**Interagency Council for Genetic Services**
**Resource Allocation Plan**
**2004-2005**

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, accounting for more than 20% of all infant deaths. (Sever L, Lynberg MC, Edmonds LD. The impact of congenital malformations on public health. Teratology 1993;48 (No.6):547-549)

- In the United State, birth defects account for $8 billion each year in direct and indirect costs. (Texas Birth Defects Research Center, July 28, 1999)

- Of about 120,000 U.S. babies born each year with a birth defect, 8,000 die during their first year of life. (Sever L, Lynberg MC, Edmonds LD. The impact of congenital malformations on public health. Teratology 1993;48 (No.6):547-549)

- In addition, birth defects are the fifth-leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. (Sever L, Lynberg MC, Edmonds LD. The impact of congenital malformations on public health. Teratology 1993;48 (No.6):547-549)

- Because the causes of about 70% of all birth defects are unknown, the public continues to be anxious about whether environmental pollutants cause birth defects, developmental disabilities, or other adverse reproductive outcomes. (Stevenson R, Hall JG, Goodman R: Human Malformations and Associated Anomalies. Oxford University Press, Oxford, 1993)

- Birth defects are the seventh leading cause of premature death among all Texans (Texas Vital Statistics 2000 Annual Report)

?? Congenital abnormalities directly cause 24% of all infant deaths in Texas and Sudden Infant Death Syndrome (SIDS) claims another 11% (Texas Vital Statistics 2000 Annual Report)

?? In Texas, birth defects are the fourth leading cause of death for male children aged 1-14 and third leading cause of death for females in that age group. (Texas Vital Statistics 2000 Annual Report)

?? In Texas, there were 9% of births that reported an abnormal condition of the newborn and a 0.9% of births that reported congenital anomalies. (Texas Vital Statistics 2000 Annual Report)

## II. Genetic Services in Texas: Data and Analysis

Table A summarizes genetic services provided to infants by public health region. As can be seen, most of the public health regions showed a decrease in the number of services provided to infants in 2000. However, public health regions 5, 6, 8, and 10 showed an increase in the number of services provided to infants from 1999 to 2000. When data are compared between 1994 and 2000, all but three public health regions showed a decrease in services.

**Table A Genetic Services to Infants by Region, 1994-2000**

| Region | # Births 2000 | 3% of Live Births | Infants Served in 1994 | Infants Served in 1999 | Infants Served in 2000 | % Infants Served in 1999 | % Infants Served in 2000 | % Change 94-00 | % Change 99-00 |
|---|---|---|---|---|---|---|---|---|---|
| 1 | 12,261 | 368 | 114 | 66 | 51 | 0.54 | 0.42 | -56.2 | -22.0 |
| 2 | 7,405 | 222 | 54 | 66 | 21 | 0.88 | 0.26 | -65.3 | -70.5 |
| 3 | 96,682 | 2,900 | 183 | 528 | 225 | 0.57 | 0.24 | -4.3 | -57.9 |
| 4 | 14,082 | 422 | 33 | 36 | 21 | 0.26 | 0.16 | -38.5 | -38.5 |
| 5 | 10,254 | 308 | 51 | 51 | 63 | 0.52 | 0.64 | +28.0 | +23.1 |
| 6 | 85,231 | 2,557 | 435 | 453 | 567 | 0.55 | 0.69 | +21.1 | +25.5 |
| 7 | 38,696 | 1,161 | 192 | 96 | 18 | 0.27 | 0.05 | -91.9 | -81.5 |
| 8 | 35,280 | 1,058 | 240 | 264 | 312 | 0.76 | 0.9 | +25.0 | +18.4 |
| 9 | 8,225 | 247 | 69 | 48 | 45 | 0.58 | 0.55 | -32.9 | -5.2 |
| 10 | 14,664 | 440 | 96 | 33 | 48 | 0.23 | 0.34 | -42.4 | +47.8 |
| 11 | 40,545 | 1,216 | 339 | 399 | 312 | 1.04 | 0.81 | -12.9 | -22.1 |
| Unknown Region | | | 123 | 87 | 93 | | | | |
| **Total** | 363,325 | 10,900 | 1,929 | 2,127 | 1,776 | 0.61 | 0.51 | -16.4 | -15.0 |

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 underserved.

