Issues Brief: Autism Services in New Mexico

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Abstract

The purpose of this issues brief is to outline the current status of autism services in New Mexico, including 1) the need for improved coordination across all aspects of the system, including between state agencies, 2) the lack of support options for adults with autism, and 3) the necessity for increased funding to address unmet need for those with an autism spectrum disorder of all ages.

Introduction

In Fiscal Year 2008, the Department of Health was appropriated approximately $3.5 million dollars to fund services for children with autism residing in New Mexico. This funding is recurring general fund to DOH. The funding was utilized to fund several new programs for children of various ages. The Adaptive Skill Building Services (ages 5-18), Recreational Respite Services (ages 5-14), and Parent-Home Training Services (ages 0-5), were evaluated by DOH staff in Fiscal Years 2009-2010. Based on evaluation, these services are viewed very positively by families who receive them and continue into Fiscal Year 2011. The families interviewed did indicate that there is not enough money to meet current need, and there are no services being funded for adults. An additional service, Behavioral Respite for children 0-18 was unsuccessful and is no longer being offered. The funding for Behavioral Respite has been redirected to fund additional Adaptive Skill Building Services

The Issues

The Autism Taskforce and its separate members have determined that there are currently some effective services for children with autism, but no efforts to develop a comprehensive system of supports that will address broad based needs for this population. While the funding which was appropriated to DOH has become recurring state general fund, it has led to further discrepancies of how persons are supported based on age and location. Services are very limited and are only offered in 6 larger communities throughout the state. The remaining population of children and all adults receive no supports appropriate to meet their needs. There must be a coordinated, collaborative effort across the state to address the concerns of all stakeholders and develop a system of comprehensive supports appropriate for individuals of a vast range of skill and age. This will require the cooperation of various state agencies, university representatives, and advocates throughout the state. In addition to the need for this collaboration, there must also be an effort to develop quality in the diagnoses provided in the state. While one can be confident in the diagnoses provided by 3-4 different agencies or individuals, there are a vast number of false diagnoses being provided by physicians, evaluators, and school systems in the state. This creates the potential for services to be provided to some children who do not truly have autism, which does not address their true diagnosis and also leads to another child with autism waiting for services. The ASB program is attempting to minimize this effect through a review of diagnostic records by the CDD as part of intake.

Background

The Autism Taskforce chaired by DOH was charged in 2007 with determining what could be done to support individuals with autism in the state. At that time, the Taskforce was a body of various stakeholders (including families, providers, state agency representatives, providers, UNM CDD Autism Program, etc.), some of whom were directed by the Governor's Office to participate. The Taskforce reviewed the state of services and developed several recommendations. The services which are currently in place were all recommended by the Taskforce.

The Taskforce also felt that there needed to be efforts to support adults with autism, a mandate for private insurance to fund supports for individuals of all ages, and the possibility of a Medicaid benefit or Waiver to support individuals with Autism. The funding offered by the legislature was not enough to address all of these areas.

Coordination and Collaboration

The Taskforce was intended to be the main coordinating agent for the development of autism services in New Mexico when first organized. While the Taskforce was representative of the human services interests in autism in 2007, it has since dissolved into a small group of 4-6 consistent representatives primarily from DOH, DVR, and HSD, one unaffiliated provider, and the UNM CDD Autism Programs. (Recently, the PED has named a representative who appears committed to attendance.) The Taskforce has not kept pace with the changes in the system as current state funded providers (except UNM) do not participate, there is no representation from the NMSU Southwest New Mexico Autism Program (SNAP), and family stakeholders are irregular in attendance.

This lack of representation has led to insufficient cooperation between state agencies and other stakeholders to drive the system forward. While DOH and HSD worked together to develop a Medicaid benefit for young children with Autism, other state agencies have yet to devote resources to participate in such efforts. Of particular note is PED's approach to Senate Joint Memorial 25 in which they hired a contractor to respond in isolation from the Taskforce and other state agencies working with this population. PED has stated it will only share its findings regarding the SJM with the parties named in the memorial, but will not work with the named parties to develop the recommendations and report which will be presented to the Legislative Education Study Committee.

While there was representation from the DOH and UNM CDD Autism Programs on the workgroup to develop the PED Autism Manual, this collaboration only occurred after all parties external to the PED indicated significant concerns with the first version, rather than inviting collaborative participation up front.

