



TEXAS COUNCIL ON AUTISM AND PERVERSIVE DEVELOPMENTAL DISORDERS

P.O. Box 12668, Austin, Texas 78711-2668
Tel: 512.438.3512 FAX: 512.438.5768

Presentation to Medicaid Commission Meeting

May 18, 2006 Irving, Texas

The Texas Council on Autism and PDD will soon finalize our State Plan on Autism. We will submit formal recommendations to the Governor's office, elected officials, legislature and various state agencies regarding the needs of people with Autism Spectrum Disorders (ASD) in Texas.

I am here to share with you what our research and extensive public input over the last year has identified as critical gaps, needs and issues for people with ASD. Our findings reflect what we have learned from internet input from stakeholders, multiple public meetings, town hall testimony, public hearings and our own statewide network of regional advisory committees. The Council feels that many of our recommendations are salient to your discussions of Medicaid.

My first comments are of a general nature. The Council recommends that all Medicaid initiatives should raise the level of public awareness and systemic focus on ASD to a level that is reflective of its prevalence and impact. Recent state and national research has shown that ASD is the fastest growing disability in the US and occurs in society at an extremely high level: 1:166 births. The rate of ASD has been documented as rising from 10-20% per year, a level of incidence that demands our national health system respond to the needs and challenges of people with ASD and their families at an appropriate level.


More specifically the Texas Council on Autism offers the following recommendations which will be defined more clearly in our soon-to-be completed State Plan.

1. Planning activities for Medicaid services which benefit people with autism should include people with ASD and/or family members. This is a complex illness and the insights from people who have experienced it are crucial to adequate planning and understanding.
2. As the Medicaid system moves toward a more generic and functional system, it is critical to ensure the recruitment, retention and adequate reimbursement of providers who have specialty expertise, knowledge and experience in autism and pervasive developmental disorders.
3. Medicaid should work to establish the most efficient methodology and funding to support a comprehensive national system and database identifying and tracking people with autism spectrum disorders. It is critical that planning and budgeting be shaped by accurate information regarding the incidence and prevalence of ASD
4. In our efforts to combine two very different disparate systems, Medicaid and managed care, we must not lose sight of the fact that some disability groups, such as autism spectrum disorders, are unique and do not fit cleanly into a medical managed care model. I am sure you are aware that mental retardation and autism spectrum disorders do not fit well within the long term care medical model of managed care. For these people and their families to receive the supports and services they need, provisions must be made to respond to their complex individual service requirements.
5. Medicaid must find a way for the "Money Follows the Person" model to be applied to all institutional settings (not just nursing homes) so as to support the Olmstead Decision, advance the President's New Freedom Initiative, and to allow individuals to live self-determined lives.

6. The Autism Council has recommended to the Governor and elected officials that legislation should be passed to establish a Medicaid waiver that is specifically related to autism and pervasive developmental disabilities. There is adequate information to show that the service and support needs of a twenty-four year old with autism are distinctly different from a seventy year old person with closed head injury or Alzheimer's, even though many of the symptoms are similar.

Finally, on a more personal note, I am the father of a 23 year old son with autism and severe mental retardation. Brian lives at home. His mother and I work hard to see that he is safe and involved in the community - with others. He will depend on supports and services, most probably funded by Medicaid, for perhaps the next 50 years. That is frightening to me, since I obviously won't be here throughout his life to take care of him and protect him. I have to believe and depend on folks like you to see that there will be funds available to make sure he has the supports and services necessary to live a happy and involved life in a community setting. I urge you to not follow a regressive path that leads to reduced services, declining funds, and lower quality of life for Brian and the millions like him. The vision of my son being institutionalized for the rest of his life because of a reduction in funds and services is incomprehensible.

Respectfully submitted:



Dr. Richard Garnett, Chair
Texas Council on Autism and Pervasive Developmental Disorders

PUBLIC MEMBERS

Dr. Richard Garnett, Chair, Fort Worth
Margaret H. Cowen, Vice Chair, San Antonio
Opal Irvin, Dime Box
Donna Geiger, Austin
Anna Hundley, Dallas
Manny Vela, Harlingen
Frank McCamant, Austin

AGENCY MEMBERS

Dept. of Aging and Disability Services (DADS)
Dept. of Assistive and Rehabilitative Services (DARS)
Dept. of State Health Services (DSHS)
Health and Human Service Commission (HHSC)
Texas Education Agency (TEA)
Dept. Family and Protective Services (DFPS)