

FOR THE INTERIM HEALTH AND HUMAN SERVICES COMMITTEE

Developing an Autism Service Plan for New Mexico

Senate Memorial 20, House Memorial 44 Report

Autism Oversight Team

7/9/2012

This Report was put together by members of the New Mexico Autism Oversight Team, the New Mexico Autism Society, The New Mexico Autism Task Force, and staff at the Autism Programs at the Center for Development and Disability, University of New Mexico Health Sciences Center

History and Hypothesis

The charge of SM 20 and HM 44 is to look at existing systems and plans, evaluating their strengths and gaps, and using that information, along with new stakeholder input, to move forward with recommendations for a proposed system of care that will meet the needs of the 1 in 88 residents of New Mexico who are challenged by the diagnosis of an autism spectrum disorder. There have been a number of studies and reports on autism services and gaps in the past ten years. There have been numerous autism bills and memorials in the NM legislature in the same time period. The reports, studies and the status of past legislation are included in this document. They create the context from which to take recent stakeholder information and make recommendations for a comprehensive system of care for autism.

Although NM has never had a formally endorsed autism plan, there have been autism initiatives and autism planning groups. In 2004, stakeholders worked through a grant from the Robert Wood Johnson Foundation to explore systems coming together to better serve children with autism in NM. In the spring and summer of 2006, parents of children with autism in New Mexico took advantage of the Human Services Secretaries tour and made public comment about the paucity of autism services in the state. Governor Richardson then invited all interested individuals to be a part of a new Autism Task Force through the Department of Health. Stakeholders met and created funding and policy recommendations for the administration. Senator Dede Feldman of Albuquerque sponsored a funding bill that resulted in over 5 million dollars for autism diagnosis, training programs, and direct services. The Department of Health received the recurring general fund appropriation. Their staff met with community stakeholders and contractors to enhance existing services and develop new programs that include:

- Funding for the neurodevelopmental evaluation clinic at the Autism Programs at the Center for Development and Disability, University of New Mexico Health Sciences Center. (\$527,500.) This clinic serves children from ages 3 to 18 with a multidisciplinary team that uses evidence based practices to diagnose and assess autism spectrum disorders. During the 2007 legislative session, the wait list for the autism clinic was about two years. With the additional funding, the wait was initially shortened to less than three months. With the increase in prevalence and demand for autism diagnosis, the waiting time for a clinic appointment can be as long as one year.
- Adaptive Skill Building Services for children ages 5-18. This service uses the principles of Applied Behavioral Analysis (ABA) to help children acquire skills that

will help them learn and develop independence. There are 65 children enrolled in the program in four communities in New Mexico. The program also has a technical assistance component to help build provider capacity. (\$1,850.00.)

- Recreational Respite Services for children ages 5 to 14. The Department of Health contracts with a number of agencies to provide recreational activities for children with autism that are center based and give the family an opportunity to have a short break from the demands of parenting their child/children with autism. (\$86,742.00)
- Parent Home training Services for the families of children up to age 5. This service provides in home consultation with a therapist with autism expertise. The statewide program serves 60 children a year. (\$402,840.)
- Professional Development to build provider capacity and expertise (\$500,000.)

During the same 2007 legislative session, Senator Cynthia Nava of Las Cruces introduced a bill (SB 197) for private insurance to cover autism treatment. The bill passed the Senate, but a substitution was made in the House that called for “A Study of Autism Spectrum Disorders, Services, Systems and Financing.” The substitute was made late enough in the session that community members had limited knowledge of that change. The Medical Assistance Division was assigned to be the lead agency on the memorial. They convened a stakeholder group to make policy and funding recommendations. The Deputy Director of the Medical Assistance Division and community stakeholders testified at an interim Health and Human Services Committee meeting in November of 2007 and issued a written report the following month. The SB 197 group findings recommended an additional 9 million dollars in funding to address specific autism issues. The funding recommendations were sponsored in the 2008 session by Representative Joni Gutierrez of Las Cruces. The funding recommendations did not become part of the state budget, nor were the other recommendations implemented.

