



The Texas Health and Human Service Commission Council

**Public Testimony
Provided by Nagla Moussa
The Arc of Texas G.A. Committee Member
August 8, 2008**

We would like to first of all thank the council for this opportunity to provide comments on the HHSC budget for FY 2010 and 2011. The Arc of Texas is a non-profit organization whose mission is to create opportunities for people with intellectual and developmental disabilities to be included in their community and make the choices which affect their daily lives. The Arc of Texas was established in the 1950's and has been heavily involved in affecting public policy for all individuals with developmental disabilities.

We understand the difficulty of formulating a budget to meet the multifaceted needs of Texans with limited funding. We would like to extend our support at this time for all of the proposed exceptional items as well as the proposed HHS Enterprise Exceptional Items outlined in the LAR.

We would however, like to underscore exceptional item's number 1 and 12 relating to the expansion of Medicaid Buy-In. We would also like to emphasize exceptional item number 18 regarding the improvement of Medicaid funding to train Pediatricians and Pediatric Specialists but would like to see this expanded to adults. We also recognize exceptional item number 10, the increase to State Assistance to 2-1-1 Information Centers. As no surprise, exceptional item number 3 is particularly important to us as the reduction of the waiting and interest lists will provide thousands of individuals who continue to wait for community services the supports they need to be included in their community.

Since the national peak period of placing persons with intellectual and developmental disabilities in large, congregate-care public institutions in 1967, there has been "a significant trend toward deinstitutionalization" of this population across the nation (Community for All Toolkit, 2004). Since that time, medical advances, increased acceptance and understanding, as well as community based services and supports have all contributed to the continued movement of people with intellectual and developmental disabilities into the community across the nation. Community services and supports, not institutions, are what individuals with intellectual and other developmental disabilities and their families want and need.

Despite the recent appropriations allocated by the 79th and 80th Texas Legislatures, the waiting lists continue to grow exponentially with over 100,000 people waiting for community based services and supports. Unfortunately, the Legislature's efforts to reduce the waiting lists are not keeping pace with the real growth of the lists. On the HCS waiting list alone, over 33,000 people are waiting between 8 and 9 years to get the community supports they so desperately

need to live in the community. We commend and support HHSC's exceptional item to reduce these numbers allowing people with intellectual and developmental disabilities to have access to the community supports they require and deserve.

We would like to thank the department for the exceptional items numbers 1 and 12 for the expansion of Medicaid Buy-In programs. Medicaid Buy-In is another very significant issue that hit's home with many of our members. Many of our families who have children with special health care needs often find themselves with inadequate access to health care and other critical services. These families are victims of the Medicaid "Catch 22" where families earn too much to qualify for Medicaid but not enough to afford private insurance. Also, even if these families have access to private insurance, essential services are often excluded or specific limits are placed on those services making it very difficult for families to get the supports they need. Again, we thank HHSC for including this exceptional item in the FY 2010-2011 budget which will support the implementation of a Medicaid Buy-In Program for children with disabilities as allowed in the Deficit Reduction Act of 2005.

An issue which has recently surfaced among our members is the lack of primary care and sub-specialty health care providers for adolescent and young adults with significant disabilities and childhood diseases. While many chronic illnesses or disabilities such as congenital heart disease, cystic fibrosis, spina bifida, down syndrome, and sickle cell disease were once thought to be confined to childhood, today 90 percent of children afflicted with these illnesses are now surviving and living beyond 20 years of age primarily due to advancements in medical sciences. Each year in the United States nearly a half-million children with special healthcare needs cross the threshold into adulthood. Data extrapolated from the National Center for Education in Maternal and Child Health suggests that there are approximately 50,000 teenagers in Harris County alone with a serious chronic illness or disability. Unfortunately, "transition medicine" is a fairly new area of practice, and one that is not very profitable or popular amongst medical students who are considering leaving medical school with at least \$100,000 in school loan debt.

Today, Medicaid reimbursement rates represent approximately 20% of providers' billed rates in the state of Texas. The bleak reimbursement rates and the increased time it takes to treat adolescent and young adults with childhood illnesses and disabilities are many of the very few health care providers are willing to take this responsibility on. The few primary care providers who do care for these patients find that these patients require more paperwork, intensive case management and care coordination—services that most doctors are not trained or willing to do.

The truth is that many of these patients require subspecialty care, care that is even harder to obtain than finding a primary care provider for the traditional patient. This is yet another reason why primary care providers have a difficult time caring for these patients; they don't have the subspecialty support to assist them in the care of these medically complex patients. Given this information, The Arc of Texas strongly supports HHSC Exceptional Item #18 to restore a state-supported graduate medical education program. We ask that, if funded, special consideration be given to the need to elevate the importance of transition medicine.

While the State-Operated ICFs/MR system falls under the scope of the DADS and the DADS budget, we feel it is important to share with you our thoughts on responsibly reforming a vastly outdated service delivery system. As many of you know, some of our most vulnerable Texans

are being abused and neglected in our current service delivery system and significant improvements are needed to ensure the lives of these individuals with intellectual and developmental disabilities are protected. While The Arc of Texas recognizes that state schools are outdated and certainly not the preferred or best way to provide services to individuals with intellectual and developmental disabilities, we understand that all state school in Texas cannot be closed tomorrow, next month, or even next year. In Texas, the state school system provided services to 10,483 individuals at its peak in 1977. Today, that system serves less than 5, 000 and yet only two state schools have been closed. It's important to ask yourself; is this the most fiscally responsible way to spend state dollars? The answer is no, the state school system has yet to be "right-sized" and there are simply too many facilities for the number of individuals currently being served by the State school system.

Please know that we are not calling for the closure of state schools tomorrow, next week, or even next year, but would like to see responsible reform within the entire service delivery system.

In conclusion, we would like to thank the council for the effort and consideration they put into the FY 2010-2011 budget. As stated above, we support all HHSC exceptional items listed in your budget. Many of the exceptional items are very important to our families and individuals with intellectual disabilities and will give them the resources they need to be included in their communities.