



Interagency Council for Genetic Services

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

December 6, 2002

Present:

Margaret Drummond-Borg, Chair
Pat Craig, TX Dept. of MHMR
Lillian Lockhart, UT Health Science Center
Robert Cleveland, Consumer Representative
Susan Young, TX Dept. of Insurance
Hope Northrup, UT Health Science Center

Absent:

Cynthia Scott, Consumer Representative

Meeting called to order by Dr. Drummond-Borg.
Minutes from the September 6th meeting were reviewed. Motion, second, and approved.

Agency Reports

TDH - Margaret Drummond-Borg

The TX Department of Health is preparing for the legislative session. The state budget will be less and proposed savings for this fiscal year have been identified at various percentage levels. Direct services are to be kept at the same level if possible. The CSHCN Division is interviewing for a new director who will not be a physician. The Frew lawsuit regarding THSteps Medicaid services has been appealed by the plaintiff to the U.S. Supreme Court regarding the Fifth Circuit decision. The request for dismissal of the case has not been filed. TDH is awaiting the Supreme Court decision.

Pat Craig - MHMR

The waiting list for the Medicaid waiver program for MHMR services is increasing. A survey was done to determine the needs of the people on the list. 75% were living in a family home. 50% were receiving some interim services. Five years is the average time on the waiting list. Appropriations request included dollars to move 1200 from the waiting list into the program. The lawsuit regarding the waiting list may be a year away from any substantial judicial activity.

The Texas Home Living Waiver applies to people receiving state MHMR services (at least \$4,000 per person). A proposal has been made to take this funding and obtain a federal match under Medicaid. This would allow more people to receive services. This is only for support services in the community with a \$10,000 cap. Services include respite care and behavior analysis. Approximately 91% of these are Medicaid recipients.

Lillian Lockhart-UTMB

No report.

Susan Young – TDI

No report.

Newborn Screening Task Force

The task force did produce a final paper on Tandem Mass Spectrometry (MS/MS) in Texas. The report included a recommendation to introduce MS/MS into the Newborn Screening Program in a step-wise fashion. The first phase would be to screen all babies for MCAD, GAI, MSU and homocystinuria. The sensitivity and specificity would be evaluated and the demands on the medical community infrastructure assessed. Phase 2 would depend on the outcome of Phase 1. An educational component would be necessary to inform parents/pregnant women, health care providers, and payors about the new methodology, the confirmatory testing required and the interventions.

The March of Dimes is working with the Newborn Screening Coalition to provide information regarding MS/MS to legislators.

NBS Rules Update

The Newborn Screening Rules have been reviewed and minor changes made to update some of the out of date names of programs and improve the language. The Board of Health passed the final rules on November 22, 2002.

Genetics State Plan Grant

The application deadline for this year has passed for the implementations grant. A Texas State Genetics Council has been formed to implement the state plan. The council will meet in January to discuss strategies to develop a HRSA application for implementation that would be funded. The council consists of TDH personnel from various programs, consumers, specialists, geneticists, Senator Van de Putte and Brad Therrell (NNGSRC).

Next Steps

Funding of genetic services was discussed. The amount of state money available to pay for genetic services continues to be reduced. The question of why genetic services are not being funded was discussed. Funding for autism was discussed and it was suggested that the autism legislation be reviewed. The legislature mandated that 6 state agencies support an Interagency Council on Autism and Pervasive Developmental Disorders including travel and a staff support person for the council. Genetic Services need to be seen as necessary and providing benefit to those needing them. It was suggested that support letters to legislatures would be helpful. Authors of the letters could include:

March of Dimes – Jorey Berry, parents of children with genetic diseases, Senator Zaffarini; lobbyist at Baylor College of Medicine, Regional Advisory Committees, ARC, TCDD, Down Syndrome Support Group, Fragile X Support Group.

Public Comment

Mike Frazier, Baylor College of Medicine of Houston mentioned that Dr. Waisbren and Dr. Levy of Boston Children's Hospital compared children identified by newborn screening vs. clinical diagnosis for a number of inherited metabolic diseases. There was a difference in the outcome indicating that newborn screening was effective in improving outcomes.

Next meeting is March 7th.
Meeting was adjourned.