The initial work of the task force, the new services developed after funding, and the recommendations of the Senate Bill 197 report, created the framework for further action of the legislature. In the 2009 session, Senator Clinton Harden of Clovis sponsored bills for private insurance coverage of autism treatment, funding to increase existing services, the creation of an autism waiver, and a memorial around using evidence based practices in public school classrooms. The private insurance bill (SB 39) passed and became law that summer. The funding bill didn't make it into the budget. The waiver bill became the impetus to start an Adaptive Skill Building program for children ages 0 to 5 who are enrolled in Medicaid. The memorial took two years to pass. The

response by the Public Education Department was rejected by the legislature, and the stakeholder community then offered eleven IEP considerations in its place. Senator Harden sponsored that bill (SB 314) in the 2011 session. It passed the legislature, but was vetoed by Governor Martinez. The governor then signed the 11 considerations into regulation in the summer of 2011. The 2012 session brought forward two pieces of legislation important to the autism community. A bill requiring all insurance in NM to cover autism treatment was introduced by Representative Bill O'Neill of Albuquerque, but not considered germane to the session. Senator Jerry Ortiz y Pino and Representative Ed Sandoval of Albuquerque sponsored Senate Memorial 20 and House Memorial 44, "Develop a Plan for Autism Spectrum Disorder".

New Mexico has seen tremendous growth in the willingness of the legislature to support autism initiatives as well as the willingness of the administration to work with the autism community. That is encouraging. It is tempered by the fact that the autism prevalence in NM has almost doubled since the last time autism got funding through the legislative process and a set of unfunded recommendations through SB 197. The other challenge is that NM hasn't created enough policies that allow for individuals and families to seek services through existing systems. The resulting gaps impact NM families as well as don't allow for providers to build professional expertise in evidence based autism interventions. SM 20 and HM 44 request that specific issues be addressed that stakeholders thought important in creating a system of care for individuals with autism in New Mexico. The legislative intent of the memorial is to include recommendations based on past experience and current knowledge. The intended outcome is to have a document that both the administration and the legislature can use to move the development of autism service systems forward in a thoughtful and systematic manner. Recommendations that can't be implemented immediately can be the next issues to address with both policy and funding in a timely manner.

This report is written as the result of an agreement between the Behavioral Health Purchasing Collaborative, the named lead on the memorial, and the autism community. Community members met with Linda Roebuck-Homer, director of the BHPC, and decided that the report should be written by community stakeholders. The hope is that recommendations that can't be made by the Collaborative can be acknowledged by state partners, and guidance generated. The policy and funding recommendations are made by the autism community. The opportunity to speak about autism issues with the Collaborative leadership was appreciated.

The SB 197 report was approved by the Richardson administration and accepted by the legislature. It seems most appropriate to look closely at the funding and policy

recommendations in the report, and make changes based on events of the past five years.

Findings

SB 197 Study Group Findings, 2007	SM 20 – HM 44 Stakeholder Findings, 2012
<p>The Centers for Disease Control (CDC) has placed the prevalence of ASD at 1 in 150 children from birth to 21 years of age. Based on the CDC guide, approximately 3,000 New Mexico children have some level of ASD diagnosis</p>	<p>The Centers for Disease Control (CDC) has placed the prevalence of ASD at 1 in 88 children from birth to 8 years of age. Based on the CDC guide, approximately 5,000 New Mexico children have some level of ASD diagnosis</p>
<p>State and independent agencies do not have surveillance and registry programs in place to accurately identify and track individuals with an ASD diagnosis. Therefore, it is currently impossible to provide legislators or health care and service professionals with a complete picture of ASD needs in the state.</p>	<p>Same finding</p>
<p>The state does not have an evidence-based, intensive behavioral intervention (IBI) service definition. Applied behavioral analysis (ABA) is a nationally recognized early intervention service that is highly effective at addressing the core deficits of ASD, improve adaptive skills, and improve the individual and family's quality of life. New Mexicans with ASD need access to IBI services.</p>	<p>The state developed a general funds Adaptive Skill Building program through DOH that serves 65 children ages 5 -18.. Medicaid has provided billing instructions for Behavior Management Services to provide Adaptive Skill Building Services to Medicaid eligible children, ages 0-5. About 30 children receive this service. (There are an estimated 5,000 children with ASD in NM who most likely need some form of autism treatment.)</p>
<p>The state does not have specialized ASD practitioners to deliver ABA designed services to individuals with ASD. Currently, there is only one (1) board-certified ABA provider in the state.</p>	<p>There are currently 15 board certified behavior analysts (BCBA) in the state. The majority of them are working at either the university of New Mexico or for a school system. BCBAs operate with a certificate rather than a license, causing challenges to billing for ABA services through insurance or Medicaid, as well as issues around professional expertise in ASD.</p>

