

PUBLIC LISTENING
FORUM

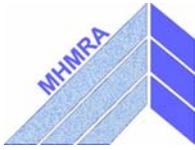
NOVEMBER 11, 2004

Sponsored by:

MHMRA of Harris County

&

Mental Retardation Needs Council
of Harris County



**MENTAL HEALTH MENTAL RETARDATION
AUTHORITY OF HARRIS COUNTY**

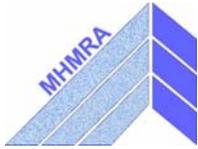
MRNC

Mental Retardation Needs Council
of Harris County

PUBLIC LISTENING FORUM

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**MENTAL HEALTH MENTAL RETARDATION
AUTHORITY OF HARRIS COUNTY**

MRNC

**Mental Retardation Needs Council
of Harris County**

PUBLIC LISTENING FORUM

Thursday, November 11, 2004

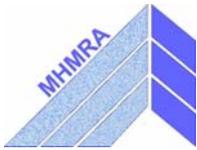
6:30pm - 9:00pm

- I. Welcome Deborah Blalock**
Chair, Mental Retardation
Planning Advisory Council
(MR-PAC)
- II. Introduction and Narrator José Ramirez, Jr.**
MHMRA of Harris County
- III. Changes and Challenges Ken Collins**
Deputy Director for Mental
Retardation Services
MHMRA of Harris County
- IV. Impact of Changes and Challenges**
.....Parents/Consumers/Providers
- V. Summary of Impacts Lynne Cleveland**
Chair, Mental Retardation
Needs Council of Harris
County
- VI. Adjournment José Ramirez, Jr.**
MHMRA of Harris County

Listening Panel:

- State Representative John Davis
Chair, House Appropriations Sub
Committee on Health and Human Services
- Addie Horn
Deputy Commissioner,
Texas Department of Aging and
Disability Services
- Janis Bane, Guardianship Program,
Harris County Protective Services for
Juvenile
Children and Adults
- Nicole Lievsay, Director of

Justice and Behavioral Health
Initiatives,
Harris County Judge's Office
- Margaret "Peggy" Boice, LMSW-AP,
Director of Public Policy, United Way
of the Texas Gulf Coast
- Steven B. Schnee, Ph.D.,
Executive Director, Mental
Health and Mental Retardation
Authority of Harris County
- Harvey Hetzel, Executive Director,
Harris County Juvenile Probation
Department
- Stephen Williams, Director of
Health and Human Services,
City of Houston
- R. King Hillier, Director of Legislative
Relations, Harris County



MENTAL HEALTH MENTAL RETARDATION
AUTHORITY OF HARRIS COUNTY

MIRNC

Mental Retardation Needs Council
of Harris County

Público que Escucha Foro

El jueves, 11 de noviembre de 2004

6:30pm - 9:00pm

- I. BienvenidosDeborah Blaclock
Presidencia, Concilio Consultivo
Planea de Retraso Mental (MR-
PAC)
- II. Introducción y Narrador..... José Ramirez, Jr.
MHMRA de Condado Harris
- III. Cambios y Retos.....Ken Collins
Director Diputado, Servicios
De Retraso Mental,
MHMRA de Condado Harris
- IV. Impacto de Cambios y Retos Parientes/Consumidores/Provedores
- V. Resumen de Impactos.....Lynne Cleveland
Presidencia, Concilio de
Necesidades
De Condado Harris
- VI. Suspensión José Ramirez, Jr.
MHMRA de Condado Harris

Group de Oventes:

Condado de Harris

- Representante Estatal John Davis
Presidencia, Cámara de Apropiación
Comité contra Salud y Servicios Humanos
- Addie Horn
Comisario de diputado
Departamento de Envejecimiento y Servicios de
Incapacidad de Tejas
- Janis Bane, Programa de Tutela,
Condado de Harris Servicios
Protectores para Niños y Adultos
- Nicole Lievsay,
Directora de Justicia Juvenil e Iniciativas de
Salud Behaviorísticas, Oficina de el Juez de
Condado de Harris
- Margaret “Peggy” Boice, LMSW-AP,
Directora de Camino Público de Política,
Unido de la Costa de Golfo de Texas
- Steven Schnee, Ph.D.,
Director Ejecutivo, Salud Mental y Autoridades
de Retraso Mentales de Condado Harris
- Harvey Hetzel, Director Ejecutivo,
Departamento de Juveniles de el
Condado de Harris
- Steven Williams, Director de
Salud y Servicios Humanos,
- R. King Hillier,
Director de Relaciones Legislativas,

Ciudad de Houston

This page is located as an attachment

Public Listening Forum Flyer
In English

Por favor de estar presente a este foro público de política para informar mejor a los líderes quien desarrollan política para el público en cuanto a cuestiones y preocupaciones que afrontan a individuos con la invalidez cognoscitiva y sus familias. Los participantes confirmados para este tiempo incluye:

- Representante Estatal John Davis
- Janis Bane, Programa de Tutela, Condado de Harris Servicios Protectores para Niños y Adultos
- Margaret “Peggy” Boice, LMSW-AP, Directora de Camino Público de Política, Unido de la Costa de Golfo de Texas
- Harvey Hetzel, Director Ejecutivo, Departamento de Juveniles de el Condado de Harris
- R. King Hillier, Director de Relaciones Legislativas, Condado de Harris
- Nicole Lievsay, Directora de Justicia Juvenil e Iniciativas de Salud Behaviorísticas, Oficina de el Juez de Condado de Harris
- Steven Schnee, Ph.D., Director Ejecutivo, Salud Mental y Autoridades de Retraso Mentales de Condado Harris
- Steven Williams, Director de Salud y Servicios Humanos, Ciudad de Houston
- Esperan a participantes adicionales, pero no aún confirmado.

Presentado por Concilio de Necesidades de Condado Harris en la cooperación con Concilio de Consejo Cosultivo de Retraso Mental de MHMRA del Condado Harris.

FORO DE ESCUCHA PÚBLICO
¡Este es una oportunidad de su voz para contar!

El jueves, 11 de noviembre
6:30 de la tarde - 9:00 de la tarde.
La Iglesia de Metodista Unida de San Luke
3471 Westheimer, Houston 77227



¿Por qué su asistencia es importante?

1. Para niños y adultos con discapacidades cognitivas como retraso mental y autismo, es importante que aquellos que desarrollan y ponen en práctica la política pública totalmente entiendan las necesidades y el impacto que aquellas políticas tienen sobre sus vidas.
2. Este "Foro de Escucha Pública" es una oportunidad de usted para ayudar a formar nuestra política pública por compartir su historia.
3. Usted puede informar personalmente nuestra comunidad y aquellos que desarrollan y ponen en práctica la política pública sobre sus necesidades o cuestiones. Tome esta oportunidad de avisarlos lo que choca cortes recientes en servicios o la carencia de servicios han tenido sobre su niño y su familia.

Si le gustara participar como un altavoz, por favor envíe sus declaraciones escritas por correo electrónico a MRNCgroup@hctx.net. Si usted tiene cualquier pregunta, por favor póngase en contacto con Judy en el Arco de Houston Mayor en 713-957-1600.

Mental Health Mental Retardation Authority of Harris County Mental Retardation Services Division

The Following Services May Be Applied For Directly

- **Early Childhood Intervention/ECI (713) 970-4900 - Children less than 3 years of age**
Provides services designed to assist parents in addressing the needs of young children with delayed development.
- **In Home & Family Support (713) 970-7229 - All ages**
Provides funding of “last resort” to individuals who lack natural resources to purchase a service(s) or item(s) that is directly related to their mental disability.
- **HCS (formerly MRLA) Program Waiting List (713) 970-7799 - All ages**
Links individuals to a community oriented service system that is driven by consumer choice.
- **Texas Home Living Waiver Program (713) 970-7799 - All ages**
Links individuals to a comprehensive service system that is community-based.
- **Transition Services (713) 970-3422 - 12 years and older**
Assists students completing public school to receive services from community-based programs including MHMRA.

The Following Services Require Eligibility Determination By MHMRA Please contact Access Center at (713) 970-7070

If an individual is diagnosed with Mental Retardation, Autism, Asperger’s Syndrome or Pervasive Developmental Disorders (PDD), s/he is classified as priority population in the MR Division of Harris County MHMRA and may be eligible for the following services:

- **Clinical Services 3 years and older**
Provides time-limited, intensive, specialized behavioral, psychiatric and speech language services.
- **Day Programs 18 years and older**
Provides training to assist consumers to become employed or to increase skills in daily living.
- **Residential Services 18 years and older**
Provides long term, 24-hour care in a community setting.
- **Respite All ages**
Provides family temporary relief from caring for the individual with disability, either in home or out of the home.
- **Service Coordination All ages**
Provides individualized planning, authorization, linkage, coordination, and monitoring of services.
- **Supported Home Living 18 years and older**
Provides training in the consumer’s home to assist them to optimize community living.

**IN CASE OF EMERGENCY
CONTACT THE MHMRA ACCESS CENTER ANYTIME AT
(713) 970-7070**

For more information: www.mhmraofharriscounty.org

September, 2004

La Autoridad de Salud Mental y Retraso Mental del Condado de Harris

Servicios de la Division de Retraso Mental

Usted Puede Aplicar Para Los Sigüientes Servicios Directamente

- **El Programa de Intervención Temprana en LA Infancia (ECI) 713-970-4900 – Para niños menor de 3 años**
Prove los servicios diseñaron asistir a padres en la dirección a las necesidades de infantes con desarrollo retrasado y/o desarrollo atípico.
- **Apoyo en Casa y Para La Familia 713-970-7799 – Para personas de todas edades**
Prove fondos de último recurso para familias que no tengan los recursos naturales para comprar servicios o artículos que estan directamente relacionados a la incapacidad mental.
- **Casa y Comunidad Programa de Servicios Basada (HCS) Lista de Espera, 713-970-7799 – Para personas de todas edades**
Une al individuo a un sistema de servicios con orientación a la comunidad.
- **Programa de Tejas para Vivir en Casa (TxHmL), 713-970-7799 – Para personas de todas edades**
Une al individuo a un sistema de servicios con orientación a la comunidad.
- **Servicios de Transición/Recursos 713-970-3422 – Para estudiantes más de 12 años**
Prove información a distritos escolares en el Condadao Harris en cuanto a servicios MHMRA.

Los Sigüientes Servicios Requieren Una Determinación de Elegibilidad de MHMRA **Favor de hablar al Centro de Acceso al Número 713-970-7070**

Si un individuo tiene un diagnóstico de Retraso Mental, Autismo, Síndrome de Aspergers o Desorden Profundo del Desarrollo, se considera prioridad de población en MHMRA bajo la división de Retraso Mental del Condado de Harris y puede ser elegible para los sigüientes servicios:

- **Servicios Clínicos – Para niños más de 3 años**
Prove servicios intensivos especializados en comportamiento especializado, servicios de psiquiátrico y halba lenguaje, por tiempo limitado.
- **Programa de Día – Para personas más de 18 años**
Prove entrenamiento para asistir a consumidores ser empleados o para aumentar las habilidades de vida diaria.
- **Servicios Residenciales – Para personas más de 18 años**
Prove cuidado a largo plazo las 24 horas en un ambiente comunitario.
- **Servicios de Descanso – Para personas de todas edades**
Prove servicio de relevo temporal para la familia al cuidar a una persona con incapacidad sea en casa o fuera de casa .
- **Coordinación de Servicios – Para personas de todas edades**
Prove planeación individualizada, autorización, conexión, coordinación y repaso de servicios.
- **Apoyos de Comunidad - Para personas de todas edades**
Proporciona habilidades independientes vivas que se entrenan para realizar la vida de comunidad.
- **Servicios de Empleo Apoyados – Para personas más de 18 años**
Proporciona ayuda de colocación de trabajo, entrenamiento de trabajo, y servicios de continuación para personas que desean el empleo en la comunidad.