## Table B Genetic Services to Infants

| | | 1999 Live Births | % Served in 1999 |
|---|---|---|---|
| | | | |
| Region 1 | Lubbock | 3,784 | 0.81 |
| | | | |
| Region 3 | Collin | 8,034 | 0.53 |
| | Dallas | 40,677 | 0.22 |
| | Denton | 6,792 | 0.85 |
| | Tarrant | 24,427 | 0.94 |
| | | | |
| Region 6 | Brazoria | 3,853 | 0.92 |
| | Ft. Bend | 4,873 | 0.33 |
| | Galveston | 3,706 | 0.98 |
| | Harris | 61,067 | 0.56 |
| | Montgomery | 4,393 | 0.22 |
| | | | |
| Region 7 | Bell | 5,002 | 0.06 |
| | Travis | 13,270 | 0.29 |
| | | | |
| Region 8 | Bexar | 23,597 | 0.78 |
| | | | |
| Region 10 | El Paso | 13,960 | 0.23 |
| | | | |
| Region 11 | Cameron | 8,021 | 1.29 |
| | Hidalgo | 14,087 | 1.03 |
| | Nueces | 5,261 | 1.48 |
| | Webb | 5,448 | 0.56 |

Statewide, 4.1% of all women who had live births in 2000 received prenatal genetic services at a genetics center, representing a slight decrease over 1999. 19.0% of women aged 35 or above who had live births in 2000 received prenatal genetic services at a center, again showing a small decrease over 1999. We estimate that a minimum of 7%[1] of pregnant women should receive genetic services. 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. In 1999, Bexar, Cameron, Galveston, Tarrant and Travis counties exceeded the goal of 7%. However, in 2000, only three counties, Brazoria, Cameron, and Galveston exceeded the statewide average. Many rural areas appear to be under served.

[1] 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.

## Table C Prenatal Genetic Services

| REGION | 1999 | 2000 |
|---|---|---|
| | | |
| Lubbock | 2.26% | 1.01% |
| Potter | 0% | 0.27% |
| | | |
| Collin | 1.93% | 1.28% |
| Dallas | 1.57% | 1.41% |
| Denton | 2.02% | 2.58% |
| Tarrant | **7.0%** | 6.32% |
| | | |
| Brazoria | 5.25% | **7.0%** |
| Ft. Bend | 4.91% | 6.58% |
| Galveston | **8.86%** | **9.15%** |
| Harris | 6.3% | 6.12% |
| Montgomery | 2.64% | 2.83% |
| | | |
| Bell | 0.23% | 0.56% |
| Travis | **9.37%** | 5.68% |
| | | |
| Bexar | **7.27%** | 6.93% |
| | | |
| El Paso | 0% | 0.02% |
| | | |
| Cameron | **7.90%** | **7.54%** |
| Hidalgo | 5.76% | 5.06% |
| Nueces | 6.88% | 3.60% |
| Webb | 3.54% | 4.26% |

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

Table D indicates that statewide, among women who had Medicaid paid deliveries in 1999, 4.4% received genetic services at a reporting genetics center. Among women aged 35 or above whose deliveries were paid by Medicaid in 1999, 29% received genetic services at a genetics center. The percentages of Medicaid eligible pregnant women served in 1999 represents an increase over all the years.