SB 197 Study Group Findings 2007	SM 20 – HM 44 Stakeholder Findings 2012
<p>Individuals with ASD requiring services affect virtually every state agency; however, each department views ASD differently, such as a behavioral health disorder or physical health disorder or developmental disability, and each has different points of entry for obtaining services.</p>	<p>Autism Spectrum Disorders have been referred to as “the orphan disability.” State agencies struggle with coordinating and collaborating in the creation of an integrated system of care for children with ASD. In New Mexico, the Medical Assistance Division funds ASD specific services through behavioral health and Through EPSDT for physical health needs. Until recently, the Public Education Department has not participated with meaningful input in the design of a system of care for children with ASD. Mandated, consistent and fully engaged participation by each state agency that provides services to children with ASD would facilitate movements towards a fully integrated ASD system of care.</p>
<p>Fragmentation in systems of care leaves individuals with ASD unable to construct appropriate and sustainable service plans. In most situations, families and adult consumers need to purchase out-of-pocket services or do without where service gaps exist between agencies or in private funding sources.</p>	<p>The autism private insurance mandate of 2009 has been helpful to families with that sort of coverage. The Adaptive Skill Building Programs through general fund dollars and Medicaid have been helpful to families. The challenges remain that families with public insurance can’t get autism treatment, and the Adaptive Skill Building Programs through DOH and Medicaid serve only a small number of eligible participants.</p>
<p>New Mexico children with ASD that need out-of-home residential care are currently being placed in out-of-state facilities. New Mexico providers have not developed this service. Cost reimbursement is significantly different as out-of-state providers receive between \$500-800 per day compared to an in-state rate of \$350 per day.</p>	<p>The Autism Oversight team was formed in 2010 by Linda Roebuck-Homer, director of the Behavioral Health Purchasing Collaborative and Secretary of Health, Alfredo Vigil. The purpose of the team is to identify gaps in services, and attempt to establish wraparound services for five children in residential treatment, and then make recommendations to build capacity in New Mexico to serve children with autism and aggressive and self-injurious behavior. The team made its first</p>

	<p>recommendations in the fall of 2011. There has been no response from the Collaborative.</p> <p>There are currently 27 children with ASD in residential treatment centers. 19 are placed within NM, and 8 are placed out of state, all of whom are funded 100% through Medicaid. There is now an in state residential treatment center. The facility charges the same rate as the out of state providers. (The amount is considered proprietary information by Optum, but is substantially higher than the published Medicaid rate.) Although it is not necessarily a cost savings to have children placed in state, it is better for them to be closer to home.</p>
<p>Adults with ASD that are able and willing to work lack the support and service systems to gain and maintain employment. These “maintenance” services are currently unavailable for most adults with ASD.</p>	<p>The Developmental Disabilities Planning Council issued a report in 2010 on Adults with Autism. The report emphasized the lack of employment opportunities for adults with autism who are not on the Developmental Disabilities Waiver.</p>
<p>As ASD youths mature, the state does not have appropriate housing to accommodate their needs. Housing arrangements must address specific aspects of the disorders, such as delayed or inappropriate social skills, communication abilities, and inflexibility in changes in daily living.</p>	<p>The Adults with Autism report by the DDPC recommended that an array of housing options to meet the needs of both lower and higher functioning adults with autism. The report recommendations haven’t been addressed by either the administration or the legislature.</p>

Recommendations

SB 197 Report 2007	SM 20 – HM 44 Stakeholder Group
<p>Expansion of state funding to meet the critical service needs of New Mexicans with ASD, as requested in both the HSD and DOH proposed budgets for FY09. The \$2.9 million for HSD would support</p>	<p>\$3.0 million to HSD to expand Adaptive Skill Building Services to children over the age of five, as well as develop additional innovative ASD specific services through Centennial Care</p>