EN CASO DE UNA EMERGENCIA
LLAME AL CENTRO DE ACCESO DE MHMRA A CUALQUIER HORA AL
713-970-7070

Para más información: www.mhmraharriscounty.org



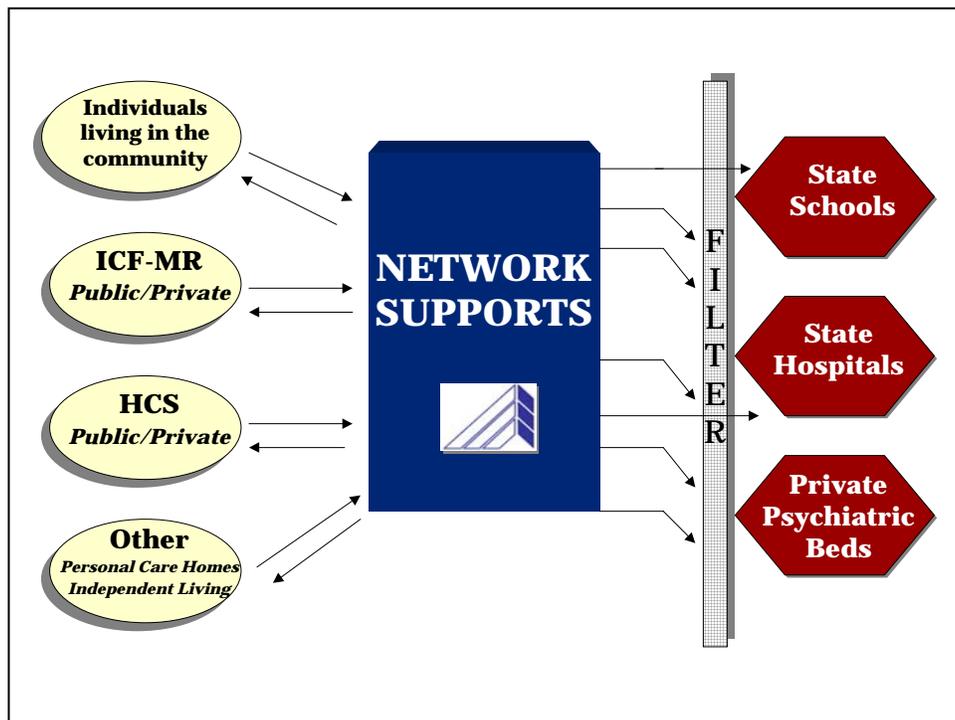
Public Listening Forum

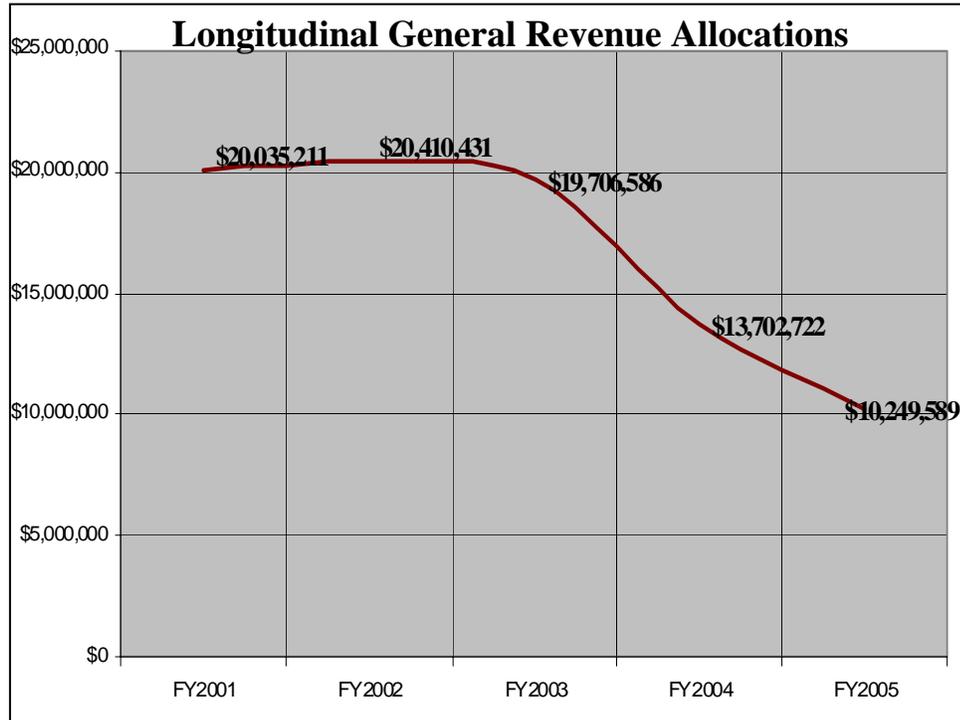
November 11, 2004



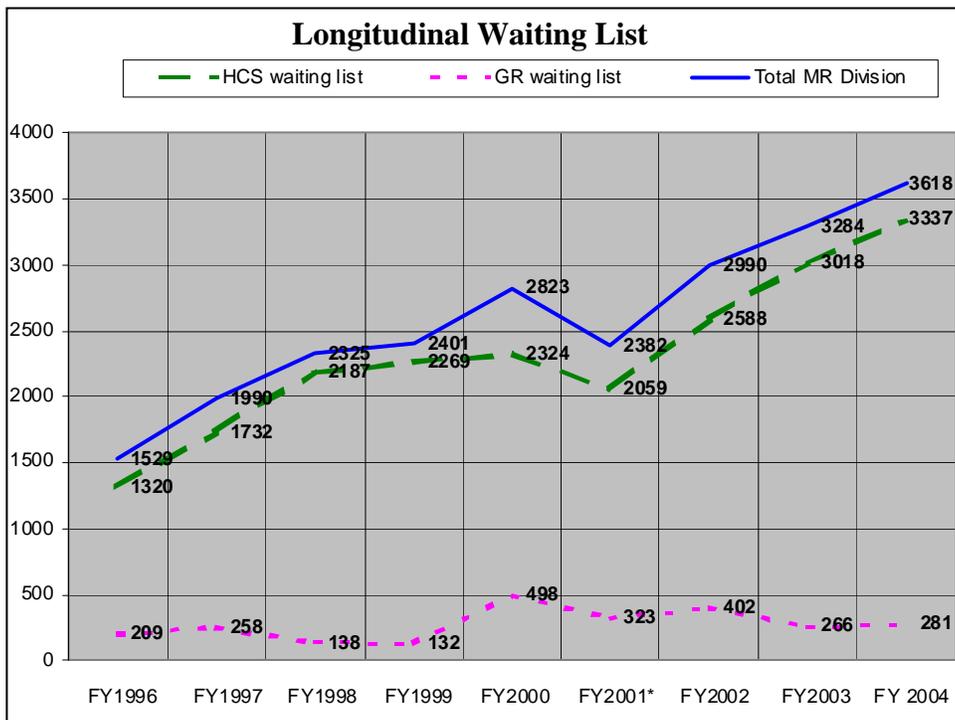
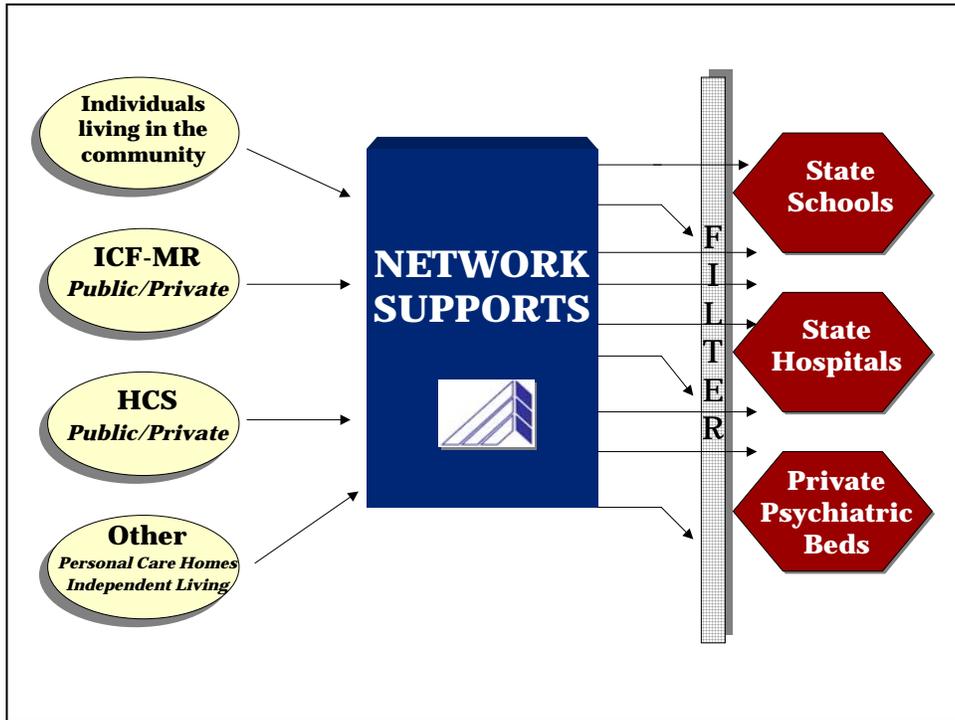
Presentation Overview

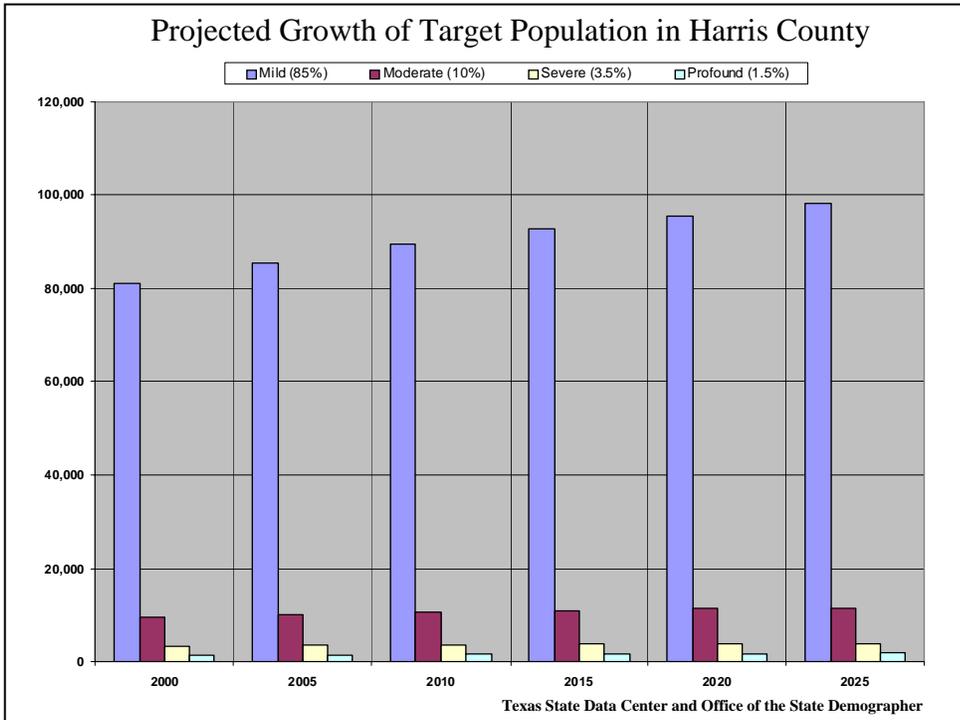
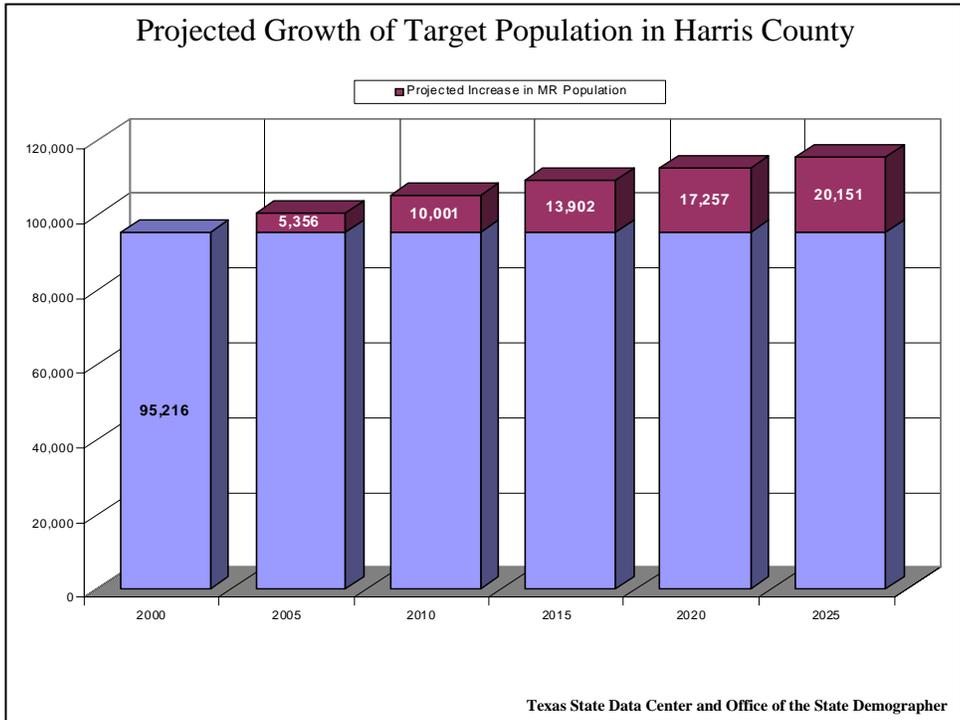
- MR Service Delivery System
- Network Support Concept
- Budget Reductions
- Impact of Budget Reductions on Services
- MR Waiting List
- Projected Growth of Target Population

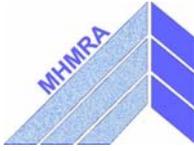




<u>Who is in the network?</u>	<u>How has MHMRA helped?</u>	<u>Service implications FY05</u>
95,216 Harris County Residents	•Network contracts	Reduced 25%
•900 in private ICF-MRs	•In-home applied behavior analysis support	Closed
•30 in public ICF-MRs	•Day program for adults with severe behavior problems	Closed
•1500 in private HCS programs	•Day program for dually diagnosed adults	Reduced 50%
•129 in public HCS programs	•Employment services	Reduced 33%
•135 in TxHmL services	•In-Home rehabilitation services	Closed
•Many others in private residential programs or personal care homes.	•Psychiatric clinic for dually diagnosed children and adults	Reduced 50%
•Others who live in their own or family homes.	•Transition services	Reduced 95%
	•Transportation supports	Closed







**MENTAL HEALTH MENTAL RETARDATION
AUTHORITY OF HARRIS COUNTY**

WRITTEN TESTIMONY
TESTIMONIO ESCRITO

If you wish to have your testimony heard or read by elected officials/policy makers, please write your comments below. You may be asked to verbally present your comments at the forum on November 11, 2004. (Please continue on back of sheet if you need additional space.)