## Table D
## Utilization of Prenatal Genetic Services by Medicaid Funded Women in Texas Public Health Regions and Counties with greater than 3500 live births

| Region/ County | Medicaid Paid Deliveries 1998 | % Medicaid Women Served 1994 | % Medicaid Women Served 1997, est. | % Medicaid Women Served 1998, est. | % Medicaid Women Served 1999, est. | % Medicaid AMA Women Served 1994 | % Medicaid AMA Women Served 1997, est. | % Medicaid AMA Women Served 1998, est. | % Medicaid AMA Women Served 1999, est. |
|---|---|---|---|---|---|---|---|---|---|
| **Region 1** | 5,594 | 5.14 | 1.82 | 1.65 | 1.34 | 42.47 | 19.91 | 15.64 | 5.36 |
| Lubbock | 1,450 | 8.21 | 5.43 | 3.43 | 4.55 | 48.00 | 54.55 | 36.36 | 13.33 |
| Potter | 1,407 | 2.21 | 0.20 | 0.00 | 0.00 | 47.73 | 5.88 | 0.00 | 0.00 |
| **Region 2** | 3,894 | 0.32 | 0.00 | 0.23 | 2.31 | 2.40 | 0.00 | 0.00 | 23.28 |
| **Region 3**** | 24,537 | 0.08 | 0.98 | 2.62 | 1.25 | 0.26 | 11.01 | 31.51 | 7.21 |
| Dallas* | 15,977 | 0.00 | 1.62 | 4.36 | 0.36 | 0.00 | 18.85 | 51.54 | 3.10 |
| Denton | 604 | 1.16 | 1.06 | 0.53 | 1.49 | 0.00 | 0.00 | 12.77 | 28.57 |
| Tarrant | 3,064 | 0.00 | 0.08 | 0.08 | 5.58 | 0.00 | 0.00 | 0.86 | 22.69 |
| **Region 4** | 7,400 | 0.09 | 0.54 | 1.49 | 1.62 | 0.00 | 9.09 | 10.39 | 12.00 |
| **Region 5** | 4,968 | 1.89 | 5.61 | 4.82 | 4.47 | 17.09 | 60.43 | 23.74 | 23.78 |
| **Region 6** | 26,922 | 1.42 | 4.86 | 4.22 | 8.77 | 7.32 | 28.15 | 22.52 | 60.00 |
| Brazoria | 1,232 | 2.28 | 4.08 | 5.10 | 10.23 | 25.86 | 33.87 | 14.52 | 76.60 |
| Fort Bend | 890 | 1.91 | 4.61 | 3.40 | 3.03 | 18.75 | 23.08 | 27.69 | 38.89 |
| Galveston | 1,229 | 7.43 | 8.08 | 9.43 | 12.45 | 15.38 | 41.86 | 27.91 | 75.00 |
| Harris | 20,217 | 1.20 | 5.03 | 4.17 | 9.32 | 6.44 | 28.77 | 21.93 | 63.55 |
| **Region 7** | 8,312 | 1.17 | 2.87 | 0.65 | 2.92 | 13.93 | 27.00 | 3.00 | 17.09 |
| Bell | 1,162 | 3.47 | 0.00 | 0.00 | 0.00 | 43.90 | 0.00 | 0.00 | 0.00 |
| Travis | 2,145 | 2.63 | 10.83 | 1.80 | 7.41 | 42.11 | 90.36 | 10.84 | 24.24 |
| **Region 8** | 14,683 | 0.21 | 5.06 | 7.07 | 4.31 | 0.36 | 35.10 | 39.15 | 28.04 |
| Bexar | 8,941 | 0.16 | 6.45 | 8.41 | 4.90 | 0.00 | 45.18 | 46.70 | 29.86 |
| **Region 9** | 5,003 | 0.43 | 0.00 | 0.18 | 0.30 | 5.36 | 0.00 | 0.00 | 0.00 |
| **Region 10** | 8,130 | 0.07 | 0.03 | 0.00 | 0.04 | 0.00 | 0.00 | 0.00 | 0.00 |
| El Paso | 7,899 | 0.07 | 0.03 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
| **Region 11** | 25,504 | 2.24 | 5.88 | 6.44 | 6.55 | 8.54 | 27.78 | 34.89 | 30.93 |
| Cameron | 5,806 | 4.95 | 10.23 | 9.19 | 8.58 | 16.56 | 65.71 | 50.48 | 45.85 |
| Hidalgo | 9,516 | 0.86 | 3.39 | 6.30 | 6.84 | 4.84 | 15.54 | 33.68 | 34.87 |
| Nueces | 2,791 | 3.32 | 8.42 | 6.16 | 6.99 | 15.45 | 16.67 | 33.68 | 24.32 |
| Webb | 3,596 | 0.00 | 2.72 | 5.53 | 3.09 | 0.00 | 12.18 | 28.93 | 15.46 |
| **TEXAS** | 134,947 | 1.13 | 3.43 | 4.14 | 4.36 | 6.29 | 22.48 | 26.09 | 29.00 |

