

# Autism Oversight Team

8/10/12

## Work Summary and Final Recommendations:

### The Autism Oversight Team (AOT) History and Mission

The AOT was created in the fall of 2010 by Linda Roebuck Homer of the Behavioral Health Purchasing Collaborative and Alfredo Vigil, Secretary of Health. The purpose of the AOT was to bring state stakeholders together to develop safe and appropriate discharge plans and services for high needs children with autism spectrum disorder placed in residential treatment centers in Texas and New Mexico, and to make recommendations for services necessary for successful home and community outcomes. The Developmental Disabilities Support Division (DDSD) of the Department of Health, the Medical Assistance Division (MAD) of the Human Services Department, the Children Youth and Families Department (CYFD), Divisions of Clinical Services and Protective Services, the Public Education Department (PED), Special Education Bureau, Optum Health New Mexico, and the Autism Programs at the University of New Mexico Center for Development and Disability (CDD) assigned staff as team participants. Families, treatment centers serving the children, local school districts, and Core Service Agencies were asked to participate in individual discharge plans. The Autism Programs offered to hire a facilitator for the project from federal autism funding received through a state improvement grant from the Health Resources Services Administration (HRSA). The HRSA grant allowed for two years of funding for the facilitator, giving the AOT the opportunity to work until September 1, 2012. The AOT decided to develop discharge plans for five children, using their situations as models from which to make recommendations on service delivery to the Purchasing Collaborative.

### I. Discharge Summaries

#### 1. GM:

GM was twenty one years old and needed to discharge from Texas Hill Country School before his twenty second birthday. His diagnoses include autism, mental retardation, Prader-Willi Syndrome, and several behavioral health conditions. His mother was terminally ill, and because of her health status, the AOT helped the family ask for expedited status on the DD Waiver. The status was granted. GM's mother died before he returned to NM, and his sister became his guardian. GM returned to NM in the late summer of 2011.

For GM the AOT helped:

- Establish waiver status;
- The family with the guardianship application;
- The family choose a case management agency and case manager;
- Insure that there was appropriate staffing level at the chosen group home;
- Work with the Medicaid Managed Care Organization to provide needed dental surgery in Texas and to assign a primary care physician in NM ;
- Arrange for Texas Hill Country School to accompany GM to NM and stay for a week to insure smooth transition to new placement and to train GM's new staff on how to best work with him

– this was accomplished through an agreement between Texas Hill Country School and funding from the Behavioral Health Supports Division of DDSD.

From GM the AOT learned:

- Only the DD Waiver had the level of support necessary to meet this individual's needs and the only reason that GM was granted expedited waiver placement was the death of his mother
- Even with waiver services, the full participation of the AOT was necessary to secure a safe and appropriate discharge to New Mexico

2. KU:

KU was 10 years old and had been in treatment in Bernalillo Academy for nine months. His diagnoses included autism and mental retardation. The AOT began working on his discharge plans with the local school district, the Core Service Agency, and Bernalillo Academy. KU lived in a small community in northern NM and his father wanted him to return home. During the planning process, the AOT became concerned about the appropriateness of the services KU was getting at Bernalillo Academy and worked with his father and his advocate through Disability Rights New Mexico to have KU transferred to Texas Hill Country School. The transfer occurred in October of 2011, and KU remains in treatment in Texas.

For KU the AOT helped:

- Define services to meet his behavioral, developmental, and educational needs;
- Find residential placement that offered appropriate services.

From KU the AOT learned:

- Returning a student from residential placement to their home school district is challenging, and local school districts have no reason to participate in a planning process because the student is not enrolled;
- Wraparound services available through behavioral health were not sufficient to maintain this challenging individual in his community;
- Discharge criteria from the initial placement was ill defined, and did not address level of care or necessary elements for a successful outcome;
- Some high needs individuals will always require a higher level of care than a home setting, and appropriate residential services are now unavailable in NM;
- Suggesting treatment foster care as either short or long term placement should involve different services and reimbursement from currently available.

Important outcomes from the experience with KU:

- The AOT asked the Special Education Bureau of the Public Education Department to create guidance for school districts about the transition process from residential placement to enrollment in local school districts. Guidance was issued in the form of a letter from Deputy Secretary Paul Aguilar on July 16, 2012. Schools will receive training in the transition process beginning in the fall of 2012.

### 3. BE:

BE was almost 18 years old, and had been at the Texas Hill Country School for almost a year. He has a diagnosis of autism as well as a seizure disorder. His family lives fifty miles southeast of Albuquerque in a small community. BE has been on the DD Waiver waiting list for only a few years. His mother asked about the possibility of him going into a group home because of family challenges with keeping him safe. No funding was available for group home placement. The AOT identified the necessary elements for discharge and worked with all parties involved. BE returned home shortly after his eighteenth birthday. His behavior remains challenging, but his family has not requested additional support for services or placement from the AOT.

With BE the AOT helped:

- Collaborate with the local school district to set up an appropriate educational program;
- Support the family through their concerns about safety;
- Bring a Core Service Agency into the discharge planning process;
- Find funding for Texas Hill staff to accompany BE to NM and train new service providers on how to best work with him.