Si usted desea que su testimonio sea leído o oído por oficiales elegidos/desarrollantes de política pública, favor de escribir sus comentarios. Es posible que usted pueda ser llamado(a) para presentar sus comentarios el día de el foro el 11 de noviembre 2004. (Puede continuar detrás de esta página si necesita más espacio para escribir.)

Consent/Permiso

Date/Fecha



ORDER OF ORAL TESTIMONIALS

November 11, 2004

1. Mina xxxx (Spanish) - *
2. Rosalia xxxx (Spanish) - *
3. Maria xxxx (Spanish) - *
4. Graciela xxxx (Spanish) - +
5. Consuelo xxxx (Spanish) - *
6. Rosale xxxx (Spanish) - *
7. Doug xxxx - *
8. Georgia xxxx - *
9. Ying xxxx - *
10. Michelle xxxx - *
11. Linda xxxx - *
12. Pamela xxxx - *
13. Cynthia xxxx - *
14. Renee xxxx - *
15. Candis xxxx - *
16. Norma xxxx - *
17. José xxxx
18. Julie xxxx
19. Mary Jane xxxx
20. Linda xxxx
21. Le xxxx
22. Mary Helen xxxx
23. Karen xxxx
24. Celetina xxxx

* Presented oral and written testimony.

+ Chose not to present testimony but provided written comments

I am here today to briefly talk about my son, xxxxxxxx. Juan is 34 years of age today, and is autistic. I don't want this presentation to have a negative tone but a positive one. You see Juan today a man who you would not think is autistic. Juan has a long history; from the time he was 2 years of age to age 12, his behavior was out of control and worse than some animal's. I did not know what to do with him and at the time the educational systems were not helpful. Juan's father never cared and wanted nothing to do with him.

I left Puerto Rico, Juan's birthplace, and started my search to find help for him anywhere I could find it. The help was scarce at the time and I saw very little interest in him from the available resources as the years passed me by. I could have done more for Juan but I did not have the opportunities nor the help from the existing agencies. Our political representatives have to seriously think about providing additional assistance to our mentally handicapped children. I mention the kids especially because it is when they are young when more can be done for them. You cannot wait until they are much older, since you then cannot change and mold their future. It is not right for the state to continue cutting money and services to these children, eliminating future opportunities to keep them in their communities. If there are no early interventions, some of these kids would end up institutionalized, costing the state more.

With the little assistance I received, as you can see, Juan leads a somewhat productive life. As his mother I refuse to stop searching for assistance and opportunities for him, always looking and going where it may be necessary to go. This will always be my priority and this is why I ask you today for a little help. This help can be given more to the young children who could have the opportunities that Juan was not given.

Mina xxxx

Hoy estoy aquí para hablar brevemente de mi hijo Juan xxxx. Juan hoy cumple 34 años y es Autístico. No quiero hablar en forma negative, sino más bien positiva. Ustedes ven a Juan hoy; no parece Autístico pero historia es larga. Desde que tien dos años hasta la edad de doce su conducta fue fuera de control y peor que un animalito. Yo no sabía que hacer, porque no había mucha ayuda de los sistemas educativos. No tuve apoyo de su padre.

Dejé Puerto Rico, lugar de nacimiento de Juan xxxx, y empecé a buscar ayudar, donde fuese. No fue mucha y vi muy poco interés en el durante los años que pasaron. Pude hacer mas por Juan, pero no tuve la oportunidad ni la ayuda de las agencias que proveían servicios. Nuestros representantes políticos tienen que poner más interés en ayudar a los niños con problemas mentales. Digo niños, especialmente, porque es cuando son pequeños que necesitan que se les ponga interés; no se debe esperar a que lleguen a una edad en la cual ya no se puede cambiar su comportamiento. Los profesionales deben de hacer su trabajo, ayudar a este grupo de personas especiales y darles la oportunidad de un mejor futuro. No es posible que el estado siga reduciendo y cortando el dinero para proveer servicios y oportunidades que permitan que estos individuos permanezcan en la comunidad. Si no hay ayuda estos niños terminarian en instituciones que serian mas costosas para el estado.

Con la poca ayuda que recibí ustedes pueden ver que Juan lleva una vida decente y productiva porque como su madre no renunció a seguir buscando ayuda y oportunidades para él. Es por eso que les pido nos den mas ayuda, especialmente a los pequeños que tendrían la posibilidad de mejorar y cuales Juan no tuvo.

Nina xxxx

Rosalia xxxx

Hello, my name is Rosalinda xxxx, mother of a 12 year old boy. The reason that I am here is because I would like to share with you a great dilemma I am facing. My dilemma is in answering two questions: 1)What can I do for my son now?; 2) but more importantly, what can I do for my son in several years when he gets bigger, stronger, more disabled and more aggressive, and when I am older, with a greater level of desperation to seek alternatives in order to meet his needs.

My son Javier was diagnosed with developmental delay at the age of six months. He received physical therapy, speech therapy and special braces to assist him in walking.

At age three, he was diagnosed with mental retardation and his limitations became my own as he was extremely hyperactive and needed constant attention.

At age six, my son was diagnosed with autism. This diagnosis gave me a sense of comfort in that finally I understood what was wrong with him. Unfortunately, knowing his diagnosis did not lessen his inappropriate behavior. Today, at age 12, my son paces a great deal, he routinely destroys things, he will take out all of the clothes from the closet and throw them around the room, he hits himself on the head, daily he bites my fingers when I brush his teeth, he pulls my hair and that of others. I am afraid to think about how he will be in five years when his sexual development occurs, when I have to shave him, when his physical aggression may be seen as one where police might place him in jail.

I am deeply embarrassed to say that I need help now and not in five years. Services for my son do not exist at the moment and my strength is diminishing. Every day is a challenge.

Yesterday I lost my marriage, in part, due to my husband's inability or unwillingness to understand our son.

Today my own mother urges me to place my son in an institution as she sees no hope for his future. The only support I currently receive is from women who understand my situation as they are experiencing similar dilemmas.

For tomorrow, my desire is to stop feeling that I am imprisoned. I have never done anything wrong in my life. I want to feel the freedom to leave my tiny apartment knowing that my son is receiving appropriate services and his aggressive behavior has lessened.

I dearly love my son and will advocate on his behalf until my last breath. I have believed that he has not learned because I have not been a good teacher and mother, but I've come to realize that what he needs is services provided by trained professionals. Regrettably, the state is taking away these professionals my son needs as funds continue to be cut.

Thank you very much.

Rosalia xxxx

Hola, mi nombre es Rosalia xxxx, la madre de un hijo quien tiene 12 años. La razón que estoy aquí hoy es porque yo les quiero platicar de un gran dilema que tengo yo. Mi dilema es en qué hacer con mi hijo hoy, pero más importante, que voy hacer con él en unos cuantos más años cuando este más grande, más fuerte, más incapacitado, más agresivo, y yo estoy más vieja, con más desesperación y con menos alternativas para poder darle lo que necesita.

Mi hijo, Javier, fue diagnosticado con desarrollo atrasado a la edad de seis meses. Él recibió fisioterapia, logopedia y equipo especial para que pudiera caminar.

A los tres años, él fue diagnosticado con retraso mental y sus limitaciones fueron limitaciones más también, porque llegó hacer muy hiperactivo y necesitaba mucha atención.

A la edad de seis años, mi hijo fue diagnosticado con autismo. Este diagnóstico me dio consuelo en por fin saber que es lo que él tenía. Desgraciadamente, sabiendo su diagnóstico no ayudó para aplacar su comportamiento. Hoy a la edad de 12 años, mi hijo está muy inquieto, destruye cosas, saca toda la ropa de los cajones, se da topes en la cabeza, todos los días me muerde los dedos cuando le lavo los dientes, estira los cabellos a mí y otros. Me da miedo pensar en cómo va a estar en cinco años cuando su desarrollo sexual empiece, cuando lo tenga que resurar, cuando sus lastimaduras a otros sean considerado algo en que la policía lo podrá encarcelar.

Me da pena en decir que yo necesito ayuda hoy y no en cinco años. Los servicios para mi hijo no existen al momento y mi fuerza no es como antes. Cada día es un reto.

Ayer perdí mi matrimonio, en parte porque mi marido no comprendía a nuestro hijo.

Hoy mi madre me dice que debo de enternar a mi hijo porque no tiene remedio. El único apoyo que recibo es en mis compañeras quien comprenden mi dolor porque ellas también tienen dilemas similares.

Para mañana, yo deseo parar de sentirme como si estuviera encarcelada. Yo nunca he hecho algo malo en mi vida. Yo quiero mi libertad para poder salir de mi pequeño apartamento sabiendo que mi hijo está recibiendo sus servicios propios para que él se pueda mejorar y no ser agresivo.

Yo quiero mucho a mi hijo y lucharé por él hasta el momento que ya no tenga fuerza. Pienso que él no aprende porque yo no le he enseñado, pero lo que él necesita son servicios de profesionales. Desgraciadamente, el estado me está quitando estos profesionales con el corte de fondos.

Muchas gracias.

Good evening members of the panel. My name is Maria xxxx, single mother of three sons with multiple disabilities. I am here to say that, for the moment, I have plenty of services for my children through the HCS Program. However, I am also here to let you know that prior to 1996, the lack of services cost our lives dearly.

I came to this country at age 14, with limited knowledge about life and no knowledge about problems with genetics which greatly impacted my children. Today I am a U.S. citizen, own my home and work part time.

I married very young, and in a span of five years, had three sons. All of them are blind, deaf, mute and have cerebral palsy and severe mental retardation. My husband worked seven days a week in construction in order to support the family. With my family living in another country and his family's rejection of our children, I felt alone. I felt so alone as if I was the only woman on the planet with three parts of my blood in need of my help..... hour after hour, day after day, week after week, year after year.

For 12 years, I received absolutely no assistance for my children from the state, primarily because I did not know how to advocate on behalf of my children, Eraklio, Luis and Roberto. During this time I lost weight to the point of being unhealthy, cried constantly, had disagreements with my husband, never left the house and experienced severe depression, and the only reason I did not end my life was because of my children. I got to the point where my life was dark and bleak, did not have time for others or myself and my husband and I fell out of love.....and we divorced.

My world was closing, until I found some friends who were my own image in a mirror, except they had life and energy. They helped me apply for respite care and funding from the In Home and Family Support Program, which made it possible to provide ramps, grab bars, lifts and special bathrooms, and they led me to the waiting list. They offered me their shoulders for me to cry on and taught me how to drive even though they did not have a driver's license. They taught me how to speak on behalf of my children and helped me develop a hard shell when hearing "no" to my requests for help. The only thing I have not learned to do is to ask the question about what will happen to my beautiful children when I am no longer available.

But, for the moment, I think in a positive mode, practice my English and sign language, serve as coach for the Special Olympics, dedicate my spare time to help others and continue to stay young at heart.

Unfortunately, this positive approach cannot continue as the state proceeds to cut back on funding for children loved by us to have a happy life.

