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To: Linda Roebuck Homer

Autism Oversight Team Report to the Behavioral Health Purchasing Collaborative

Background:

Formation of the Team: The Autism Oversight Team (AOT) was formed in the fall of 2010 at the request of the Behavioral Health Purchasing Collaborative. The team was formed to pilot a model for discharging children with autism spectrum disorders (ASD) from residential treatment centers into appropriate lower levels of service in their homes and communities. The team initially decided to develop discharge plans for five children with ASD, and inform the Purchasing Collaborative of systemic issues that could be addressed through policy change. Team members include staff from the Developmental Disabilities Services Division of DOH, the Medical Assistance Division of HSD, PED, CYFD OptumHealth/NM (the current single entity), and the Autism Programs at the UNM Center for Development and Disability. The team hired a facilitator through the use of federal Combating Autism Act funds that the CDD received through HRSA. Funding for the facilitator continues through August, 2012.

Immediate Issue: There are currently 23 NM children with ASD in residential treatment centers (RTCs). 14 are placed within NM, and 9 are placed out of state. All are funded through Medicaid, at the approximate cost of 4.4 million dollars per year. (1) Children are primarily placed in residential treatment because they meet the criteria of being "a danger to self or others" and because those involved in their care believe that they cannot be safely treated in a less restrictive setting. There is currently no research that supports residential treatment alone as being an evidence based treatment for ASD. Safety issues mandate the use of residential treatment. The center providing the treatment should be using evidence based practices, not serving as containment.

Important Considerations:

- The prevalence of autism in the United States is now 1 in 88 births, with an estimated growth rate of 10-17% annually. (2)
- There are presently over 2,000 residents of New Mexico with a diagnosis of ASD.(3)
- A study by Harvard University found that each child in the U.S. with autism will cost society about 3.2 million dollars in medical and non-medical costs over his or her lifetime, concluding that spending money on early autism treatment, even expensive treatment, is actually a savings.(4)
- The Autism Society of America reports that lifelong care can be reduced by 2/3 with early diagnosis and intervention. (5)

New Mexico hasn't yet invested in a comprehensive, community based system to meet the needs of this growing population. The result is the increased need for the RTC to

address the health and safety issues from challenging behaviors. The team believes that NM is spending the majority of Medicaid service dollars for children with ASD on high cost, crisis-driven residential placement. Although this modality of treatment is now necessary, the team feels that there is a direct correlation between the paucity of community based services and the need for RTC. Another challenge of using residential treatment is that it often does not include regular intensive skills training for the parents of these children for the purpose of maximizing the benefit of the treatment and positive outcomes when the children return home.

Autism Spectrum Disorders have been referred to as "the orphan disability," because there isn't clarity about which state agency has responsibility for treatment. The result is that children with ASD in NM often don't have access to necessary interventions. NM continues to be challenged by the lack of agreement on the role and responsibilities of behavioral health in services for children with ASD. These complex issues provide context for the Autism Oversight Team's work on individual cases moving toward discharge.

Observations:

The AOT immediately noted that there isn't a consistent level of care criteria for placement of children with ASD. Children are determined to be "a danger to self or others," by the treating facility. Children with ASD are almost always placed in sub-acute RTCs. Sub-acute RTCs are reimbursed at about two and a half times the RTC rate. The difference between "regular" and "sub-acute" RTC criteria and placement wasn't clear. It seemed logical that a child could step down from a sub-acute placement to a regular placement as part of their treatment and discharge plans. No such options were discovered. The team noticed that NM must utilize this higher level of care because of the lack of lower level residential treatment, treatment foster care, parent training, and community based autism specific behavioral health treatment.

The team learned that planning and implementing appropriate discharge from a RTC takes significant time. Children have been staffed for over eight months as there is lack of consensus and subsequent training for parents, guardians and caregivers regarding what constitute the necessary components for discharge. Community providers also lack ASD specific training, and community capacity for appropriate behavioral health treatment also is lacking. For example, Comprehensive Community Support Services, a care management service offered through Core Service Agencies that is a key to identifying needed community resources, is only available 30 days prior to discharge. The lack of timely preparation for the home community to receive a child adds significantly to the challenges that the families and the individual child encounter at discharge.

