses, and recommendations into its biannual plans. The group's last survey was conducted in 2001 due to loss of federal funding. Without a resource for funding for data collection, the IACGS depended on data from the 2001 survey and from recent needs assessments conducted by applicants for the Request for Proposals for Title V Genetic Services.

For the Fiscal Year 2005, the former Texas Department of Health issued a competitive Request for Proposals for clinical genetic services and a teratogen information service. As part of the requirements for submitting an application, prospective applicants conducted a needs assessment for their service area. These applicants provided documentation of their experience in public health assessment, general information about their service area, description of their target population (including demographic, socioeconomic, health status, behavioral data, and opinion data), and a description of the gaps in resources and barriers to improving health status. The applicants also identified the top genetic health priorities for their service area, which will be discussed in the next section of this plan.<sup>52</sup>

While it is not as inclusive of genetic services providers as previous data collection processes, the IACGS chose to utilize information from the Title V applicants' needs assessment in this Resource Allocation Plan. These applicants for Title V funding were self-selected and do not necessarily represent the needs and priorities that might be determined by a broader study of the state. However, many of the needs identified were common to all areas of the state represented by this group of providers and they are congruent with findings from previous surveys by TexGene.

### **Gaps in Services**

Almost universally, the genetic service providers identified gaps related to education and to service capacity. With regard to education, many identified the need for more education directed to health care providers. One provider noted the lack of education for PCPs regarding genetics. Despite a lack of cure for many conditions, others pointed out that needed treatment can address and reduce some of the physical and emotional complications. Providers noted the overall lack of information available to patients, including information regarding healthcare availability. A need for education of families related to recurrence risks in children and future generations was also identified.

With regard to service capacity, providers noted the small number of clinical geneticists in Texas and the lack of such qualified physicians specifically in rural areas. Also identified were the lack

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<sup>52</sup> Texas Department of Health, Associateship for Family Health Services, Fiscal Year 2005 Competitive Request for Proposals, F4.



of funding available for genetic services, lack of resources for diagnostic testing, and lack of access to comprehensive genetic services. As a result, many patients have a long waiting period for appointments.

### **Barriers to Service Delivery**

The service providers also identified barriers related to patient access to care. A universally identified barrier to services was transportation. Related barriers were inconvenient locations and hours of operation. Another barrier noted by many of the providers was that of language, including lack of Spanish-speaking personnel and of Spanish language informational materials. A final barrier identified was the immigration status of many patients.

## **V. Priorities**

Based on the needs assessment results, applicants for Title V genetic services funding were asked to identify genetic priorities for their service areas. Their responses were quite comprehensive and involved education of healthcare providers and patients, services and education prior to conception, prenatal care, development of rural capacity, and expansion of services and funding for these services.

### **Education, services prior to conception**

The results of the needs assessment conducted by the Title V applicant service providers indicated a need for education for professionals. These services providers called for education of healthcare providers regarding the importance of genetic services and how to refer patients and their families to genetic service. They also advocated educating of pediatric caregivers and educators regarding the availability of genetic services and especially educating school personnel regarding children/families with genetic conditions.

The services providers also supported education for patients and their families, particularly improved availability and dissemination of health related information. Specific areas identified were 1) better availability of educational information on prenatal drug exposures, 2) education regarding prevention of birth defects, 3) education regarding the importance of prenatal care and appropriate testing, 4) education of the population regarding the importance of medical care, 5) education of patients and families regarding recurrence risks, and 6) education of families regarding the importance of follow-up care for their children. Finally, the services providers supported pre-conceptual education and folate supplementation.

### **Prenatal care**

Service providers advocated for early prenatal care and education, an increase in the number of women receiving early prenatal care and an increase in the number of women receiving adequate prenatal care. Specific priority areas included a reduction in the number of women having babies with birth defects, a reduction in pre-term and low birthweight babies, and a reduction in infant mortality rates. Among strategies identified to support these priorities were prenatal education to prevent birth defects, adequate resources to provide prenatal genetic counseling for women at an increased risk of having a child with a birth defect, better education regarding screening testing for birth defects during pregnancy, implementation of expanded first trimester screening for birth defects, and risk assessment for pregnancies and an accompanying provision of early intervention.

### **Capacity**

A priority identified with regard to equitable distribution of services throughout the state was the need to be able to offer genetic services in rural areas. One strategy presented was to develop and utilize telemedicine in order to expand the availability of genetic services in these areas. In addition, there is a need to specifically target rural areas in education efforts (see above section).

Service providers also recommended expanding the settings for medical students to acquire genetic services experience and knowledge in the care of patients.

## **Funding**

While many service providers identified overall increased funding for genetic services as a priority, they also targeted special situations. One of these was the provision of funding assistance for those who are unemployed or those whose employers do not provide health care coverage and who cannot afford care without outside assistance. Another priority area was having the resources to provide patients with metabolism disorders with adequate accesses to care and treatment. Finally, the resources needed to provide adequate laboratory evaluation of an individual at risk for a genetic condition was identified.

## **Services**

Service providers offered a number of priorities related to service delivery. More generally, they called for improved access to quality health care and more equitable distribution of medical services within the community, genetic or otherwise. They also advocated for a decrease in the burden of genetic diseases carried by the local communities and an increased awareness of improvements in genetic medicine designed to improve public health.