Please stop cutting back on funding for our children. We must avoid a chapter such as the one I experienced.

Buenos noches estimados panelistas. Mi nombre es Maria xxxx, madre soltera de tres hijos con un multitudine de impedimientos. Yo estoy aqui para decirles que, por el momento, tengo bastante ayuda para mis hijos por parte de el HCS. Pero tambien estoy aqui para platicarles que la falta de ayuda antes de 1996 me costo much en nuestras vidas.

Yo vine a este pais a la edad de 14, sin saber de la vida ni mis problemas geneticos que afectaron a mis hijos. Hoy tengo mi ciudadense, tengo mi propio hogar y trabajo de medio tiempo.

Yo me case muy joven y en cinco años tuve tres hijos con retraso mental severo, parálisis cerebral, falta de vista, sordos y mudos. Mi marido trabajaba siete días a la semana en construcción para poder sostener a la familia. Con mi familia en otro pais y la familia de mi esposo rechazando a mis hijos, yo me quede sola. Sola como si yo fuera la unica mujer en el mundo con las tres partes de mi sangre en necesidad de my ayuda, hora tras hora, día tras día, semana tras semana, año tras año.

Por 12 años, yo no recibí absolutamente nada de ayuda de el estado porque no sabia como defenderme y luchar por mis hijos, Eraklio, Luis y Roberto. Durante ese tiempo delgase a un nivel que no era saludable, lloraba constantemente, tenia playtos con mi marido, no salía de la casa, tenia una tremenda depresión y la unica rason que no termine mi vida fue por mis hijos. Llego al punto en que mi vida estaba siempre oscura, no tenia tiempo para otros ni para mi y mi marido y yo nos desenamoramos...y nos divorciamos.

Mi mundo se estaba cerando, cuando me encuentre a unas compañeras quien eran mi espejo, pero con vida y animo. Ellas me ayudaron a aplicar para dias de descanso, para recibir fondos de el programa de familia y apoyo (IHFS) para renovar mi casa con rampas, baras de agaraderas, baños especiales, y informarme sobre la lista de espera. Ellas me ofresieron sus hombros para llorar y me enseñaron como manejar aunque no tenian licencia. Ellas me enseñaron a como hablar en parte de mis hijos y desarrollar una concha de tortuga. Lo unico que no he podido aprender es de pensar qué es lo que pasará con mis lindos hijos el cuando yo falte.

Pero, por el momento, yo pienso en un modo positivo, practicando mi ingles y comunicarme por señas, ser entrenador de los juegos olímpicos, dedicar tiempo a ayudar a otras y seguir siendo joven y bella de corazon.

Desgraciadamente, la actitud positiva no puede continuar para todo mundo porque el estado sigue cortando fondos esenciales para continuar la vida y felicidad de nuestros hijos quien solamente las madres aman.

Por favor no sigan cortando los fondos para nuestros hijos. Necesitamos que evitar un capitulo como el mio.

Good afternoon. I am here today to see if I can be heard about the many problems that exist with programming, that as mothers we are faced with children who have many needs and which funding cuts impact existing programs. My child has been on the HCS waiting list for eight years with no possible movement in the near future. I am pleading that something be done about this lengthy waiting list so that our children may receive needed services.

I am the mother of Patricia xxxx who has cerebral palsy, mental retardation, and needs disposable diapers, someone to care for her while I attend to other family matters, and a bath chair. My child does not walk, cannot speak and needs 24 hour care. My daughter is 18 years old and attends special education classes, but in a few years she will not have any programming and faces a lifetime of being restricted to her bedroom.

With the availability of HCS, the family would be able to send Patricia to day programming, and get her a custom made wheel chair to fit her body, bath chair and disposable diapers. If I do not receive this assistance from HCS, I may have to consider placing her in an institution at a cost of over \$45,000 per year and the cost absorbed by the government. My wish is to keep her at home and avoid institutionalization. I beg you to please listen to our concerns, and the needs of our children. My daughter has difficulty moving inside our home with narrow halls and doorways, but HCS can help us correct this. We have learned the hard way not to be narrow in our thinking and have united to form one voice on behalf of our children.

Without funding, we are unable to properly care for our children. Therefore, we are here to request that sufficient funding be made available to eliminate the waiting list. The availability of respite will allow us to do more for our families.

We all hope that something can be done to help all of our children with disabilities.

Graciela xxxx

Buenas Tardes Sres. Leisladores:

Yo mando esta carta para ver si me escuchan y ven los problemas que hay con los programas, que tenemos tanta necesidad las madres de estos niZos especiales y que cada día son más recortes en los programas. Yo tengo 8 aZos en la lostade espera de HCS y no hay repuestos, no hay nada. Yo quisiera pedirles a Ustedes que ya no este tan larga la lista de espera porque nuestros hijos necesitan las ayudas.

Yo soy mama de Patricia xxxx, mi hija tiene parálisis cerebral y retraso mental y yo necesito much ayuda con sus oanales, alguien que me ayude a cuidarla, ahorita tengo mucha necesidad de una silla de baZo que no me la han podido aprobar. Mi hija usa silla de ruedas, no camina, no hablam tengo que ayudarle las 24 horas el dia. La nina tiene 18 aZos y en un poco tiempo termina la escuela y si no hay un programa que la reciba a ella despues de que salga de la escuela, no se lo que voy a hacer para ayudarle aqui encerrada en la casa todo el dia.

Si tuvieramos el programa HCS podiamos ayudarnos un poco con mandarla a algun programa de day-habilitation, podriamos conseguir la silla para el bano y panales. Ella tambien va a necesitar una silla de ruedas nueva porque sigue creciendo y la silla que tiene ahorita, al rato ya no le va servir. Yo quisiera que la programa HCS nos diera un poco de ayuda porque si no, de lo contrario yo tendria que poner a mi nina en una institucion y el gobierno tendria que pagar mas de \$45 mil por ano para cuidarla. Pero yo no quiero ponerla alli, yo quiero cuidarla y tenerla con nosotros y siga con su papa y su hermana y conmigo, por eso necesitamos la ayuda del HCS. Yo les pido que nos escuchen y que hagan algo rapido para nosotros poder hacer algo para nuestros hijos. Aqui en la casa las puertas estan muy angostas y el bano no es amplio para meter la silla de ruedas pero no tenemos los recursos para arreglarle el bano como debe ser y por eso juntamos nuestras voces para que Ustedes sepan nuestras necesidadesy

Sin recursos no podermos hacer nada y por es estamos aqui pidiendo que nos ayuden y que pongan dinero en los programas para que se termine la lista de espera, necesitamos un poco de Respite porque hay dias que las mamas nos sentimos mal o estamos enfermas y tenemos que seguir cuidando nuestros hijos, y con Respite puede venir alguien a ayudarnos aunque sea una o dos horas al dia.

Por eso pedimos que puedan hacer also para todas las madres con hijos incapacitados.

Sinceramente,

Sra. Graciela xxxx

Dear panel members, my name is Consuelo xxxx, I am the mother of a young girl who does not receive any services. I feel concerned and saddened by this. She is in need of services essential to a person with disabilities.

My daughter was born with cerebral palsy, uses a wheelchair and pampers and is enrolled in special education. Her name is Christina xxxx, age 13 and last year she received services from CHIP and CIDC (children's disability). My family is comprised of me, my husband and our daughter. My husband is a very good father and works hard to keep a roof over our heads and food on the table. On many weekends, he works Saturday and Sunday. Unfortunately, the family has been punished for his good work by being considered ineligible for CHIP and CIDC for earning a few dollars more.

Ladies and gentlemen, because of my husband's hard work, my daughter no longer has access to therapists, pampers, medical and mental care, and wheelchair. The most important need is medical care because of her respiratory problems and asthma. Currently she can be seen at Shriner's Hospital every nine months, but she does not receive disposable diapers, medicines nor therapy.

Our daughter is desperately in need of a ramp to enter our home, a lift to bathe her and a wider door to enter her bedroom. The In Home and Family Support Program used to provide this assistance, and with a reduction in funds by the State Legislature, our daughter is now on the waiting list.

At the moment, the only hope for help is if the State Legislature allows more money for HCS so she can come off this waiting list, but we have been told we might have to wait eight years for this service.

I beg you to please help in having my daughter to again receive services from CHIP and CIDC. I cannot ask my husband to stop working on weekends as we still need food on the table, but I can ask each of you to help with funding so that she can come off the HCS waiting list.

Thank you for your attention and hope that you can persuade those in Austin to not forget our special children who are voiceless and need your help.

Rosy xxxx

Dear Ladies and Gentlemen,

I am Mrs.xxxx, mother of a 16 year old child who has Rhett Syndrome, a genetic and chronic neurological disorder, as well as cerebral palsy and mental retardation.

I am very concerned about all of the recent changes, adjustments and cuts in funding for persons with chronic disabilities. It is certainly sad to see how these decisions are impacting our disabled children, as well as us as parents who serve as teachers and guardians for them. It is extremely difficult for me as a mother to meet all of my daughter's needs. In attempting to meet her needs, I have had to serve as her nurse, social worker, physical therapist, chauffeur and more. We dearly love our daughter, but we are not made of stone, and do get physically tired. We need help. These children as individuals cannot be ignored and we must advocate on their behalf.

WE ARE ONE VOICE, DO NOT IGNORE US!!!!

My name is Doug xxxx. My wife, Vickie and I are the parents of eight children ages 23-30, most of which are married and living in other states. Our twenty-seven year old daughter, Autumn, has been handicapped since birth with severe mental retardation, cerebral palsy, and autism - with epilepsy showing up at age 12. Developmentally, Autumn is at the level of 1½ year old child. She needs someone to feed and dress her in care for all her needs. Autumn has always lived at home. Until her "graduation" five years ago, she attended programs in the public schools. She currently attends a private pay day program (Monday - Friday) for 3-4 hours a day.

Twenty months ago Autumn became seriously ill with pneumonia and was in the hospital for ten weeks. Because she suffered damage to her lungs, Autumn continues to need supplemental oxygen and respiratory treatments every six hours day-and-night.

Autumn receives a monthly SSI stipend. Medicaid pays for her prescriptions, and we get a little help with paying for an occasional babysitter. We are very grateful for this help and for my employee health insurance continuing to cover her. However, our portion of her medical and other costs such as day programs, diapers, etc., range from around \$6,000 a year to over \$12,000 if she is hospitalized. These costs are exclusive of the normal costs of food, clothing and shelter that SSI partially offsets. While we are able to afford these costs at this time, it would not take much to change that. I should mention that there are many people caring for their adult handicapped children who truly struggle with costs involved.

Autumn is our daughter, and we intend to continue to care for her in our home for as long as we are physically able. Because that, combined with an appropriate day program, is what is best for her. However, we are concerned about her future care when we become too old to carry the load. Each day it is necessary to spoon feed Autumn her meals, dress her, bathe her, change her diapers, manage her oxygen needs and equipment, give her oral and inhaled medications, suction secretions from her lungs, clean and care for her trach, transport her to and from her day program, and generally keep her out of trouble—it is not easy to find someone that can take over Autumn's care for more than a few hours much less a day or more.

We are also concerned about short term situations that may jeopardize our ability to care for her. For instance, Vickie will be undergoing a surgical procedure on December 1st. Fortunately, one of our married daughters is available and we will be flying her in from out of state to help with Autumn while Vickie is in the hospital. But sooner or later we are going to be in a real bind.

Autumn has been on the HCS waiting list since March of 1998. Will she make it to the top in the next 15-20 years that Vickie and I expect to be able to care for her? Your guess is as good as mine.

Again, we are grateful for the help and support that we receive in caring for Autumn, but we do worry about what the future holds for her.

Thank you,

Doug and Vickie xxxx

I am the mother of Garrett, who is 24 and has a rare neurological disorder similar to autism. Garrett is incapable of self-support. He is unable to speak and has profound cognitive difficulties.

However, he is a very active young man who loves life and is fully engaged with the people around him.

We recently moved from out of state because my job required it.

Unfortunately, Garrett's life and our life as a family have suffered. We have gone from having \$25,000 a year in needed services provided to having NO help.

I've been told we can expect the same for at least several years.

This is our situation now that we have moved to Texas:

Garrett has day habilitation during my work hours only because I pay for it out of pocket.

He has none of the other services he needs for his physical and mental well-being. He is bored. He has gained 30 pounds. He has behavior problems. But it's not only Garrett whose life has changed.

My husband and I accept that we have full responsibility for Garrett because he cannot be left alone for even a minute.

However, now that we have no respite care we must provide 24/7 supervision. We have no time to ourselves - - no life as a couple - - ever.