There is also an opportunity to improve collaboration with the SNAP program at NMSU. SNAP receives funding through the Department of Higher Education,which has not participated in the Taskforce. It appears that the funding for SNAP is being used to replicate certain services being funded through DOH under contract with UNM CDD Autism Programs (namely diagnostic evaluations). We believe collaboration between UNM and NMSU as well as with other state agencies funding various supports for individuals with autism would improve the efficiency and effectiveness of all resources.

Unmet Need

Currently, there are no services or supports directed specifically to support adults with autism or autism spectrum disorders. The few adults with autism disorders who receive any support must be on the DD Waiver. However, most adults on the autism spectrum do not meet the federal level of care criteria for the waiver. This lack of support is one of the key weaknesses being addressed on a national basis, as only a handful of states have developed any service system for this population (i.e. Pennsylvania, Indiana).

While the significant lack of supports for adults is unfortunate, there also is significant unmet need for most children with this diagnosis. With the exception of special education through public schools, in fiscal year 2010, only 129 children were served in a combination of adaptive skill building and recreational respite. These children were served in only the Clovis, Roswell, Las Cruces, Albuquerque, Santa Fe, and Farmington areas. If one lives more than 10 miles outside of these cities, they will not be able to access services. With the current level of funding unchanged, this situation has not improved in Fiscal Year 11.

While there is a new Medicaid benefit, This support is only available to children aged 0-5 years. There are no services available to Medicaid participants older than this age. Additionally, while private insurance must cover benefits for children with Autism, these private insurance carriers are successfully avoiding approving any services in most cases. At this point, only a handful of children have been able to receive private insurance benefits.

Finally, there is a residential treatment center (RTC) in New Mexico (Camelot for Kids) which is charged with serving those children who are unsafe to live in the family home. Unfortunately, this RTC is currently full and thus has denied services to children who are most difficult. This continues the historical pattern of those with the most significant needs being sent out of state for treatment.

Moving Forward

One of the original recommendations of the Autism Taskforce was the creation of an "Office of Autism" which could either be a separate state entity or could operate under the auspices of one state agency, but oversee the autism specific activities of all relevant agencies. This would allow for a coordinated effort towards system development and service provision across all relevant agencies. Additionally, this would allow for a global perspective towards development of a comprehensive system which would support individuals throughout the state regardless of age. This continues to be a recommendation of the current membership of the Taskforce, in particular because the Taskforce has seen this done in Pennsylvania to great effect.

Creating an "Office of Autism" should remove the obstacles to collaboration and cooperation, however there are associated costs. At a minimum, this office would require at least one full time staff person to coordinate the various programs, activities, and state agency efforts. If the direction chosen was to pull all autism services from current state agencies, this would require a number of staff to oversee the various efforts.

While the PED is currently working on the SJM 25 project, it is unclear that the community of autism advocates will assign any value to the effort. This is due in part to the perceived reluctance of PED to discuss this project with those with autism experience in the state, including the members of the Autism Taskforce, UNM CDD Autism Programs, and the other parties named in the memorial. It continues to be recommended that PED conduct some form of collaborative effort with the relevant participants prior to finalizing their recommendations to the Legislature.

In addition to the SJM work being completed by PED, the DDPC is currently conducting a study to develop an Adult State Plan for persons with autism. Additional representation would enhance the effectiveness of this effort. While DOH/DDSD and DVR are participating in the efforts, there is no representation from PED, HED, HSD, ALTSD, UNM CDD Autism Programs, or NMSU SNAP. It is recommended that the DDPC reevaluate this situation and work with the Autism Taskforce to identify additional relevant participants to support their efforts.

While the state has limited financial resources to direct towards individuals with a specific diagnosis, it is worth the effort to consider methodologies to further leverage Medicaid funding to support individuals. The state could either investigate a HCBS waiver or expand the service definition currently in place to support more individuals with the current funding. Each of these options has associated benefits and costs which should be researched prior to implementation of changes. What is clear, however, is that even with a reversion to the regular FMAP which the state receives, the number of individuals served through DOH funding could quadruple to 400 or more individuals based on the current service model funded by DOH depending upon the percentage of those who are Medicaid eligible.

Finally, there must be an examination of the admissions at the RTC being funded through behavioral health funding to assure that those individuals with the most significant needs are given priority for admission.