Full participation by the local Public Education entity from the beginning of the discharge planning process is critical to a successful transition of the individual to home. The AOT found that local school districts dis-enroll their students who leave home to go to an RTC placement and are not required to be an active part of the discharge planning process until the student is physically back in the home district. This lack of ownership of these students by their local school districts creates a 'tragic gap' in planning which

certainly may contribute to a very difficult or unsuccessful transition back to the home community and the local school.

Other challenges the AOT encountered included the quality of the data that came from one of the residential treatment centers. This made it very difficult to determine: 1.) whether the individual's treatment plans were appropriate; 2) were treatment goals being met; and 3.) when the individual would actually meet criteria for discharge. In fact, based on information made available by the RTC, the team suspected that treatment at the RTC wasn't evidence-based and questioned the effectiveness of the particular placement. This concern is being addressed by an audit of in-network RTC's who serve youth with ASD by United Behavioral Health autism experts.

The team also made positive observations! The most striking of these is that the expertise of the collective team led to solutions. Although the process is lengthy, it was clear that the key people working together (interdisciplinary team, guardian, advocate, RTC, community providers, schools, State Agencies – HSD, DOH, CYFD, PED, and the Autism Programs @CDD) effected change more quickly than if individuals tried to work through these complex situations in isolation of one another. Most of the members of the team found the work to be important and valuable and were willing to participate in frequent meetings.

Recommendations:

1. **Standing Team**. The Purchasing Collaborative should continue using the Autism Oversight Team as a standing multi-disciplinary, multi-departmental team for children as a forum to address these complex cases. The use of the facilitator is critical to keeping momentum on the team going and to assure outcomes. The Collaborative should find funding for the facilitator role.

2. **Scope of Oversight**. The AOT should expand its scope to include developing clearer policy on admission and discharge criteria and quality assurance issues, including clarifying expected levels of care and treatment for children with ASD while in the RTC. Team reviews prior to admission, during treatment, and during discharge planning are critical to delivering appropriate services. The attached template should be used by the Autism Oversight Team for individual cases.

3. **Optum and Core Service Agency (CSA) Work Group**. The Optum RTC work group should coordinate with the CSA work group in order to develop expertise in ASD and other developmental disabilities. This group should advocate increasing CSA's access to Comprehensive Community Support Services (CCSS) funding while the child is in the RTC to assist with discharge planning. The current 16 units of CCSS made available prior to discharge are deemed extremely insufficient given the complexity involved in a successful transition of these children. Further, the fact that CCSS units can only be accessed 30 days prior to discharge hinders the discharge coordination process (90 to 120 days would be more appropriate for this population). It is also recommended that

this group review behavioral health group home guidelines/standards as an appropriate lower level of care when appropriate.

4. **Use of Restraints**. An evidence-based "Patients' Bill of Rights" should be developed that clarifies the definition of restraints and their use. All levels of restraint should be noted in patient files and shared with the funder; physical prompting when used should also be reported.

5. **Proactive Discharge Planning**. The RTC treating the child must develop a robust discharge planning process to insure that the home community is prepared for the child's return. Specific training for families and caregivers should be incorporated as part of a successful discharge.

6. **School District's Role**. The PED must clarify the role of the local school district in preparing for discharge and issue the necessary guidance.

7. **Evidence-based Practice**. NM must develop evidence based continuity of interventions for children with ASD with an autism-specific in-state residential treatment center as the highest level of support. Incentives for autism specific expertise, including appropriate accreditation, should align with the Medicaid Pay for Performance planning.

Respectfully Submitted,

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References:

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2. Autism Society of America Website: http://www.autism-society.org/about-autism/facts-and-statistics.html
3. Autism Programs @CDD – estimate based on state population

4. Michael Ganz, Understanding Autism: From Basic Neuroscience to Treatment, CRC press,2006,Steven O. Moldin, editor

5. Autism Society of America, based on GAO report on Autism, 2007