I am here to appeal to you to help Garrett and others like him. These are people who, through no fault of their own, completely depend on others every minute of everyday of their lives.

I love my son and I'm more than willing to do my part. But I need your help.

Thank you for considering my remarks.

Georgia xxxx

November 11, 2004

Honorable guests:

Three years ago, in the summer of 2001, my autistic daughter started having mood swings. By the end of that year, she started running away whenever her anxiety level was too high for her to handle. Because her social skills were equivalent to those of a five-year-old, we had no choice but to follow her. The first time she eloped, we walked 10 miles. Soon we started getting police involvement. A month later, on a Sunday which happened to be my husband's birthday, she took off and we almost lost her. An HPD officer and my husband finally found her and brought her back. When she was found, however, she was emotionally unstable and exhibited violent tendencies, so the officer handcuffed my daughter and transported her to a packed ER at Southwest Memorial Hospital. After hours of waiting, it was agreed that my husband should go home first, for he was to leave town the next morning for a business trip and he needed to get things ready. Also, his 87-year old father was living with us, and we left without dinner prepared. When a doctor finally saw my daughter late that night, she had calmed down on her own, and the doctor would not admit her because she was neither suicidal nor homicidal.

I remember going home exhausted, thinking that was a very bad day. But the worse was to come.

In the months that followed, my daughter began eloping on a weekly basis. Luckily, after a 5-year wait, she got an HCS slot and we put her in a group home. Her condition, however, continued to deteriorate and in May of 2002, she was admitted to Harris County Psychiatric Hospital where she was diagnosed with Bipolar Disorder. To stabilize her condition for release so the bed would be available for others in need, the hospital jacked up her meds too quickly too high, and she developed seizure-like symptoms shortly after her release from HCPC and had to be taken to ER. Yet such high doses of medication did not stop her dangerous behavior and physical restraint was necessary at times. Then in June and July, in a span of 5 weeks, two care staff used improper restraining methods and broke both of her arms. She had casts that cover both of her arms from below her shoulders to her hands. And for three months, she needed someone to feed her, to dress her and to help her in the bathroom. And for three months, she would scream and kick in agony when the physical therapist worked with her locked shoulders and elbows to help regain the range of mobility.

A week after her second fracture, her provider called to tell me that with the low reimbursement rate and my daughter's level of difficulty, she could not continue to serve us. We needed to look for another provider.

That was when I broke down. For a week, I cried everyday. I felt so exhausted, so helpless, so alone. Even now, it is very painful and difficult for me to recount those dark moments of my life in public. But I've come forward to share my story.

I've come forward because I know there are other parents out there in similar situation that I was in, who are drowned in the daunting task of caring for their disabled love ones, who are too tired to come and feel that nobody really cares.

I've come forward because I know there are parents in worse situation than I was because there is no service for them. Currently in Harris County alone there are over 3000 waiting for an HCS slot.

I've come forward because the situation today is far worse than two years ago for those without HCS. Between the shrinking general revenue and 61% cut in IHFS funds, parents of disabled adult children who have aged out of the school system today face the overwhelming task of caring for their love ones 24 hours a day, 7 days a week without a break. Worse still, with the ever limited GR dollars, the community safety net no longer exists. State schools become the only resource for families in crisis.

I've come forward because I am scared for my daughter. Even though her condition has stabilized, she still suffers relapses from time to time. With a lower reimbursement rate, my provider can only afford one staff member to care for three clients. Next time my daughter forces her way out, should the staff chase after her? Or stay with the other two clients?

I've come forward to ask for your help, honorable guests. Please spread the words that with all the love and devotion we have for our disabled children, we simply cannot do it alone. We need help.

Thank you for your attention.

Ying xxxx

Hello,

My name is Michelle xxxx and I have a son who has autism and mental retardation. I am listowner and facilitator for www.TexasAutismAdvocacy.org and I am a Regional Coordinator for the TEAM Project of Partners Resource Network.

I would like to share our family testimony from the perspective of being a middle class married family of 4 who has been denied services because of income. We have been on waiting lists for services since our son was 3 - he is now 10.

I would like to share how I spend hours doing paperwork to try and receive services - only to later be denied - again - because of income.

I would like to share how the only other agency we did receive respite funding from - UCP- we no longer qualify for because - again - of income. The new rules and regulations have cut us off from the only source of respite we have received.

I want to share positive testimony on how our family is surviving Autism - but how much easier our journey would be if we could access services - and not have to access our life savings and retirement just to get the money our son needs for therapy and services. I would like to share the reasoning behind legislative policy and decision that cause us as parents to have to make choices no parent should have to make: Like having to make the choice between choosing to save for long term care for one son - versus being able to save for college for the other son who does not have a disability. A very real choice my husband and I are having to make. Like having to make the choice to give parental rights for our son in a residential facility just so he can receive the treatment and support he needs - because we cannot now - afford to do otherwise. No parent should have to give up the rights of their child as the only option to get the child the help they need.

I look forward to hearing from you.

Michelle xxxx

My name is Linda xxxx. I live in Houston and am a parent advocate for my 24 year old son Tim, who is dually diagnosed with moderate mental retardation and autism. I am speaking on Tim's behalf and other's like him who are unable to speak for themselves.

It's a well-known fact that people usually aren't "aware" of things unless directly affected by them. As of September 1, 2004 many people were affected by changes in the MHMR System due to HB2292. Twelve agencies were condensed to five due to budget cuts. Because of this, many jobs were also lost, but our "system," that people with disabilities depend on was supposedly being changed in order to become more "efficient". Agency names were also changed again, which leads one to wonder if they're not trying to confuse us rather than help us.

Tonight I'd like to share an "awareness" that happened to me at the end of September while attempting to obtain information for my son's doctor regarding his Medicaid Identification sheet. If any of you receive these monthly forms, you know that there are 11 toll free phone numbers on the back.

None of these numbers pertained to what I needed, so I attempted to contact the Texas Department of Human Services office in our area, as it had stated that I do on the form. I called our Houston number (713-767-2000). No answer, no recording.....nothing. So, thinking I dialed the wrong number, I redialed. This was around 1:30 in the afternoon. Needing information, I let it ring and continued to let it ring for 5 minutes...no answer. I have a timer on my phone, so I know how long it rang. Not getting any answer, I called The Arc of Greater Houston, as I am on the Board and knew the staff would be able to get the info I needed on who to call. Judy Kantorczyk, our executive director, gave me the number for The Texas Medicaid Hotline! NOW, I thought.....I'm getting somewhere.

The number for three Texas Medicaid HOTLINE is 1-800-252-8263. When you are connected to that number a machine answers and says:

"You have reached the Health & Human Service Commission's Medicaid Hotline. For English, press 1. If you do not have a push button phone, please remain on the line. (Spanish translation is then spoken...then a recording comes on the phone). "Thank you for calling the HHSC Client Hotline. Our menu has recently changed. Please listen carefully and have a pen or pencil and paper ready."

"Questions about your medicaid ID form, Medicaid case, how to apply for Medicaid or make changes to your case such as change of address, please press 1. Since this seemed to be what I needed, I pressed 1. (If you press 1, this is what you hear..."Please contact your local Texas Department of Human Resources office. The phone number is in the Government section of the Phone Book")...it then hangs up...

You NEVER speak with a human being and if you're lucky, you might have a phone book to refer to as they have suggested. If not, possibly calling information, which will cost you \$1.00 for services will work. I did, however, dial 411 asking about Medicaid info because there is not Government listing in the directory for Medicaid Hotline that I could locate. The operator then gave me the Harris County number for Social Services (713-696-7900). After calling this number, a young lady said, "I don't know why information gives everyone this number...you need to call 713-767-2000. This is, ONCE

AGAIN, the local number in Houston on Polk for Texas Department of Human Services that never answered before when I tried them. So now I've been full circle.

If you continue listening to the recording on the Medicaid Hotline, and DON'T press 1, as I did before, here is what you hear....

"If your question is about the enrollment in the Star Managed Care Program or how to enroll, press 2."

"If you have a question about Tx Health Steps Program or need assistance in getting to a Doctor appointment, press 3, (if you do press 3, more info is given and then another phone number to contact. For questions contact Tx Health Steps and another number is given).....

Need information about co-pays and ID form questions, press 4 (if you press 4, it gives you info about your co-pays...It goes on and on and says, "If you need more information, press 1 (we know where THAT gets you!).....

If you are enrolled and calling about a Medicaid medical provider, press 5.....

Calling about a bill problem or your spend down medically needy case, press 6.....

If you want to know about Medicaid benefits or services, press 7.....

And then of course, to repeat this menu, press 8.....

Still not getting the information I needed, I then attempted calling the DADS office in Austin only to be given 2 other local numbers which never answered. I then called the Health and Human Services toll free number in Washington which of course answers with a recording of a website and then asks you to hold. Not wanting to bore you with numbers I received and attempted, nor do I have the 3 hours tonight that I spent on the phone that day, I finally ended up calling one of the numbers on the back of my son's Medicaid ID Form which has NOTHING to do with what I needed, and I actually spoke to a kind young lady named Nelly who recognized my frustration. She had to put me on hold to find out what I needed but did so in record time!!! At last an answer.....

Perhaps my difficulty in finding information was due to all the budget cuts of September 1st and the changes made in the system to make it more "efficient".... So, in all fairness, now being November, and thinking problems might have been "ironed out", I thought I'd try some of these numbers again. I STILL had the same problem with the Medicaid Hotline, but if you follow the directions and push all the numbers and continue to hold for a length of time, you might FINALLY someone on the line if you have the time and patience. Also, I did manage to have someone answer the local Health and Human Services number in Houston, only to refer me to 3 other numbers.

My experience was admittedly not only frustrating but one of "awareness". Knowing how much trouble I had obtaining information, I wondered "How can a person with a disability locate information themselves and go through what I just went through?"

While trying to create more independence daily for those with disabilities, it seems like we're going backwards. I know we now live in a world of technology but doesn't always mean things are "better"It is NOT acceptable to have so much difficulty when searching for services and answers to benefit those individuals served by these agencies. Afterall, do we have to be reminded why all these agencies were created in the first place? Let's use what little money is provided in running this system to the best interest of those who need it.

Continued advocating and educating for better services on the State level is essential, since answers, understanding and compassion for people with disabilities need to come, with as little difficulty as possible, from real peoplenot machines.

(Spoken to the panel)

Thanks to all of you "real people" for caring enough to be here tonight and listen.

Good Evening,

My name is Pamela xxxx. I would like to take this opportunity to thank each of you for coming tonight to listen to our concerns and stories. When you leave tonight I hope you gain insight to the increasing needs of individuals with disabilities and the families.

I come here tonight to explain how my son Roy has become a member of our community from intervention resources made available to him. Roy's diagnosis is Autism, Mental Retardation and Seizure Disorder; he is also legally blind. These conditions are severe and require constant supervision from trained staff and family members. Roy's seizure disorder can not be controlled but only maintained through medication but he still has over 100 seizures a year. As a family we have researched and taken Roy for in-depth testing for brain surgery and implants to control the seizures but his brain damage is too severe to allow it. He can not have the implant due to his self abusive behaviors and the fear of him yanking it out of his body.

Twenty-eight years ago Roy was described as a devil child, in need of placement, who would not live to adulthood. Now here we are surviving and striving to obtain basic human dignity. Roy is one of the lucky few who are receiving HCS. This allows him the opportunity to live, work and socialize within his home community. He has a support network of family, friends, ex-teachers, and professionals who have helped raise him within minutes of home, if he is in need.

The intervention we received has helped keep Roy at home with his family. It all started with MHMR's early childhood intervention. When Roy was three we were referred to the local school district. Let me mention here that Roy did not have any form of communication at this time, he did not talk. At the age of 10, I filed a due process complaint with TEA. The hearing officer ruled that Roy and I should live at the Autistic Treatment Center to obtain skills. We became the first parent/son team to ever live at the center. Seventy days later we returned home filled with hope, knowledge and skills.

Understanding how to work, teach and communicate with Roy changed our whole family. Roy learned how to take direction and one morning, quite soon after we returned home from the treatment center, Roy woke up and stated "I want pancakes for breakfast." After this tremendous leap of Roy's ability to learn and communicate, we as a family decided the world was our oyster.

I became actively involved in every agency that dealt with individuals with disabilities. Through the years I have continued to support the efforts of families who try to attain resources for their child or family member who has a disability. Although it has not always been successful, I have watched children move off the waiting list at various agencies and receive services, however, I do not see the shift progressing as I once did and this is becoming alarming in Texas.

