

INTERAGENCY COUNCIL FOR GENETIC SERVICES

September 6, 2002

Present:

Margaret Drummond-Borg, Chair
Pat Craig, TX Dept. of MHMR
Lillian Lockhart, UT Health Science Center
Robert Cleveland, Consumer Representative
Cynthia Scott, Consumer Representative

Absent:

Hope Northrup, UT Health Science Center
Susan Young, TX Dept. of Insurance

Meeting called to order by Dr. Drummond-Borg.
Minutes from the June 7th meeting were reviewed. Motion, second, and approved.

Agency Reports

TDH - Margaret Drummond-Borg

The main concern in the last few months has been the budget and the shortfall in Medicaid and CSHCN. Medicaid is looking for ways to save money. Since the last session, Medicaid enrollment has increased because of simplifying the enrollment process and allowing children to be on Medicaid for a year instead of re-enrolling every month. In Medical Case Management (MCM) the amount of money being spent has gone up significantly. There are a number of children that the program was designed for that are not receiving case management. The case management rules are being revised to ensure that the children that need the service the most are being served. The rules will be presented to the Board next year. The CSHCN rules were presented to the Board yesterday. The CSHCN Program budget has been cut. There is a waiting list now. The CSHCN staff has been working in the regions to make sure that everyone on CSHCN re-enrolls to ensure continuity of service.

The Newborn Screening Program will be getting a new software program to enable TDH to report results quicker. This should be installed in the next few months. The laboratory staff is gradually moving into the new laboratory building.

Pat Craig - MHMR

The Association for Retarded Citizens (ARC) of Texas and Advocacy, Inc. have filed a lawsuit against Dept of MHMR and Dept of Human Services. The lawsuit primarily focused on the waiting list for Medicaid waiver program. The waiting list is over 18, 889 and the DHS Class program waiting list is about 7,000. There are a lot of other states that have had waiting list lawsuits filed against them. Some of the states are coming up with plans to address the suit. The causes of action are: failure of amount of duration in scope, failure to provide choice of services, and failure to provide an opportunity to

apply. Technically, the reasonable promptness criterion does not apply is because we don't determine someone's eligibility until there is a slot for them.

Most of the people on the waiting list are probably diagnostically eligible. Almost by policy, we have not determined their eligibility for the program because it could change and it is expensive to do that until they have a slot available to them. The main concern will probably be "failure to provide prompt services". There are some federal regulations stating that once you can determine someone eligible for Medicaid, they are to be provided within reasonable promptness, which is generally within 90 days. Some interpretations have said that only applies to true entitlement services and really doesn't apply to the waiver program. In some of the states, some judges have basically mandated that the state serve the people on the waiting list within a certain period of time. There is no national standard regarding that yet. In the last 2 years, we have seen a dramatic increase in the amount of people that are being added to the waiting list. In the last 2 years, we have had about 1,000 added each quarter. California and Oregon have been mandated by law not to have a waiting list. The way they do that is that the services are limited. They may be only service coordination.

A TDMHMR advisory committee came up with a proposed plan for waiting list reduction. Their goal was that no one would have to be on a waiting list for more than 2 years. There would be some difficulty serving this many new people immediately even if there were funds. Pat stated that there were a few ways to do that. One approach is for more family members taking care of the individual but there are legal restrictions also. For instance, a parent cannot be paid to take care of a minor child.

There are a number of assessments that are used, primarily one called the Inventory for Client and Agency Planning (ICAP), which is an adaptive behavior scale which measures, self help skills, daily living activities, and problem behaviors and on the basis of these, a score is produced. The amount of funding that one receives in a group home or facility depends directly on the score that is produced from the ICAP on a particular individual. It can range from (for example) \$65.00 a day for a person that is mildly retarded up to \$500.00 a day for someone who might require one-on-one supervision or who may profoundly retarded and/or pose a threat to themselves or others. The same type of assessment is used in the waiver program, but it is not a direct reimbursement. We basically have guidelines that, if you have ineligible level of need on the basis of the ICAP score, you can get a certain amount of hours in a category of services, for example respite services. A person may be able to get 60 hours a year if they are profoundly retarded as compared to someone who is mildly retarded, who wouldn't get as many hours.