More specific to genetic clinical service delivery were the following priorities: 1) expanded newborn screening, 2) availability of comprehensive testing batteries for individuals with birth defects, 3) access to genetic services in a timely manner, 4) expanded services for those with metabolic health care needs, 5) provision of genetic health services in a way that is meaningful to the consumer despite potential barriers, 5) provision of comprehensive genetic services, and 6) referrals for other required services. Finally, in order to address some of the access problems, service provider noted a need for local sophisticated diagnostic services and full-time service availability.

## VI. Recommendations

Data provided by the Bureau of Vital Statistics, the Birth Defects Registry, and the genetic services providers through TexGene surveys document the growing number of births in Texas and the resulting need for preconception, evaluation, and counseling services. IACGS members report the financial pressures placed on genetic service providers by the decreases or limitations in funding or reimbursement. Lack of third party resources (private or public) for 26% of Texans limit their access to services. Those with private insurance may also have limited access to specialized services through their insurer's provider base, policies, or exclusion periods. Public services are available from multiple resources; some of these services are quite comprehensive but most have stringent eligibility requirements and some have long waiting lists. As the need for services continues to grow, the current environment lacks resources to adequately address these needs. While the IACGS, state agencies, and the service provider system can undertake some strategies to strengthen and improve services, many recommendations require additional resources. Investment in prevention and early intervention will save both public and private dollars and enhance the quality of life for our citizens at risk or affected by genetic disorders, birth defects and prematurity.

The Interagency Council for Genetic Services respectfully submits the following recommendations for consideration:

1. Revision of Section 5, Chapter 134, Human Resources Code. A revision of the code is needed to reflect the new health and human services agencies with IACGS representation and to enable the IACGS to continue data collection:

- \* The IACGS recommends that the Department of State Health Services and the Department of Aging and Disabilities replace the Texas Department of Health and the Texas Department of Mental Health and Mental Retardation.
- \* The IACGS requests provision of an ongoing source of funding for data collection (which does not take away current service dollars).

2. Development of strategies for increasing genetic services to rural and underserved (including areas in large population centers) areas of the state. Difficulties include the limited of genetic services providers overall as well as the general lack of all types of health care services in various areas of the state. Another barrier is patient transportation. Many areas of the state do not have public transit systems. Even in areas with extensive public transportation, a patient may spend an entire day traveling to and from an appointment (with bus transfers and waiting time often in the heat, cold or rain). The hardship this presents to an individual who is pregnant and/or who must bring their children due to lack of childcare is enormous. To address the issue of unserved or underserved areas of the state, the IACGS proposes several specific strategies:

- \* Development of telemedicine in underserved areas. Resources required may include appropriate facilities, new equipment, and technical assistance in identification of potential partners and in contract negotiation. To ensure success, coordination of appointments for patients will be required as well as patient education regarding telemedicine.
- \* Identification and utilization of successful models that educate medical students and local health care providers and allow for their participation in genetic services clinics.

- \* Licensure of genetic counselors and the development of supports to supplement the work of clinical geneticists in unserved or underserved areas.

3. Coordinated and expanded education. A number of constituencies could benefit from education regarding prematurity, birth defects, and genetic disorders. Women of childbearing age and pregnant mothers and their partners need education regarding the dangers of teratogens, the potential impact of lifestyle decisions on their future children, family risks for genetic disorders, and the importance of early prenatal care and testing. Childcare workers and school personnel need education on the availability of genetic services and needs of children with genetic disorders. Health care providers need education regarding genetic services and on how to refer individuals/families to genetic service providers. Several strategies are proposed:

- \* Increased education of obstetrical providers, family planning service providers, school nurses, and primary care providers regarding Texas Teratogen Information Services.
- \* Development or purchase and distribution of relevant educational materials.
- \* Establishment of an ad hoc group sponsored by the IACGS to assess and address educational needs relating to genetics for medical and other health care students and to provide recommendations to medical school curriculum committees.
- \* Development of strategies by the IACGS to increase the impact of their respective entities' educational initiatives.

4. Strategies to address language and cultural barriers.

- \* Development of recruitment strategies to attract diversity in genetics training programs.
- \* Provision of information and training in cultural competency for practitioners, including but not limited to the following:
  - o Development and distribution of appropriate counseling tools and aids for special populations.
  - o Training in understanding the impact of family and cultural beliefs of patients/families on acceptance of genetic counseling and in crafting appropriate counseling techniques to address the patient's beliefs and practices.

5. Legislative or executive assistance in addressing the trend to transfer the costs of providing genetic services to the clinical geneticists or their employer. With regard to Medicaid and CHIP, it is recommended that contract provisions for HMOs be written to require prompt and sufficient payment for appropriate claims and that the provisions be enforced.

6. Restoration of Title V funding to at least FY97 levels. In FY97, the former Texas Department of Health awarded \$1,834,134 in Title V funds to contractors; this included over \$1.3 million in direct patient services and \$498,276 in education and population-based services. Currently, only \$1.2 million is available for contracting. The restoration of Title V funding will support implementation of many of the above recommendations, allow for expanded prenatal care, and increase the overall number of individuals and families served, thereby addressing many of the needs and priorities identified by genetic services providers and by the IACGS.