* Does not include data from UT Southwestern Medical Center in Dallas in 1994, 1997, 1998, and 1999.
** May represent better reporting.
Note: 1998 Medicaid Paid Deliveries were used.

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, 1998, and 1999 (Table E). In 1994, Medicaid funded patients were less likely to receive these services than patients with other funding. In 1999, 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 since 1994. There was little difference in prenatal services provided between 1998 and 1999.

## Table E

| Statewide Utilization of Prenatal Genetic Services: 1994, 1997, 1998, and 1999 | | | | |
|---|---|---|---|---|
| | 1994 | 1997 | 1998 | 1999 |
| All Prenatal Patients | 2.5% | 4.3% | 4.8% | 4.5% |
| Medicaid Prenatal Patients | 1.1% | 3.4% | 4.1% | 4.4% |
| All AMA Prenatal Patients | 11.1% | 21.4% | 20.9% | 19.7% |
| AMA Medicaid Prenatal Patients | 6.3% | 22.5% | 26.1% | 29.0% |

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

Medicaid represented the major payer for prenatal as well as clinical genetic services in 1999. Title V provided only a small portion (4.3%) of the funding for clinical (primarily pediatric) patients, and funded 11.9% of prenatal genetic services. Most recipients of the total Title V funding were prenatal clients in Austin (4%), Houston (54%), Corpus Christi (29%), and Galveston (8%).

## III. Genetic Services Delivery System

### A. Barriers to Service

A barrier to service refers to a condition or situation that may prevent families from receiving needed genetic services. Barriers are generally related to the financing of genetic services, such as insurance issues for patients and reimbursement to providers. Barriers also include cultural and linguistic limitations of the present system.

Health insurance is vital for the receipt of genetic services. The cost of paying for these services is virtually impossible without health insurance.

Even with health insurance, families are burdened with related costs to their coverage. Premiums, co-payments and annual deductibles place a tremendous financial burden on families. In many instances, these costs may be the determining factor whether medical services for their children are pursued.

Public insurance such as Medicaid also presents similar dilemmas. Families who may be working for commissions or flexible hours are faced with monthly eligibility issues. If families cannot pass a means test based upon gross pay their child may be excluded from publicly funded health insurance.

Compounding the issue are situations where parents are faced with rulings by their health insurance plan that treatment for a genetic disorder is considered an ineligible expense. Many families are unaware that their child's genetic disorder and required treatment will not be covered by their health plan. Additionally, having health insurance is no guarantee that there will be coverage for speech therapy, physical therapy, occupational therapy or other specialty therapies.

Cultural differences can create barriers that interfere with patient education and counseling. Cultures that require that women not speak to a man other than her husband or other family member will require interpretations. The woman may not have the opportunity to effectively communicate to the genetic service provider her perception of what the needs of her child may be.

Linguistic differences can create additional barriers to patient education and counseling. Service providers who do not speak the same language as family members or their patients may run the risk of losing effective communication through a translator. Additionally, most genetic service programs do not have proficient bilingual service providers. This leads to misunderstandings and potentially ineffective treatment plans.

B. Psychological Issues

Psychological issues refer to behaviors and thought processes that affect how a person receives information about a suspected or confirmed genetic disorder. Genetic services providers assist families and patients with these issues every day, and are also expected to provide family support as they adjust to the news of a suspected or confirmed genetic disorder.