Please do not see my son as a tax burden because he would like to be a tax payer. Employers are hesitant to employ individuals with disabilities due to liability reasons. However, Roy has had some wonderful and exciting job placements, such as: the county courthouse, police station, Wal-Mart and the parks department. Currently Roy has been

with Wal-Mart for 7 years restocking the items people return to the store. Roy volunteers there 3 days a week for 4 hours giving back to the community that supports him.

Without intervention from MHMR, the educational system and HCS program, Roy would not be home with us being a productive member of society. Roy can now purchase items independently, write his name, read on a 3rd grade level, drive a golf cart or electric scooter and do his own banking. By teaching these skills to Roy has allowed his father and me the opportunity to maintain employment and continue our education. Presently I am a student at the University of Houston-Clear Lake studying social work and interning at Juvenile Probation. I have worked and gone to school for 30 years to achieve my goal to work in the human service field to provide resources to families.

Although Texas is lacking funding for services I firmly believe funding can be found and allotted for programs. By not serving individuals who have mental or physical disorders will only lead to one of two places: more state institutions or more jails! Would you accept this future for your child or family member? I could not and I will not. I ask you to stand up and speak out for those individuals who have no voice. Watch out for us, we, as parents and supporters of individuals with disabilities. We will teach our loved ones how to vote and get policy changed to accomplish our goals. Look at the waiting list there are a lot of voters on it.

Remember with a ounce of preservation people with disabilities can become productive, active taxpayers within their own home communities and not tax burdens to the State.

Thank you.

Pamela xxxx

Some of the ideas that I would be interested in speaking include:

1. The General lack of understanding within our community which serves clients with Autism:

Autism that is a neurological disorder which may or may not be co-morbid with another condition.

Children with autism have underlying medical conditions that are often unaddressed (digestive conditions, allergies, seizures).

That with the right kind of early intervention, half of the population can make enough progress to not need significant supports as adults.

2. The need to educate emergency personnel about autism.

Because of tendencies to escape or be aggressive or both, chances that a family with a child with autism will have an encounter with CPS or the police is high. Recently, my son escaped from our yard on a Sunday morning. The police were called and the policeman actually called the DA's office to see if they wanted to prosecute me for child endangerment. The DA's office told him no because of his condition, but he should have known enough not to call.

3. Only the school is keeping track of the incidence of autism in Texas.

This is grossly underestimated because about half of the parents are pulling out their children out of school because school personnel have little to no training in how to educate these children. In fact a recent autism workshop sponsored by TEA at Region IV had a lawyer as the keynote speaker basically sending the message that if a parent wants services in school for your child with autism, you will have to sue or go to due process.

4. I work for a program that supports families who have children with special health care needs. Autism is not defined as a health care need in Texas because it is still considered to be a psychological disorder. We only serve families with children with autism if the child has a co-existing condition of seizures or CP. Families on Medicaid have little to no access to training or care in Harris County because the waiting lists for services are so long. The families that we serve are all waiting for funding to community programs that could help with behavioral training, and respite - a huge need. The per capita funding for programs in Harris County is the lowest in the state, so families are waiting 3 - 5 years. The problem is that the biggest difference can be made through early intervention, yet the families are told they must wait. This policy is merely creating bigger problems for later.

Please let me know if any of these topics will work for the forum.

Cynthia xxxx

As the director of a medium size agency serving over 350 people, I receive at least 25 calls a week from parents and other interested parties looking for services for those they love. I want to tell you of a call I received a month ago from a woman who used to work with me. She is an artist and was working in a home along with other workmen when she overheard one of the carpenters telling another worker about his daughter. She is 11 years old and has been diagnosed with bi-polar, schizophrenia, and mental retardation. The school district refused to serve her anymore saying they could not handle her and suggested to the parents that they needed to find a placement for her. The school district refused to assist and he was worried about his two young children 2 and 3 years of age who were being abused by the older child. He said his wife and he both worked and no sitters could handle the 11 year old when she was left at home. At the time he was talking to me she was about to be discharged from a psychiatric hospital and he did not know what to do.

I suggested to him that he call Advocacy and Texas Education Agency. I explained to him that it was the responsibility of the school district to provide education or obtain it for his daughter. I gave him a name of someone at Advocacy Inc., and at Texas Education Agency to contact. About two weeks later I called him and asked how it worked out. He stated that she had been placed in a place in Waco. He thanked me saying he did not know what his family would have done without help. This is just one of many calls I receive and in many cases I cannot help because there is no help or if there is help available it is difficult to find. I have been working in the fields in Houston for 30 years and I should know all of the players and what is available in the way of services for people with developmental disabilities. What I do know is that services that were once available to people waiting for Home and Community Based Services have been so severely cut that more and more people will be forced to go to more expensive services such as in institutions.

Thank you

Renee xxxx,

Aidarene "Renie" Jessop – ARC Parent Forum November 11, 2004

Candis xxxx

Testimony:

Renie is 11 years old and in the 6th grade. She was diagnosed with Autism just before turning 3. She was PPCD until 4, when she went into Pre-K. She was fully-included with a one-on-one aide until 4th grade. I asked that she be allowed to go to school when the aide was absent, because the year before she was not allowed to attend the 20+ days the aide was gone. The school refused, so I filed a complaint and the school decided without an ARD to remove her from class during a spelling test for echolalia...really because I filed a complaint after being ignored. This went on an entire year as Advocacy, Inc., professionals, and others trying to explain that Renie needed to be on the same campus and in the classroom with other children to the school officials. It ended in mediation, 3 days before Due Process that summer before 5th grade. Great things came out of mediation.

Renie re-entered the regular classroom and despite not being allowed to have 4th grade curriculum, because the principal said she did not "deserve" it, Renie picked up with 5th grade, modified in quantity only. Renie did extremely well for a child who was not allowed to be around other children and who had nothing more than kindergarten cut and paste the entire year before.

Renie stood up and read a 2 page report in class the 3rd day in 5th grade. Great things were happening. She had a new aide, like every year, but this one was different.

January 27, 2004, came and she was injured by a school administrator who felt she would surreptitiously crawl into my vehicle and pull Renie out by her feet and by a set of cement steps - against everyone's wishes.

Renie received contuses and bruises. We got past that or so I thought. In February the one-on-one aide was sent home for standing up for Renie without my knowledge. An Administrator informed the aide that she would never work with my daughter again and that my daughter was not to receive any more services, because I refused to drop charges on the administrator who had badly hurt her.

I did not receive a 5 day notice, as law requires, but quickly learned the problem and picked my daughter up from school for her safety. She stayed home from February 11, 2004 until March 22, 2004, when they decided they could hold an ARD.

Renie has numbing in her hands and feet and will say, "Hand where are you". The school knows this as it is a new problem since Oct. 2003, so with the help of a consultant they made it a matter of manifestation determination in an IEP meeting in Nov. 2003.

On March 22nd, Renie returned to school with a new aide, who was not trained as in our mediation agreement. Within 8 school days, I was called before 9 AM to come and pick Renie up from school four times. Three times because she was simply refused to do her school work. She was not angry or upset; they said she would not make contact. Each time I went she and I engaged in school work, once starting and completing 50 math problems - her least favorite subject without objection from her.

Then March 31, 2004, the last time, the principal called me and asked me to pick Renie up from school, she was being "suspended for assault". Wow! Assault! I asked what happened and she said Renie had hit someone. I told her that they could not suspend her for "hitting", because she has a manifestation determination for that behavior and that it was illegal. She said the police officer said she needed to be suspended.

So, thirty minutes later, the Special Education director called me and told me that she had called their attorney at Bracewell & Patterson and he said that it was an "emergency removal", so I said ok. She asked when I was coming. I told her I was on the freeway from work trying to get there. I arrived at 9:50 and I asked the aide what happened as the Special Education Director stood there. The aide said that they were coming around the hall and Renie was jerking her hand and saying "Hand where are you" as they turned the corner and she hit a visitor. I asked if Renie knew the woman was around the corner and the aid said no. The Special Education Director said that it did not matter. I asked the Special Education Director if the woman was hurt and she said no. I asked if she was offended and she said no, that she works with children with disabilities and she understood. Then I asked if she wanted a written report and she said no. So then I asked whose idea it was to call the police and the Special Education Director said it was the superintendent's idea and then she added herself.

She gave me a discipline referral stating my child, who had already been kicked out 3 times in that week could not return for 10 more days. That's against the law too. It turned out to be 30 more days. Once in ARD on April 15, 2004 with attorneys, the superintendent refused to allow my daughter back in school period.

The superintendent was so unprofessional that the two lawyers she hired on behalf of the district physically escorted her to her vehicle as she spoke loudly and out of control.

They brought in the Special Education Director who upheld the superintendent's idea of not allowing my child to come back to school. I spoke with the free attorney I had from a reputable government agency and she said I could do nothing about it, because it was all up to the superintendent if she was going to let my daughter back in or not.

So, I reluctantly and under counsel signed to homebound services for my daughter. The first day of services came and no one showed up to teach my daughter the 7 hours a day. I called and left a message, as no one was answering that day. Monday came and I called the Special Education Director and told her no one was there and she acknowledged that. I said we need to have another ARD meeting.

So, after being forced out of school for 30 days for "hitting" a behavior listed on the manifestation determination IEP, we had another ARD on April 26, 2004. This time I disagreed, but my daughter was "allowed" to attend ½ day and only in a former closet

with the aide. She was not allowed to attend her former classes. She was not allowed to be taught by a teacher, she was not allowed any on level academics.

Our annual ARD came May 21, 2004. It was for 6th grade, her current grade level. I disagreed here too. They were going to allow her ½ day of school with NO academics. I guess they really want to punish her in a big way.

She is now suppose to be in school, but the injuries she has had to endure were so devastating that she has been too afraid to go back.

My daughter has not only been denied an education, she has been accused of things that do not exist and she has been injured multiple times. She was so excited to go to school this year and be in the middle school and now the school district has taken that hope and dream of being a normal kid away.

I have written documentation to substantiate all my claims.

Candis xxxx.

UNADDRESSED MENTAL RETARDATION CRISIS SITUATION

34-YEAR-OLD MALE WITH MENTAL RETARDATION AND MANIC DEPRESSION(Bipolar)

- In manic episode up and down for last 5 months (May through September)
- Doctor specializes in dual diagnosed individuals
- Group Home(HCS Program) tried everything to accommodate his situation to the point of moving everything in the house that was an issue which was unfair to other individuals.
- Staff was provided during the day hours for his care for which there is no reimbursement to the HCS Provider - it will take a change in the law for this to happen
- All psychiatric hospitals in Harris County refused to serve him because he was mentally retarded and could not participate in a "treatment plan" which would prevent payment to the hospital
- The psychiatric hospitals would not furnish one on one
- The psychiatric hospitals would not allow the provider to furnish staff, train their staff or them train our staff
- Last resort was to call Al Barrera, Superintendent of Richmond State School and beg for client to be taken into the infirmary. This did happen.
- The current HCS Provider furnished staff from Friday thru Tuesday for which they will not be reimbursed.
- The need is for medical stabilization only and return to the community and his current HCS provider as soon as possible.
- The infirmary only had six patients and 6 more beds in all for others. Other space has been turned into offices and storage.
- There is NO security at the school. Anyone can drive in and go to any area, which they please. I have yet to sign in.
- I am subsidizing my HCS program to pay for the staff at the infirmary. This money is coming from my son's very small trust fund. Looking at the number of possible days left, he will be broke. I understand that it will take a change in the law for Medicaid to reimburse the HCS programs for funds used to care for someone who is ill and having to stay in their residence.

- Also, the level of need issues payment classification needs to be revisited. When you are ill and need help at home the program is not reimbursed. If you get the level of need bumped up as a result of the illness and they are well, the need for additional staff is no longer there and they will not go back and reimburse. We truly need your help on these issues.

At this point he is ready to return but we are waiting on paperwork for his HCS slot, which is very time consuming. He will probably have to stay days or weeks that are unnecessary.

Client Name: xxx xxxx

Parent/Guardian: Norma and John xxxx

Second Issue: I also have a foster daughter who has mental retardation and bipolar. She needs dental work done. The best price that I have been quoted in my research is \$4150.00. This includes surgically removing 7 teeth that have root problems and are crumbling, putting her to sleep and dentures. HCS pays a maximum \$1,000.00. What are these individuals to do in cases like this? I know she is not the only one.

Dear Panel Members,

Thank you for participating in this important forum.

My name is Jose xxxx. My wife, Aurora, and I have already passed our 70th birthday, but we are very concerned about the recent cuts in funding. We have only one question for the panel members..... At our age, how long can we outlive our son to ensure that his needs are met by us?