The question was asked as to what exactly the waiver program is. Pat explained that it is a waiver off of the institutional program. In Texas, there is an entitlement for the institutional program. If a person has mental retardation or a related condition and has medical necessity, as long as the state chooses to participate in the program, anyone who meets the eligibility criteria has to be served.

We have requested funding to serve 1,344 people on the basis of equity. These were people coming off of our waiting list as well. Because of historical funding patterns, some areas state get more money per capita than others do and so typically the large metropolitan areas did not get as much money per capita as some of the rural areas. We are limited on how much federal funds we get by how much state funds the legislature will allow us. We are trying to get areas of the state to have equal funding, which has been a multi-year project. Basically we want to move 1,344 people off of the waiting list and give priority to people in the areas that are underserved.

The institutional program has been capped in size and the goal is to gradually reduce it.

The Texas Association of Mental Retardation Conference took place in July and Dr. David Coulter was the keynote speaker. He gave a talk about the surgeon's general's report regarding the health status of people with mental retardation in general. The report revealed that most people with mental retardation are not in very good health, & have problems with obesity and other issues. The report showed that these people do not always get good medical care. A lot of them are on Medicaid and some physician's do not want to deal with that and this needs to be addressed nationally.

Lillian Lockhart-UTMB

No report.

Task Force on Expanded Newborn Screening-Margaret Drummond-Borg

The last meeting of the Task Force was in July. At that time, the decision was that it would be recommended to introduce Tandem Mass Spectrometry in the Newborn Screening Program. What is needed is "seed" money for the first year to buy instruments and set up the instruments. Then after that, the cost could be incorporated in the newborn screen.

What we have so far is the initial cost. If TDH buys the equipment, the capital authority that is needed is \$2.85 million. This amount is needed because we would be buying all the equipment up front. If we lease the equipment, then the amount is \$.9 million per year over approximately 5 years, which is a total of \$4.5. The difference is in the maintenance agreements for which we also have to have capital authority. With this new equipment, it makes better sense to lease because leasing gives the option to buy or in some cases, they will replace the equipment in 3 years as long as you continue to lease. If we lease, then each year we would need the capital authority. The newborn screen fees would cover the actual cost after the initial start up costs. We think the cost that would be added on to the newborn screen would be only \$2.00 per screen. The actual cost for the first year would be 4.8 million dollars, this includes setting up all the instruments, the new software, a courier service to ensure samples are received and sent **of the** in a timely manner, the FTEs that are required, all of the reagents, and the utilities. The new system will not replace the old system; it will be in addition to the old system. The new equipment cannot be used to do four of the tests that we do now. It will be only used for PKU tests.

It has been decided to start with a small number of disorders in the panel. We want to make sure that the disorders we do screen can be treated and treatment will effectively prevent a severe problem such as mental retardation.

Jorey Berry of the March of Dimes, is putting a coalition together of people that can help advocate for expanded newborn screening. TDH staff cannot be advocates but they be can be a resource for a coalition and provide information.

Newborn Screening Update-Margaret Drummond-Borg

The Newborn Screening Rules will be present to the Board next month. We had changed some of the language and some names that were out of date but there were no major changes to the rules.

Other Business

The Case Management Rules are presently in “draft” form. Dr. Drummond-Borg will distribute the final copy at the next meeting.

We still do not have a final copy of the Genetics State Plan. When the final copy is received, it will be distributed to the committee members also.

Senator Leticia Van de Putte is interested in looking at trying to promote the State Genetics Plan but she feels the cost to implement will be a barrier.

The Resource Allocation Plan (RAP) is being written at present. The purpose of the plan is to look at how funds have been spent in the past and what resources would be needed in the future for genetic services. As soon as it is completed, Dr. Drummond-Borg will send out to all members for approval.

Next meeting is December 6th.

Meeting was adjourned.