There is a high degree of anxiety associated with genetic testing. It is not unusual for patients to express a high level of anxiety when they receive abnormal results from their triple screens (a test that provides special medical information about the health of the developing baby) and other genetic tests. Much of this anxiety may be attributed to patients not being adequately informed about the possible decisions they might have to make if the results should come back abnormal. This same type of anxiety is often expressed among patients who undergo amniocentesis or other chromosomal studies.

This anxiety can sometimes provoke distress in patients, which in turn, can generate mistrust of genetic testing and genetic service providers. Even when genetic testing is conducted, it does not guarantee that a patient is fully informed about the procedures, or understands the possible implications.

Families get frustrated when the results of repeated genetic testing are inconclusive. When the results of genetic testing are inconclusive, family members may begin to question the value of additional tests. Inconclusive results often leave family members feeling helpless.

Denial of the condition is common among patients and their families and should be expected. Coming to terms with a diagnosis can be overwhelming for family members. Service providers have many opportunities to assist families in accepting the diagnosis.

Also, there is not enough emotional support available to families with children who have genetic disorders. Parents are emotionally overwhelmed upon learning that their child has a genetic condition. Pursuing emotional support is difficult in many situations. Families may feel ashamed upon learning their child has a genetic disorder and are reluctant to discuss their situation with family or friends.

The value of emotional support should not be underestimated. Emotional support is a way to help others cope with the experience of having a child with a genetic disorder and the new stressors and care demands placed upon them. Emotional support should be available at the time the sonogram shows something that is a potential problem. Families need support from that moment on.

C. Unmet Service Needs

Unmet service needs include affordable services that do not exist currently but should exist to support families with children who have genetic disorders. These services are necessary to sustain the health of the child, to support the family member's efforts to earn income, or to increase the capacity of the family to manage the care demands of a family member with a genetic condition.

It is difficult to find funding to support the dietary needs of children with metabolic disorders. Metabolic disorders demand specific medical care and follow up, the most important of these being nutritional support. While Texas law requires insurance companies to cover some formulas, the supplemental foods patients require are often difficult to obtain and require extra effort and cost on the part of families to procure them. Families who do not have private insurance, their employer self-insurances, or do not qualify for public assistance, can place their children at risk for additional medical problems if resources are not found to provide their children with adequate and appropriate nutrition.

Another unmet need is appropriate day care centers. There are very few day care centers that provide services or will accept children with certain genetic disorders. Parents need day care services so they can work and support their families. There are acute shortages of these types of services in communities.

Some parents have no option but to work. Paying for day care increases their financial burdens and anxieties about finding quality day care for their children. Locating appropriate day care services for children with special health care needs is not only difficult but is also expensive.

Some parents attribute the lack of appropriate day care to discrimination against children with complicated care needs. Because of this unmet need, some parents choose to remain home with their child and opt for reduced family income instead.

Finally, more testing and diagnosis of genetic disorders is needed. Complicated and rare disorders are not easily diagnosed and may require extensive testing in order to confirm the diagnosis. Cost is a major hurdle for families and the programs that serve them.

The prohibitive costs of testing can interfere with giving patients the very best care that can be provided. Thus, service providers take extraordinary measures to help families secure the approvals they need. In spite of these efforts, insurance programs do not generally allow approval and funding for additional tests.

D. Educational/Information Issues

Educational/information issues pertain to the need for more professional and public education about genetic conditions and genetic services. It also pertains to informational materials for family members who care for a loved one with a genetic condition.

There appears to be a general lack of information about genetic conditions in our communities. Most parents do not know much about genetic disorders until their children are diagnosed with a genetic condition. They are unfamiliar with the science of genetics and the extent of health problems that genetic disorders can cause. Parents who are told their child has a genetic disorder realize almost immediately that they have limited knowledge and understanding about their child's condition, much less the science of genetics. The learning curve is steep and requires extensive support from service providers.

Referrals for genetic services are minimal. Only a small proportion of potential patients receive the services of a geneticist. This deficiency in referrals can be attributed to medical professionals who do not recognize a possible genetic disorder or simply do not seek consultation from a geneticist when treating a condition.