From BE the AOT learned:

- Having staff from the treating facility engage with both community providers and the local school district in a meaningful fashion facilitates successful outcome;
- Discharge expectations need to be clear in provider contracts and should be monitored for appropriateness;
- There needs to be a funding mechanism to address staff support during transition.

### 4. TC:

TC was fourteen years old and he had been in residential placement at Bernalillo Academy for two years, then discharged in late December of 2011 to treatment foster care through Hogares. The AOT became involved in his discharge planning at the request of Hogares. AOT involvement became limited because of communication issues with both the family and the core service agency. TC is due to be discharged to home in August, 2012. He is no longer being followed by the AOT.

With TC the AOT helped:

- Educate the core service agency on individual issues related to TC's autism.

From TC the AOT learned:

- Success in a team discharge process involves active and transparent participation of all members.

### 5. JP:

JP is seventeen years old and has been in residential placement at Bernalillo Academy since November, 2011. He has a diagnosis of autism and pica. He lived with his father thirty miles east of Albuquerque, and had not been able to stay safe or be successful at school. His father did not think he could safely maintain JP at home, and asked about available group home placements. JP had been on the DD Waiver

waiting list for over ten years, and received an allocation letter from DDSD during the discharge planning process. He is due to discharge from Bernalillo Academy to residential placement through the DD Waiver in a few weeks.

With JP the AOT helped:

- Get permission for JP to be in an adult group home at age 17;
- Work with JP's father to understand and navigate the DD waiver allocation process, and to consider educational placement until JP turns 22;
- Get permission for JP to get waiver services prior to the start of the new waiver in October, 2012.

From JP the AOT learned:

- The level of support necessary for JP was available only through the DD Waiver. Had JP not been on the top of the list for allocation, there would have been no services or family supports to insure neither safety in the home nor community, or an adequate plan of care;
- Full participation of the AOT was necessary to work through administrative issues and help JP achieve a more appropriate and timely discharge.

## II. AOT recommendations to the Purchasing Collaborative:

The AOT sent a report with recommendations to Linda Roebuck-Homer on September 16, 2011. The report was never acknowledged. In later discussion about autism issues, AOT members learned that Ms. Roebuck- Homer did not believe that the responsibility for ASD services were in the scope of behavioral health, but fit better within education or physical health. The AOT believes that ASD services need to be developed within all appropriate public agencies, including behavioral health, and that the development of community based services and expertise is critical to successful outcomes for children with ASD in NM. The AOT recommendations of September 2011 should be implemented. Additionally:

- There needs to be a transparent process for admission into residential treatment with an active approach on first creating community supports to meet the child's need;
- Behavioral health core services agencies are available throughout New Mexico and must develop the expertise and the ability to treat challenging children with ASD;
- The family of the child with ASD needs support through the admission and discharge process. Families often have unmet behavioral health, physical health, and economic issues arising from their situation, which must be addressed as part of an appropriate treatment plan;
- Children with ASD have unique service needs and a team approach is beneficial to successful outcomes. Funding mechanisms need to be in place to support teams to work together to develop both, appropriate admission and discharge plans, and to insure delivery of necessary wraparound services.

## III. Final Observations:

The AOT was created to help move children from residential treatment to their homes and communities. Medicaid stakeholders believed that too much money was spent on often unnecessary residential treatment and that resources should be shifted to community programs. The hope was that the AOT could recommend innovative approaches to care that would allow for successful discharge and prevention of further placements. The team realized that goal could not be accomplished without

significant resources and new policies. Two of the five children could not have been successfully discharged without the support of the DD Waiver. One child was transferred from in-state treatment to more appropriate out-of-state treatment. One child has returned home, and his family continues to report significant challenges. One child's outcome is uncertain as the family chose not to engage with the AOT meaningfully. The AOT learned to work the system on behalf of five individual clients, but was not allowed to create opportunities that could be a substitute for residential care or serve as model wraparound service approaches.

Members of the AOT developed good working relationships, functioned effectively as a team, and appreciated the opportunity to work on the complex issues brought forth. A facilitator was critical to building group consensus and keeping the process moving forward. If state stakeholders determine that the AOT would be useful in developing a system of care for individuals with ASD, the team recommends that a facilitator be hired.

AOT members:

Human Services Department, Medical Assistance Division: Kim Carter

Department of Health, Developmental Disabilities Support Division: Cheryl Frazine, Les Swisher

Children Youth and Families Department: Craig Sparks, Jeff Tintsman, Teresa Larson

Public Education Department: Sandra Schwarz, Deputy Secretary Paul Aguilar

Optum Health: Wendy Corry, Ellen Curley-Roam

Autism Programs @ the Center for Development and Disability, University of New Mexico: Amber Hayes, Michael Harle, Pat Osbourn, Gay Finlayson

Facilitator: Mark Bennett

Attachment:

PED guidance from Deputy Secretary Paul Aguilar, July 16, 2012