I am also here as a representative of a group of mothers. These mothers have a similar problem as that of my wife and I; however, theirs is of greater importance. Some of these mothers have 2 to 3 children with disabilities. Also, up to 90% of them are single parents as their husbands have abandoned the family. These women work either part- or full-time in order to survive. Now, does this not seem to be out of balance? We must be able to open new doors for assistance, but we must start by first knocking on these doors.

I end my comments by reminding everyone that we live in the most beautiful country on this planet. We must unite and allow it to flourish. However, we must first find ways to assist those with disabilities and reduce the amount of time one must spend on the waiting list.

I am coming to you as a grateful parent who understands the impact of the services my daughter receives. I am the parent of a 24-year-old Autistic, mentally retarded and bipolar daughter, Emily. Like many other Autistic persons her psychiatric condition periodically reaches a critical point where her behavior becomes erratic, violent and upsetting. During these times, sometimes for months, my husband and I would take turns sleeping because Emily would not sleep through the night. We were unable to go anywhere as a family for more than about 15 minutes without tantrums and screaming. We survived because Emily went to school during the day. Emily attends the Carlton Center which was able to deal appropriately with her behaviors.

As she approached her 22nd birthday, the time came when the special needs students are finished with school. She had become very difficult to handle and would punch holes in walls, flip over heavy furniture and be aggressive towards people who would challenge her behavior. The idea of staying home all day, everyday, unable to go to a store, a doctor, or anywhere 7 days a week, 365 days a year was a frightening thought. At least when she was in school I could go grocery shopping or run errands, but that would end with school. When I had to take her to the store, I would then likely have to deal with an outburst. I would have to abandon a shopping cart and spring for the door if she would cooperate and hope we could get to the car before she would be in a full blown temper tantrum. This was a scary proposition to live the rest of my life in this way.

We tried to find day programs. We found one that would take her. She lasted there for two days before she was asked to leave. For less than \$20 dollars a day that they were paid, they said that would not pay for damages that she did. The escalation of all of the other consumers was unacceptable and they were unwilling to take her back. We were so lucky, blessed even, when Emily's name came up on the waiting list for HCS. When day program refused to take her, they created one for her. I am grateful everyday for her care. After several months, we had the option to place her in a home with other women with similar problems.

This was extremely difficult decision for me. It was hard to let go of my daughter that I had cared for the majority of time in my life. My husband wisely suggested I look at it from Emily's perspective....she was obviously unhappy and we had to change something.

She is so much happier now. They are able to maintain a strict routine, that helps her to thrive. They have a home that is safe, with heavy, simple furniture that is not easily turned over. There are staff there who are there as a job on a rotating basis, so when they are there they can give full attention to the women. The stable atmosphere has allowed Emily to thrive. I miss her terribly, not seeing her everyday, but she is so much happier, her behavior is so much better and she truly likes where she is living. What I would really like you to understand is that Emily received services in 2002, she was on the waiting list since February 1997. It is now the end of 2004 and the waiting list has only moved few months in this time period. With very simple math it is easy to see that people may have to wait decades for any hope of help. This is just to help the people already on this list, not counting the people who are continually being added. It is clear that something will have to change. Policies, priorities. Why am I here when I have what I need? Because I am so very grateful and feel panicky for other people who are faced with an unknown number of years of doing this all by themselves. Most people that I speak to in the general public assume the services are there for the people who

really need them, but the truth is that for many people they are not. My daughter is admittedly a more extreme case, but I know of many more who are similar. It is easy to get discouraged, when you are trying to do this by yourself. You can say that friends at churches should help. In my case and many others, it is a liability to let a volunteer take care of my potentially violent daughter.

There are almost no options for parents who are now in similar situations. You may not see them here because they are trapped at home, unable to participate in a normal life. I hope you will consider these families, their special needs family members and what we as a community are willing to do to make life safe, sane and worthwhile. Many of these families I hear from are in such desperate situations. It is frustrating for me to see these families cast aside as an acceptable loss in a time of financial hardship.

Julie xxxx

My name is Mary Jane xxxx and I thank you all for coming to here to listen to us tonight. I came here this evening because I have two children with autism spectrum disorders. As a family, we enjoy going out to restaurants for lunch, camping or going to parks for hikes. My daughter Rachel is 11 and has Asperger's Syndrome. She loves participating with Katy Visual & Performing Arts in their drama productions. While Rachel's needs are less significant; my son, Christopher is 14 and his autism requires more supports. He is a beautiful young man and he enjoys life and music. He wants to be a fireman one day and he wants to live in his own apartment. Recently, a young lady has caught his eye. He now talks about marrying Kseniya. Yikes, I am not prepared for that! I am happy that he can finally express these ideas to me, in his limited way - something I could not have imagined when he was in 1st grade. Back then he did not speak at all, screamed a lot and use to run out of the school building. Throughout elementary school, with proper supports and services, he has made significant progress. While Christopher has these desires, he also has needs that will require assistance for him to live independently within the community according to his choice. He will need supports for money management and to ensure that he takes his daily medication. He may need support with transportation to his job or in participating in other recreational activities. I do not see him needing 24 hour care like is available within the state school system.

As a family with children with autism, according to state law, we are entitled to additional services within the school system and we have been lucky enough to choose school districts that have been knowledgeable about autism. This was a significant factor for us as we could not have afforded outside therapies during this time. I think the fact that we got such good services at an early age was the reason for my children's current successes. Working for Family to Family Network, a local non profit that provides education, training, support and referrals services to parents of children with disabilities, I can tell you that this is not the case for all parents. People who are limited English speaking, who are working two or three jobs to keep their family alive, or quite possibly are single parents, are not always given the same supports within the school system. Sometimes even for well educated parents, school districts attempt to limit the amount of services they provide.

I never thought I would have problems. I was educated, I over volunteered at the school - I helped educate other parents. How naive I was. And then last year I received a phone call from the school district that they had called the police on my son. You see, Christopher loves to play tag. And rather than ask other students to play, he taps them on the shoulder and say "your it". Tag though is an elementary school game and not a jr. high thing, and obviously the others in PE class did not appreciate it. Christopher did have a behavior plan to address these sorts of communication issues; on his autism supplement, it also stated that he could have a helping teacher/assistant in all regular education classes (PE being one of them). Unfortunately, there was no one providing supports and no one was following the recommendations of the Behavior Plan to teach Christopher other replacement behaviors. When I arrived at school, I brought my Individual Education Plan and as I sat there attempting to redirect my son to answer the police officers questions, the principal reviewed it. Obviously upon reading, she realized the error of their ways and asked the officer out into the hall. When they came back, the officer stated that he had to perform his job. We then received a ticket for Class C Misdemeanor Assault. We endured a day in court (with many people around us wondering why our child was even there); and rather than invest more \$\$ and time with a court battle we

accepted community service option, just to end the nonsense. Besides the court date wouldn't be for another 9 months after the initial incident - what would my son remember? We completed the community service, but cannot say that it had much meaning for my son.

I am concerned about the overwhelming numbers of students with disabilities, especially with autism, we hear about it in the media and through phone calls at our office where the school districts are calling the police rather than educating and training students with behavioral difficulties. I have received 2 phone calls in the last month alone. If the schools are failing those students now, what will happen with them when they leave the school system? Where will these students end up? If the community services are not available to support them in the community, will many end up within the prison system? I spoke with a Houston Police Officer last week and he told me that police officers receive no training on how to deal with people with disabilities. Are our courts going to be overburdened with large numbers of students with autism because they are not getting the services within the school systems now, and there are no supports for them when they leave the educational system. Will the prison system become the next state institution for people with disabilities?

Christopher has been on the waiting list for HCS services since he was 7 years old. I am lucky that I learned about this listing while he was young....I feel for parents that don't learn about this until their young adults leave the educational system. While we as a family have survived without any particular service or supports (except the educational system) despite having no extended family locally, there have been times when I was at my wits end. I am worried that Christopher will still be on a waiting list when he graduates. We will be there to support him as long as possible saving the state thousands of dollars, but what will happen when we are gone? I want to ensure that Christopher always has a choice in where he lives and works. I want the supports to be available so that I don't have to worry about another call from police some day.

Thank you again for your time.

Mary Jane xxxx

When a child with a developmental disability is about to turn 18, parents are often encouraged to seek guardianship. I listened to parents who had made the decision to do so. I made an appointment with a lawyer recommended by other parents and advocates who specialized in guardianship and it has been nothing but a nightmare.

I am here to ask that parents have easy access to the pros and cons of guardianship and all probate courts follow the same rules. It has been a steady stream of surprises because we naively trusted the attorney and had no other source of information to refer to. For instance, guardianship was presented as an extension of parental rights. In reality, it is inviting the court to enter your life and tell you what to do. We were told we needed to have a psychiatrist fill out competency papers, the lawyer then stated efforts would have been made to retain our son's right to vote and right to drive. When the psychiatrist did not return the papers in a timely manner, I was given the name one who could - life altering decisions being made by someone unfamiliar with the case and who would not be following it! After the papers arrived, was the first time we heard of court investigators. I'd like to know what they do besides make sure there is a valid address!

Ad Litem are appointed to protect the interests of the "proposed ward." It was the Ad Litem's idea that we had to obtain Guardianship of the estate of our son's UGMA accounts. Funds set aside by his grandparents for his education. We had specifically asked if we had to set up a special needs trust before seeking guardianship and were told no. We sought the advice of a person who sets up special needs trust shortly before our son turned 18, discussed the fact that we were seeking guardianship and were told there was no rush. We were asked by the Ad Litem if we were seeking guardianship to gain control of assets; we replied, "No. We wanted to do one thing at a time, so we were going to set up a special needs trust after we cleared the expenses of guardianship." We had receipts that proved we had spent at least the amount in UGMA accounts for therapies, tutors and medications.

Because of Ad Litem, we have guardianship of the estate, and now we do not have control of our son's assets, the court does. The court constantly rejects accounting done inaccurately by a lawyer, and still approves the attorney fees. The court orders bonding to be paid at an amount over the value of the estate and we have to pay it. They ordered us to consolidate accounts into a bank account, because we were ordered to report the exact amount in an account on a specific day of the year which a mutual fund company could not do and they did not honor our request to change the account from UGMA to Guardianship as the court told us and we tried to comply with. Our account, which is CD's still refuses that request and apparently that of our lawyer also, so we are now having no guardianship papers because the court refused the annual accounting. So now we have no current letter of guardianship. We sought guardianship for school and medical reasons. Now that our son wants to quit school, we have no valid letter to present. He has a co-morbid mental illness and recently was at risk of hospitalization since his medications needed adjustment. We have no letter of guardianship. We get his medications from a mail order pharmacy and recently they filled his prescription with the old dosages of medication, half his current dose. They will not even discuss this concern with us because of HIPPA regulations and more of our son's assets are down the drain because we have no letter of guardianship.

Our son would like to have a job. Now if he is successful, his earnings will go into this court ordered checking account and become part of his estate. He is not allowed to have his own account or handle funds over \$50.00, but a percent of his earning will go to bonding agents to protect his estate from misuse.

Now, I have also come to find out that not all judges require bonding, and that some judges do allow the estate to be placed in a special needs trust. Apparently every judge is different and you are randomly assigned to a court. Not all courts/judges require accounting to the penny, and those who do order someone of the court's choosing to handle the accounting to the court's liking with all these expenses paid from the ward's estate. In our case, grandparents sacrificed to provide for their grandson's future and instead it goes to bonding agents and lawyers. We protected these funds and paid out of pocket for expenses that far exceed those of rearing a kid without the challenges our son faces, and all so lawyers and bonding agents can benefit.

Is guardianship in the state of Texas set up to protect the well being of the vulnerable, or as is our experience, to pad the bank accounts of lawyers and bonding agents? Is it fair to have the same criteria for competency for an 18 year old as for a 40 or a 60 or an 80 year old? Is it fair to remove a person's rights to vote because of mental illness?

Families need to know exactly what to expect from guardianship, and there should be some means to hold the courts accountable to families.

Linda xxxx

My son Brian was diagnosed with Autism when he was two and a half years old, during this time his father and I were getting a divorce. Brian will turn six in a couple of weeks. His father has never acknowledged Brian with this disability. He has never been involved in any activities with Brian or shared any financial responsibility except paying for child support.

