



Interagency Council for Genetic Services

Texas Department of State Health Services * Genetic Services Contractors
Texas Department of Aging and Disability Services * Texas Department of Insurance
University of Texas Health Science Centers * Consumer and Public Representatives

Meeting Minutes June 3, 2005

Present:

Margaret Drummond-Borg, DSHS, Chair
Bob Cleveland, Consumer Representative
Lillian Lockhart, UTMB
Mary Kukulich, Provider Representative
Janet Shephard, Consumer Representative
Alicia Essary, DADS
Elaine Braslow, DSHS
Michele Goddard, DSHS

Absent:

Charles Reyna, TDI

Elaine Braslow was introduced as the new genetics coordinator at DSHS. She replaces Marjorie Doubleday.

Alicia Essary was introduced. She is representing Texas Dept of Disability Services (DADS) and is replacing David Rollins.

The minutes from March 4th were reviewed corrections made, approved and seconded.

AGENCY REPORTS

❖ DSHS - Margaret Drummond-Borg

DSHS is still working through the consolidation. We are now in the stage of optimization. There have been some changes, which affect the Newborn Screening Program such as the consolidation of all of the automation staff. Human Resources staff has been outsourced, which has caused a little more difficulty in the hiring process. All of the vacant positions in the Newborn Screening Program were filled before the hiring process was changed.

❖ DADS – Alicia Essary

DADS is also going through the consolidation process. Long-term care programs from the former DHS and Department on Aging have been combined with MR programs from the former MHMR. DADS is now serving all Texans over age 60 and those who need long-term care services, more or less, with the exception of those people needing long-term care for mental health.

Dr. Kukulich - “regarding the patients that have diagnoses of MH &MR, who would they fall under now?” Alicia stated that it depends. One of the issues that we are looking at is that the

population of people with MR is living longer. We didn't previously have many elderly people with MR, but now we do.

MDB asked if all children on SSI were included under DADS. Alicia stated that DADS has some responsibility for the medically dependent children program's waiver. A fair number of children receive services on Primary Home Care, which provides non-professional services. Children's policy in general rests with the Health and Human Services Commission (HHSC). There has been talk that they may move all of the children's long-term care programs into HHSC. This may depend on the outcome of the lawsuit that is pending. There have been many issues surrounding long-term care services for children in a world that is accustomed to dealing with long-term care services for adults. For primary homecare services, eligibility is determined by a functional assessment. That instrument was developed for adults and it is inappropriate for children and we do not have anything better at present. Solving the problem of an appropriate instrument for assessing the level of need will take years.

❖ **TDI – Charles Reyna**

No report.

❖ **UTMB – Lillian Lockhart**

No report.

NEWBORN SCREENING PROGRAM REVIEW – Margaret Drummond-Borg

Packets were given to each member present, which included a draft of the review held in March by the National Newborn Screening and Genetics Resource Center (NNSGRC). The NNSGRC holds these reviews by invitation from a state Newborn Screening (NBS) Program to try to improve the program's services. Their recommendations basically are that all NBS programs try to meet similar standards so that they all provide similar services in terms of lab testing, follow-up and the actual long-term care. DSHS had sent out notices inviting people to come and talk to the reviewers about their concerns with the NBS Program.

Since receiving the draft report of the review, DSHS has convened a project group to go through the report and look at all the different concerns and see how they can be addressed. Some of them require significant fiscal support, which would require Dr. Sanchez' approval. There are some concerns we can address that do not require a significant amount of money. DSHS is to come up with a plan of how to respond to the report.

One project the review team is involved in is developing a survey to be sent out to people involved in newborn screening, to verify and ask them to expand on some of the concerns that were mentioned in the review.

79TH LEGISLATIVE SESSION – Margaret Drummond-Borg

HB 790 did get passed and is now at the Governor's Office waiting for his signature. HB 790 modifies our newborn screening legislation in that it allows for expansion to include the 19 metabolic disorders that were recommended by the American College of Medical Genetics (ACMG). It actually states that we can expand to the 29 disorders, depending on monies available, however DSHS does not plan to expand to do cystic fibrosis screening or biotinidase screening at this time. We were planning to expand to include tandem mass spectrometry. In

the process of the bill being passed, there were many comments and concerns about the Newborn Screening Program. NBS will not be able to expand on September 1st as we had hoped. We have to go out and get bids for out-sourcing the whole NBS Program. Once we get all of the bids in, we will have to look at which would be the most cost effective way to provide newborn screening. Dr. Sanchez said that even if HB 790 was not passed, he would look at out-sourcing because that is part of the optimization process.

There is no funding in the bill for the first year. There is funding for 2007 and the funding for 2007 provides funding for start-up costs plus increased follow-up. The Texas Medical Association (TMA) strongly supports us implementing the expansion and they represent a major portion of the physicians involved in the newborn screening programs.

There was a BMI (Body Mass Index) bill, which would have diabetes and obesity screening done in the schools, but it was not passed.

SB 1329, related to certifying genetic counselors, did pass through the Senate but did not get on the calendar in time to be passed by the House.

OTHER BUSINESS

Elaine Braslow mentioned a forthcoming RFP to be issued by the State of Wyoming. The request is for the provision of genetic services throughout the state.

Dr. Drummond-Borg mentioned that the Newborn Screening survey would go out soon. This survey is based on concerns voiced during the newborn screening review. It will be sent out to about 4,000 people who are interested in newborn screening.

Dr. Kukolich will get information to Dr. Drummond-Borg regarding telemedicine program.

The next meeting date is August 26, 2005.

Meeting adjourned.

7/20/05
rev. 8/16/05
rev. 8/22/05
rev. 8/23/05