On the other hand, service providers have witnessed an influx of self-referrals for genetic studies. This is attributed to increased public awareness about the role of genetics in the development of disabilities.

E. Program Resources

Program resources refers to the way current resources are utilized to support the missions and activities of genetic services programs in the state. It also pertains to issues related to the staffing of these programs and the need for better coordination of services for families with children who have genetic disorders.

Genetic services programs are not reimbursed adequately for the costs of their services. Estimates of reimbursement to regional genetic services programs by private and public sources ranged from 40%-85% and most programs operate at a loss.

The costs of hospital-based and university-based programs are generally subsidized by their sponsoring organizations that view genetic services as part of a necessary provision and public service. But even with this support, deficits of revenue to support and sustain programs are unavoidable because of the volume of need and the amount of work it takes to provide comprehensive services.

Families need a tremendous amount of time from the genetic service provider. Discussions include communication, cultural issues, education on basic biological concepts, working with insurance, finding an appropriate referral, and ensuring families receive social services. These activities take a large amount of time to do well and properly. There's virtually no reimbursement for these services at the state or private level.

Current levels of reimbursement do not cover the true cost of care for most programs. Dietary, genetic counseling, nursing, and social work personnel are employed at many of the clinics across the state. But public or private insurance programs generally do not reimburse programs for the costs of employing them even though they provide vital services to families. Subsequently, regional clinics must find ways to absorb these costs.

The dilemma is clear for most programs. Genetic services programs must somehow continue to provide the services that families need, as well as secure adequate resources for their programs, while potential sources of revenue dwindle and costs continue to rise. Genetic testing is very expensive. To make matters worse, programs see their opportunities for generating revenue to make their programs self-sufficient dwindling. Outsourcing laboratory services to out of state, low-cost, high volume providers has also reduced revenues for genetic services programs. Local laboratory services were at a higher cost but they helped support genetic services in Texas.

There are inadequate numbers of geneticists to support current services, much less an expansion of services. The current genetic services system is struggling to manage the current demands for genetic services and cannot plan for expansion.

Expansions in newborn screenings and public awareness about the role of genetics in the disease process are expected to increase the demand for geneticists. But the number of persons interested in entering the field is decreasing. Unfortunately, the disincentives for entering the field of genetic services appear to outweigh any incentives at the present time. The severe lack of resources in manpower and funding are discouraging programs from expanding their efforts, even though they know their services are needed.

Another concern is how to organize and coordinate services for families. Programs which provide coordination efforts are the state Birth Defects Registry and the Children with Special Health Care Needs (CSHCN) program. But these efforts are limited and only partial responses to the need for systematized and coordinated services for children with genetic disorders. Presently, there are approximately 1200 children on the CSHCN program waiting list. The number of clients eligible for the CSHCN program is growing at a rate of 100 per month.

## IV. Defining the Need for Future Services

### A. Barriers to Service

Financial means testing for public health insurance places a significant burden on families with children with a genetic disorder. In many cases, families must travel a hundred miles to visit a geneticist or their income may be slightly higher than the required eligibility ceiling. Consideration should be given to eliminating income means testing for services for children with genetic disorders or flexibility to adjust for added expenses in finding and receiving genetic services and consultation.

Appropriate, professional translation services for counseling and patient education should be available at all genetic service centers. Professional translators with experience in the medical field can assist in ensuring that the information provided by the geneticist or counselor is accurately presented in the native language of the patients and their families.

### B. Psychological Issues

Patients should be given appropriate and quality information about genetic testing in order to alleviate some of the fears associated with a potential problem with their child. Information presented to the patient should include the purpose of the test, why it is being performed, what will transpire during the test, what the risks may be, what the test results may indicate, and outcomes of a potential abnormal result. This information should also be available in several languages and translated appropriately to reflect the meaning as presented in English.

Additionally, family support should be emphasized. Assisting the family with coping with the prospect of caring for a child with a genetic disorder is essential for quality medical treatment and care. Resources must be made available to allow families the opportunity to be educated and to understand the complexities of treating a child with a genetic condition and to identify the infrastructure that will be needed to ensure systematic and uninterrupted care.