Brian is non-verbal and has behavioral problems. He throws temper tantrums when his demands are not met. His tantrums consist of biting, kicking, scratching, stripping, spitting and screaming at me. If I am not around, he destroys things around him. Anything he can pick up, he throws. Anything he can't, he hits and kicks. I can only take him to a few places, places he likes and has been to before. He is usually the one who decides where we are going and when we are leaving. I cannot control Brian by myself and usually he gets what he wants. For instance, one evening we were at McDonald's, after the second hour, I asked Brian to go home. He screamed when I grabbed his hand to take him out. Brian dropped down on the floor and started licking and screaming until I moved away from him. I called around and couldn't find anyone to come and help. Luckily, Brian decided to leave an hour later. If I take him to the places he has been to or likes, Brian gets out of the car willingly and stays as long as he pleases. If I take him to places he doesn't like or never been to, he starts kicking and screaming as soon as I stop the car. He continues kicking and screaming until I start the car and leave. When we drive by a place he likes, he grabs whatever he can reach in the back and tosses it to the front at me. When he runs out of things to grab, he takes his shoes off and throws them, he then kicks the windows and screams. Within these two years, Brian has destroyed my personal computer, three VCR's, three videocassette rewinders and a television set.

My major concern with Brian is his violent behavior. Last January, his teacher mentioned to me about Brian's behavior in school and my mom had a tough time caring for him after school as well. I realized Brian's behavior has worsened. I immediately called a private trainer from Behavior Treatment and Training Center (BTTC) to help him. The trainer worked strictly with Brian's behavior from February 2003 to August 2003. Brian's behavior had improved. Unfortunately, I could no longer afford the service. In January, the center started to open a Day Treatment Program mainly working with kids who have behavioral problems like Brian. When I heard about the Day Treatment Program, I spoke with the Director. Since I could not afford program, I volunteered to work a few hours at the center, in return, I benefited from observing their technique working with the kids. I applied what I learned and worked with Brian at home. My volunteer service came to an end a few months later, Brian's behavior became out of control and my mom wanted me to be home with Brian on the days I was off. During this time, Brian was attending school for half days. When my mom had mentioned that I needed to look into a daycare center for Brian because she could no longer handle his behavior, I stopped volunteering to stay home with him. My mother has tried her best, but Brian becomes stronger and stronger for my mom to handle. One time mom was frustrated to the point, she had screamed out "Brian was better off born to be deaf than to be autistic. At least deaf people still can understand right and wrong." I can understand her frustration and pressure on her part. Taking care of Autistic children is a challenge. There is so much my mother can do. She has her health problems. I cannot rely on her so much. She does not drive nor does she speak English.

Although there's no cure for Autism yet, there are trainings out there than can improve his behavior. The longer we wait, the tougher it will be to shape his behavior. Trainings are costly and insurance would not cover it because it's not life threatening. Last month, I took Brian to see a dentist. Due to Brian's behavior, the dentist had recommended to perform intravenous sedation on Brian in order to clean his teeth and work on cavities. On that day, the anesthesiologist was called in to sedate Brian before the dentist could work on Brian's teeth. The anesthesia cost me an additional \$700.00. I was told this would not be covered by insurance. I went ahead and submitted the claim to the insurance and have not heard anything from them yet. Brian's total bill after the dental insurance's coverage was \$1400.00 and Brian's dad refused to contribute any of it.

Autism is not a short-term disability, not even a long-term disability, it is a permanent disability. I am here begging you to look at autism as a life threatening disability that needs help right now, especially with my son, Brian. The earlier we can provide help for these kids the better improvement it will be on their lives. These kids cannot speak out for themselves and they cannot live to be labeled for the rest of their lives. Please help me to afford training and therapy, because the training and therapy are costly and insurance will not cover it. When I look back from the day Brian was diagnosed with Autism, I try to see what I could have done differently to help him improve today, and there is nothing without money. Please make services to be more affordable. For the past years, I have used every ounce of energy, spent whatever I could afford and spent as much time as I could with Brian. All my vacation hours are spent on Brian, I am with him when he is sick or when my mom is out of town, I have to pick him up when the school calls, take him to the doctor or training. His father does not help take care of Brian, when Brian is sick, when Brian is on vacation from school or when his father is on vacation from work. His dad does not keep Brian for any of the holidays or summer. He only keeps Brian every other weekend, from Saturday morning to Sunday evening.

This year Brian is in school full time. His speech has improved over the years. We use sign language and pictures to communicate. Brian can learn except he tends to let his behavior interfere with his learning. He refuses to work and throws tantrums. Brian depends on me so much. He would not allow my mom to help him. Every night I have to be home by six, right after work, otherwise he gives my mom a hard time at home. When I come home, I have to feed him, bath him, play with him, help him with his homework, brush his teeth and tuck him in to sleep.

My name is Le xxxx and I am Brian's mom. Thank you for reading my story.

My name is Helen xxxx. My son Joaquin is 26, has Down Syndrom and I am happy to say that he is one of the lucky few on HCS. So why am I standing here before you? I am here because if my son is to stay in the community the level of funding that Harris County receives has to increase.

Harris County needs more and better programs to serve the diverse needs of its citizens. Needs do not stay the same and the programs we have must be able to change and meet the needs of all its clients. To do this they need funding.

A year ago, Joaquin's quarterly visit to the podiatrist was covered, as were all his prescriptions. This is no longer the case. Now he is limited to three prescriptions a month and the doctor's visits are no longer covered. It is not exactly a happy feeling to go to the pharmacy and be told that the medication prescribed by your child's doctor is no longer covered, that he has to prescribe something else. It takes many telephone conversations to finally have someone tell you that the medication your child takes is no longer on Medicaid's preferred list. I just wonder what else will be cut in the next few months?

As you can see I am not exactly young, I worry about the day when I will no longer be here for my son. What kind of services will be there for him in the next few years? Will he be able to look forward to a brighter and better future or will he have less than what he has today?

Our leaders are always talking about how "This is the way we do things in Texas" or "This is what is good for Texas" so why don't they make it a priority to provide better services to it's citizens with cognitive disabilities?

Thank you for listening to me.

Mom of 13-year-old High Functioning Autistic Son

He's been on meds since age 3 and diagnosed with Aspergers in 3rd grade.

We moved to the Woodlands (Conroe ISD) in June 2000. He started 5th grade (middle school of 5th and 6th graders) in August 2000 and by mid October 2000 the school called the police on my son and we were looking at a juvenile record. Long painful story. By the time we had to go see the probation officer, the Guidance Counselor who signed the complaint offered to go with us. She had gone to an Autism workshop shortly before and realized all the things she had been doing wrong with my son. The charges were dropped, however the lack of understanding & cooperation from this school continued through the end of the school year.

Later this same year, while my husband and I were in the administrative offices of the school dealing with my son's behavior, the Asst. Principal called the police again! I verbally blasted her and told her she just didn't get it.

This 5th grade year was the toughest on my son and I was ready for a nervous breakdown. My ex-husband and I decided to have my son live with his dad and attend school in Lewisville, Tx. Toughest decision of my life. He has been in the same school for 6th, 7th and now the 8th grade. In all Advanced Placement classes (no question getting this, they just looked at TAK scores & grades). They also called the police early in 7th grade and we had to hire a lawyer, go to court, etc, in Lewisville. (Had David Beinke with us for our ARDS then)

So I guess I am qualified to talk about the public schools and their lack of understanding about Autism.

Look forward to meeting you.

Karen xxxx

Darlene xxxx

Dear Madams and Sirs:

Thank you for the opportunity to address members of the Mental Retardation Needs Council of Harris County and the Mental Retardation Public advisory Council of MHMRA of Harris County, in order to shape our public policy for individuals with cognitive disabilities.

I have been blessed to have two wonderful daughters, and an equally marvelous son-in-law. My youngest child is a delightful 26-year-old lady who has Down's Syndrome. Valerie is not only a blessing to my family, but she is a vibrant member of our community.

In the last couple of years, the Special Olympics of Texas has been a great blessing in Valerie's life. However, I am aware of no other personal growth opportunities for our citizens with Mental Retardation and Autism, who reside in this great area – consisting of Clear Lake, Webster, and the Bay Area, as a whole. In fact, except for the SOTX, since the end of January 2004, there have been absolutely NO programs for Valerie, nor any personal contact by any individual from any state agency. This is quite a sad situation!

As a mom who must work to provide for her daughter, and as a contributing involved citizen myself, I feel we are alone, distant from any agencies that are set-up for the sole purpose of assisting those with special needs. I would love to see Valerie using and developing skills she so greatly worked for, from birth through age 22, while attending public schools and working in the community. For Valerie to attend a local college or even earn an income, we need help. Offering reliable safe transportation and job finding Service, locally, would be a great way to assist the parents who worked so diligently; and, who are committed to continue doing so.

Questions: Where are the funds going? What is happening with the waiting list situation for programs? My daughter was on the waiting list for HCS prior to our move in 1996 from Austin, Texas, and ever since then, upon re-enrolling. Where does the state stand in rank currently compared to other states (much lesser in size, and economically more deprived), with respect to programs for those with developmental delays? How about education in general? Our department of Human Services? I believe they are still in the lower 5% to 10%. Why???? Again, a very sad situation. We just appear to be wasting our money and other great resources; as, our priorities and many great lives are left underachieving.

While blessed, and often discouraged, I remain hopeful! I trust that we together can improve on the whole situation. In fact, we must! I believe you agree, and I commend you for bringing the many diverse gifts and talents of so many together. I appreciate this public forum greatly! Thanks! We must share these gifts and impact the love within each of us! We must never give up!

I challenge us to take this step further, and come together here locally, with the many children and adults, and their parents in this area – maybe at the Clear Lake City/Harris County Library, or the United Way! I believe this method would work most effectively,

at least to help those who live locally get a process started, with a liaison from each agency/group representing the state. Why not try it all over the Greater Houston Area. It's imperative that we reach out to all – everyone is important! Thanks for caring.

With faith!

Darlene

November 11, 2004

Denise xxxx on behalf of
Clayton xxxx

To whom it may concern,

I write to you today on behalf of my son Clayton xxxx. Clayton is a 20-year-old young man who is Medically Fragile due to congenital CMV, Cerebral Palsy, Mental Retardation, Pulmonary Issues, a seizure disorder among lots of other issues (please see attached skilled nursing orders at the back of this letter).

As of today I have contacted Medicaid, MHMRA, Nursing Agencies, and other state agencies. While all the people on the other end of the telephone line have been very kind, they have not given me an answer to my one specific questions. "What happens to Clayton xxxx on December 10th? This will be the day after his 21st birthday.

They tell me in the beginning that he will just automatically roll into a new program, however, when I tell them that he currently receives 84-100 hours of SKILLED NURSING a week that is covered by Medicaid, they soon put me on hold, seeming to go and find someone in the office that can give an answer. Is there an answer? If so, what is it?

In just a few weeks my sweet son whose just happens to be very important part of his family will soon become a statistic instead of a child with special healthcare needs. Will he have to leave his bedroom that is decorated with beautiful blue lights and dolphins to go and live in some nursing home with cold white walls and no love?

We just need an answer. My daughter, Clayton's sister, who is 17 years old, sums it up quite well, "What changes about Clayton on the day after his birthday party? Won't he still be Clayton and need Ms. Rhonda?" Wow, doesn't that hit home? She has always been one to call it as she sees it. As the family photos show, she has grown up with her older brother a big part of her life. He has always required that extra care. I think deep down she fears what will happen to our family if we don't have the nurses like Ms. Rhonda and Ms. Debbie. Who will care for Clayton to allow her mom and dad to continue to attend High School events, work at their jobs, sleep and live a close to normal life?

This could be settled so easily. Medicaid could continue to cover Clayton xxxx just like they are now. They could continue to provide SKILLED NURSING hours for Clayton on December the 10th just like on December 9th. You see, nothing about the xxxx family changes on that date other than life as we know it will CRATER!

Who can help my son? All his life we have attempted to make him a vital part of society. I bought into the goal of community, family and independence just like I heard at every disability conference that I have ever attended over these last 20 years? Will it all be for nothing? I certainly hope not! I want to see my son Clayton continue to live in our home, attend church with us on Sundays, have a peaceful nights sleep in his room

surrounded by his dolphins and receive care from a nurse like Ms. Rhonda who has faithfully cared for him for the last 3 years of his life.

Will you help us? Will you tell us a plan? Will you lead us in the right direction? This is Texas, a huge state with a huge heart. Will you tell me what to do while my heart is breaking?

Thank you for your time, while ours runs out, will you help our family?

Sincerely

Denise xxxx

On behalf of Thad, Clayton, Lauren and Dillon xxxx

Ivelisse xxxx

RE: Yousef xxxx

My son Yousef was diagnosed with Autism and Mental Retardation at the age of 3. We have had difficulties getting help or assistance of any kind. Yousef is presently aggressive and is in need of medication which we cannot provide because of lack of medical/prescription coverage. I am not able to work full time because we cannot afford “after-school –care” for our son. We have been close to bankruptcy, divorce court and family crisis many many times.

We desperately need your help and financial support to take care of our son.

Thank you.