



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

May 30, 2003

Present:

Margaret Drummond-Borg, TDH, Chair
Cynthia Scott, Consumer Representative
Bob Cleveland, Consumer Representative
Lillian Lockhart, UTMB
Pat Craig, MHMR
Dixie Camp, TDH

Absent:

Susan Young, TDI
Hope Northrup, Provider Rep.

Minutes from December 2002 and March 2003 meetings were reviewed and approved.

Agency Reports

MHMR – Pat Craig

The waiting list continues to increase. The lawsuit regarding the waiting list is still pending. The Texas home living waiver has not yet been approved.

The agency still has a hiring freeze in effect, although we recently filled a new position for the Autism Council. The new employee will begin work on June 2nd. She will be the contact person in the state of Texas for people with autism. The “In Home Family Support” has been resurrected on the MR side. The appropriations bill that made it thus far but is only 1/3 of the funding that was available this year and on the MH side, it was totally eliminated. We are getting a basic percentage decrease in our current funding so obviously we will not be taking anyone off the waiting list unless it is someone in a state facility.

One of the other proposals was to convert all of our ICF-MR group home facilities to the Medicaid waiver program. This was done thinking that there may be some cost savings because the group homes get a fixed rate by the type of individual that they serve, where the Medicaid waiver is a fee-for-service, so they could deny certain services. However, this did not go through so basically for now it stands the same. There is a proposal to actually lower the rates that they are paying both to the group homes and requiring a percentage decrease in the Medicaid waiver program, which is becoming our largest program. They did not eliminate the Level I MR facilities, which are currently serving people with mild retardation. There was also a proposal to close one state school and one state hospital and that has been removed. They will study it and present a proposal for the next legislative session. In the past, before anyone could get into a large state facility, the criterion for admission was more restrictive. A person had to have severe to profound retardation or the person had to exhibit dangerous behavior or life threatening conditions and there has to be a local team from the local MHMR Center, which goes to court and says there is not a less restrictive setting available for this person. That is actually in the law. There is a now a workgroup to help determine what a “less restrictive setting” is. Texas has the largest number of people in institutions, which is just below 6,000. Most of the other states in the top ten have around 2,000 people in institutions. One exception, which is Ohio, which has about 2,000, has a fairly flexible admitting policy. They are admitting

people on the same basis as Texas but most other states are admitting people is if there is simply not anything else available in the community and they cannot find anything else anywhere in the state and there is an emergency situation that is life threatening. Although many of them are changing their institutions to serve people that are criminal offenders with mental retardation.

There was a bill on restraint, which would have a lot of impact on TDMHMR, but the bill was not passed.

TDI – Susan Mills

Susan Mills filled in for Susan Young. There was a bill regarding PKU formula, which had an amendment added and is not excluded. Another bill was the coverage of newborn babies for one month on either the mother or father's insurance without having to be enrolled. When the baby is born, it would have at least one month's coverage.

UTMB – Lillian Lockhart

UTMB is still trying to find places to cut funds instead of having to cut programs. The HIPAA act has had an impact on us and we feel it may slow down the process in providing information on patients. In our department, Pediatrics, we have to cut \$700,000 for the rest of this fiscal year. No faculty is being hired at this time.

TDH - Margaret Drummond-Borg

The agency has a hiring freeze at present. If a position needs to be posted, it requires an exemption, which requires a lot of justification. A few positions are being filled because the agency is losing employees. Anything considered educational will not be filled. There has been a lot of fluctuation in the budget. There were things changed initially, like the cancer registry and the birth defects registry, which were both omitted from the budget. They are no in the budget and somehow to do that, they have found some administrative dollars. There is a possibility that administration will be cut due to the consolidation of the agencies. All of human resources will be consolidated. The TDH human resource staff will be supporting other agencies as well. The fiscal staff will be combined and will support multiple programs.

We have also changed staff management ratio to one supervisor to 11 employees.

There will be cuts in some programs at TDH. We have a general revenue (GR) overmatch for the Title V Maternal and Child Health block grant. We will still get the same amount of federal dollars but will have to reduce the amount of GR, which means we will have to reduce a lot of services that TDH provides. They are looking at anything up to a 10% cut for some of the services and possibly even a greater cut on the population-based services. Some of the contracts may be eliminated completely. There is also a possibility of a Medicaid reduction in what is paid for services, which could be a 5% reduction across the board.

CSHCN is still working on their reduced budget. They will continue with a waiting list.

The contracts that would have normally been sent out for Title V Genetics will not be sent until we have a budget.

The question was asked regarding any response to the Resource Allocation Plan. There has been no response as yet.

March of Dimes Initiative - Newborn Screening

The March of Dimes (MOD) has been very active in promoting a few bills in the house regarding tandem mass spectrometry and in trying to get the equipment purchased so that we could start expanding newborn screening. The bill was not passed because of the significant fiscal note attached. Judith Zaffarini did co-sponsor one of them so that means we do have people that are interested in expanding newborn screening. The MOD is going to ask for a committee on newborn screening to look at newborn screening in between the sessions.

They are proposing to do some legislation that will provide grants, which will allow hospitals/medical facilities to buy tandem mass spectrometers so they could screen themselves and to provide grants for the states to provide follow-up.

Legislative Session

There were a number of bills that the Health Department was following. They are trying to prevent cloning of human beings/embryos. Cloning of tissue would be done but not embryos. None of the cloning bills were passed. The abortion bill has gone through. This was the bill, which requires women to wait for 24 hours. This bill affects genetics because we do counsel people regarding their options. There was one bill on hearing data for Newborn Hearing Screening, which stated we could only collect aggregate data and it wasn't identifiable data. This bill was passed.

There is a bill that states that advisory committees will be abolished. It states that advisory committees as defined by section 2110 of the government code. This section talks about state agency advisory committees and the question is whether all these interagency councils are considered advisory committees. The TDH lawyers do not feel that the IACGS is an advisory committee. The IACGS has listed duties listed that are not advisory.

UTHSC – No report

Next Steps

We do need to look at trying to get funding. The statute does say that if money comes to the state for genetics, then that money comes to this council. We have the authority to get money from other organizations.

Cynthia Scott stated that there is a new state genetics sub-committee that is the group that awards the grants. There are grants available and genetics is definitely a strong interest of MOD. She feels that through the interaction of the IACGS and the sub-committee, we could identify something that is needed and do a proposal and get that funded, but we need to connect with the genetics sub-committee and define what the project would be.

The question was asked about the state plan. Margaret stated that the state plan was developed and ways of trying to implement bits of it are being looked at.

Cynthia stated that this meeting would be her last. Janet Sheppard has applied to be the new consumer member.

Other Business

The next meeting date is September 5th.

Meeting was adjourned.