C. Unmet Service Needs

A systematic mechanism for informing and helping parents needs to be developed. When a genetic disorder is identified, parents should be provided with information on accessing services. An 800 number linked to a statewide maternal and child health services database would be instrumental in assisting all families with identifying resources.

More case management services are needed. Many services are age-specific, that is, once the child reaches a certain age, services are discontinued including case management. After services are discontinued families must once again navigate the social services system to find comprehensive and appropriate care for their child. A continuum of care managed by a social worker would effectively assist the parents with their child's therapies.

More incentives to bring genetic services to remote and rural areas of Texas are needed. Genetic services are typically found in large metropolitan areas of the state. Families may need to travel over a hundred miles to receive services. Geneticists have little incentive to hold clinic in rural areas due to the amount of time they must expend traveling to remote areas. Appropriate compensation is necessary to encourage geneticists to hold clinics in rural areas of the state. Reimbursement should be available for airfares, rental cars, hotel rooms, and meals.

Additionally, a statewide coordinated system needs to be in place to guide families to appropriate genetic services. A single-point-of-contact for schedules of clinic locations, hours of service, fees, transportation, etc. should be maintained to be current and easily accessible. The system should be well-promoted through an aggressive outreach education effort.

D. Educational/Information Issues

More education and information for medical providers and other health care professionals is needed. Physicians need to be educated about genetic services so that they would invite people to utilize the services available. A health promotion initiative for identifying children with a genetic disorder should be

implemented. These activities include statewide distribution of pamphlets to all Texas physicians, distribution of videos to health professionals regarding indicators for a genetic referral, and a television campaign promoting genetic services, what they are and why they are needed.

Also, partnerships should be developed through like organizations that work with children with special health care needs. Public and private organizations should create a consortium to address a comprehensive system for identifying and promoting genetic services. Ideally, these organizations would provide a single-point-of-contact to assist physicians in locating both case management and local services for their patients.

Finally, local resources should be identified for outreach education activities in communities. The promotor(a) or community health worker services should be trained in genetic services and indicators for a genetic referral.

E. Program Resources

More support services to families are needed. Support for families should be available at the time a potential genetic disorder has been identified. Physicians need to be educated to encourage families to see a geneticist and counselor. Physicians need to be given the resources to help their patients secure the support they may need to provide care for their child.

Incentives for pursuing a career in the field of genetics need to be created for providers. Without an active plan to increase the number of geneticists, public education efforts will overwhelm the few geneticists presently practicing in the state. A solid infrastructure needs to be in place to ensure adequate services are available at the time physicians and families seek them out.

More genetic services are needed for different age groups and across the lifespan. While many cases of genetic disorders are diagnosed early in life, geneticists in Texas are beginning to see an increase in the number of patients who are in the middle school and high school age group. Additionally, geneticists are reporting increased numbers of inquiries from patients who have a history of colon cancer and breast cancer in their families. Geneticists are now seeing the second generation of family members with genetic disorders.

The current reimbursement structure for genetic clinics needs to be examined. Innovative strategies need to be assessed to determine if they can be adopted as a means to increase monetary support to clinics and services to families. A team approach to genetic services, where different aspects of the evaluation could be billed separately, the nursing, the genetic counseling, the dietician, the speech therapist, the evaluation, anyone involved with the evaluation as well as the physician, for the huge chunks of time any one of these people might put into the evaluation or the treatment of this patient.

## V. Recommendations

The Resource Allocation Plan for Genetic Services describes current constraints that impinge on a family's capability to access comprehensive services for children with

genetic disorders, and recommendations about how future priorities ought to be set, in order to minimize these constraints. The following are recommendations by the Interagency Council for Genetic Services:

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

Acknowledgements: *Perceptions About Genetic Service in Texas*, College of Health Professions School of Social Work, Southwest Texas State University for The Texas Department of Health Genetic Services Division, Sept. 2001.