



# Interagency Council for Genetic Services

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Texas Department of Mental Health and Mental Retardation ☞ Genetic Services Contractors  
Texas Department of Health ☞ University of Texas Health Science Centers  
Texas Department of Insurance ☞ Consumer and Public Representatives

**March 7, 2003**

**Present:**

Margaret Drummond-Borg, Chair  
Cynthia Scott, Consumer Representative  
Bob Cleveland, Consumer Representative  
Lillian Lockhart, UTHSC  
Pat Craig, MHMR  
Hope Northrup, Provider Representative  
Dixie Camp, TDH  
Mike Frazier, Baylor College of Medicine

**Absent:**

Susan Young, TDI

There were no minutes to review due to technical difficulties from the December 2002 meeting. Approval of the minutes was deferred until the next meeting.

**Agency Reports**

**TDH - Margaret Drummond-Borg**

The agency is trying to develop new budgets with approximately 7-12% reduction in funding. TDH receives some of the unclaimed lottery money, which is used for distribution to those hospitals providing indigent care. This will be used this year to meet most of the required budget reduction for the rest of this year. All positions have been frozen in the agency. Travel has been cut. There is no more out of state travel for this fiscal year. No more large purchases will be approved. For FY 04 and 05, TDH started with a zero budget. They used building blocks based on a priority list of programs to build the budget. When the total amount of money was reached that was allocated for health services, all the programs not listed were slated for elimination. All the programs had reduced funding. There was a ten million dollar reduction in funding of CSHCN, which had already taken place in the last biennium. CSHCN did pass its rules so that they can provide fewer services but will maintain a waiting list.

CSHCN has had a waiting list and they have approximately ten million dollars that is projected to be unspent by the end of the fiscal year. Therefore they are releasing people off of the waiting list depending on severity of their condition and need.

The question was asked that if someone is on the waiting list that is not receiving services, could they get knocked off before they get to the point of receiving services? The answer is no.

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Another budget that will be affected is the Maternal & Child Health budget but it is not clear as to how it will affect the different programs. They may eliminate all the population-based grants. There is talk of reducing the primary care health program. All of this is being discussed at this time. We may lose the population based genetic grants but it is not known for sure at this time. We are not sure if there will be a reduction in the amount of money available for the PKU formula. We pay for PKU formula on a sliding fee scale for people that have a family income over 200% of federal poverty level. That money comes out the Maternal & Child Health budget. The big concern is that the Birth Defects Registry and the Cancer Registry may be cut. The March of Dimes has been very active at present advocating to keep the Birth Defects Registry.

There is a concern about a bill that allows insurance companies in Texas to write insurance that does not include any mandated benefits. This could include prenatal care, family planning, and PKU formula.

### **MHMR – Pat Craig**

The waiting list has increased by approximately 5,000 people last year and about 600 were taken off. In our building blocks for next year, there will not be any attempts to take anyone off the waiting list. The lawsuit regarding the waiting list is still pending. Any slots that we get will be simply to take people out of institutions.

As for this year, we have a hiring freeze also & travel is limited and about 48 positions will be eliminated by the end of the year in our central office alone. We imposed on the state facilities, state hospital, state schools and community MHMR centers flat cuts for the remainder of this year to help us make up a 14% reduction. Right now we're waiting to see what comes out of the legislative session.

We have a popular program called "In Home Family Support" where they get cash vouchers to purchase home modifications if they have a physical disability; get respite services, etc. This program was eliminated because it was general revenue (GR) funded.

One of the other proposals is to close one of the state schools and one of the state hospitals and to convert all of our group homes funded through Medicaid (ICFMR facilities) to Medicaid waiver programs. At present the people who run those programs own that facility. If they discharge someone they can choose who will come in the program and they can choose to discharge someone without their consent if the person is dangerous, etc.

What the switch to the Medicaid waiver program would do is it would allow the person who is receiving services to take their money and go anywhere. That would be a major change in how the business is done. The group homes are paid flat rates for 5 levels of service. The Medicaid waiver program requires billing on an hourly rate for each service and utilization review may deny services. There is also a possibility of eliminating Level I MR facilities.

### **UTMB – Lillian Lockhart**

UTMB has already had some cuts. At UTMB the hyperbaric chamber has been cut, rehab in-patient unit for adults has been cut. There are no state funds for travel. 57 people have been laid off including several administrators and they will be leasing vehicles instead of buying. There isn't an official hiring freeze but permission must be granted to hire.

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**UTHSC – Hope Northrup**

We have a hiring freeze and a 7% cut. In Pediatrics, the percentage from state revenues has decreased as the amount of grant money has increased. The more money from other sources, the less we have been given from the state category. We haven't been told about any lay offs. The dean is moving funds around within the school to try to cover all expenses. We are 32 million dollars short due to the flood damage a few years ago, as the insurance has not covered all the costs of the repairs/rebuilding.

**TDI – No report**

**Genetics Rules Update – Margaret Drummond-Borg**

The Medicaid genetic rules were passed within the timeline. These rules were reviewed but not substantially changed and basically state that genetic services are to be provided under Medicaid.

A proposal was put forward to Medicaid about combining local codes so that we could use the national codes rather than local codes. As far as we know now, they will be accepted without changes. There will be a Medicaid bulletin number 170 due out in April, which will have all of the local code changes in it. There were some concerns voiced about converting the old codes to the new national codes. All codes had to be switched to national codes. A modifier (TG) will have to be used when billing Medicaid. The reimbursement rate should be about the same as before under Medicaid. This change will also affect the next round of Title V genetics grants.

Mike Frazier offered to help TDH in applying for new national codes.

There are 2 state genetic coordinators willing to support Texas, Florida and Ohio, in asking for new national codes for disease specific DNA tests.

**March of Dimes Initiative - Newborn Screening**

Jorey Berry with the March of Dimes (MOD) has been very active in promoting Newborn Screening with the legislature. A brochure outlining the MOD agenda for this session had to be approved at the national level. There was a lobby day on February 18<sup>th</sup> and a group of MOD volunteers were present talking about the MOD priorities. Jorey Berry developed a MOD Fact Sheet on newborn screening and the conditions the MOD has recommended to be included in newborn screening panels.

There is a proposed bill asking that TDH be given permission to buy equipment to include Tandem Mass Spectrometry in the Newborn Screening Program.

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**Genetics**

TDH is applying for a CDC genomics and chronic disease grant for \$250,000. This would involve a coordinator who will be looking at family history and whether it would be beneficial in chronic diseases in terms of prevention. The HRSA state genetics plan implementation grant will be submitted later this year.

**Legislative Session**

One bill that may benefit people with genetic disorders will create an inter-agency council for people with disabilities where people from the different agencies would meet and review people's needs to see if they are getting all the appropriate services to meet their needs. This could be rather expensive.

**Other Business**

The question was asked as to when the terms expire for the appointees. Dixie will research this.

The Resource Allocation Plan has been sent to the legislature.

The next meeting date was changed to May 30<sup>th</sup> instead of June 6<sup>th</sup>.

Meeting was adjourned.