<p>ASD specific treatment services, including intensive behavioral intervention services, for Medicaid eligible recipients and the \$1.0 million for DOH would support expanded diagnosis and ASD specific treatments for individuals who are not eligible for Medicaid. The Study Group endorses Children, Youth and Families Department proposed expansion of funds to provide additional services to non-Medicaid eligible children.</p>	<p>\$2.0 million to DOH to support expanded diagnosis for both children and adults</p>
<p>Support the Public Education Department in a plan to work with local school districts to provide professional development opportunities for school staff in the amount of \$1.0 million</p>	<p>Develop ASD specific professional development opportunities for local school districts and implementation of the 11 IEP Considerations, in the amount of \$1.0 million to the Public Education Department</p>
<p>Provide in the amount of \$200,000 in funding to the Department of Health for creation and implementation of a statewide ASD surveillance and registration program, coordinated with all other relevant parties.</p>	<p>A registry for ASD is problematic in New Mexico because of the lack of providers experienced in making an ASD diagnosis, thus, data gathered may not be reliable. Apply this funding (\$200,000.) towards ASD specific FTE within state government, creating an Office of Autism Spectrum Disorders.</p>
<p>Support the Behavioral Health Collaborative in its efforts to convene appropriate parties to develop, if appropriate, in-state Residential Treatment Center(s) for the ASD population including related policies, standards, and oversight. The Study Group recognizes that keeping individuals in the community to receive services as the optimum; however, certain individuals with ASD may need such intensive therapies that an RTC may be the most appropriate setting. Seed money, in the amount of \$350,000 is recommended to develop and, if needed, establish this service, after which it will be self-sustaining through existing billing structures.</p>	<p>There is currently an in-state Residential Treatment Center accepting children with ASD. The state must develop policies, standards, and oversight to assure quality of care. The \$350,000 recommended by the SB 197 group should become recurrent funding for an Office of Autism Spectrum Disorders within state government. That office should be charged with developing appropriate policy, standards, and oversight for Residential Treatment Centers for children with ASD.</p>
<p>Support the Behavioral Health Purchasing Collaborative in the development of a flex-funding program for the ASD population in</p>	<p>Support the Office of Autism Spectrum Disorders in the development of a flex – funding program for the ASD population in</p>

the amount of \$1.0 million.	the amount of \$1.0 million.
Support the Department Secretaries of Public Education, Health, and Human Services through the Division of Vocational Rehabilitation, the Developmental Disabilities Support Division, and the Working Disabled Initiative to adopt national guidelines related to vocational supports for adults with ASD.	Charge the Office of Autism Spectrum Disorders to work with the appropriate agencies to adopt national guidelines related to vocational supports for adults with ASD.
Support the extension of Senate Bill 197 Study Groups charge to continue to work to enhance collaborative efforts among relevant Departments, institutions of Higher Education and local organizations to continue development of a seamless infrastructure of ASD specific services. Provide in the amount of \$100,000 to allow this body to expand representatives statewide by offering stipends to non-state employee participants and to conduct public forums to identify regional needs and priorities. Arrange for this body to report to the new Health Care Authority, once established, regarding system development, supports needed for individuals with ASD transitioning from children's to adult's service systems, and coordination of research efforts related to this condition.	Funding of \$100,000 will be added to the Office of Autism Spectrum Disorders to support an advisory group or groups on relevant community issues, and arrange for this body to report to the executive and the legislature on system development, wraparound services, and quality standards.
Provide in the amount of \$175,000 to the Human Services Department to study service needs and best practice treatments for high functioning adults with ASD who do not meet criteria for developmental disability.	The DDPC studied Adults with Autism in 2010. Increase this funding to \$1.0 million to HSD to develop and implement model programs for high functioning adults with ASD who do not meet criteria for developmental disability.
Continue support for existing initiatives to provide training for professionals working with this population in family-centered approaches, screening, and appropriate referral of children suspected of having ASD, and development of a resource tool to assist families and referral sources in linking with ASD related supports. Included in this is funding for development and support of ASD resource teams at	There is no funding attached to this SB 197 recommendation. It is hoped that a newly created Office of ASD would support professional training for community agencies and school districts.

individual school districts.	
CONCLUSION	CONCLUSION
The SB 197 Study Group proposed its recommendations with the intent of bringing some relief to the individuals with ASD, their families, and providers that are attempting to navigate systems of care with inherent barriers. By adopting these recommendations, the State Legislature is presented with the opportunity and challenge to set the direction for high quality, accessible screening and services, and standardization of critical service needs.	The prevalence of autism in NM has almost doubled since the SB 197 Study five years ago. There has been no new funding for autism initiatives since then. Knowing the challenging financial times, the SM 20 – HM 44 stakeholders keep their funding recommendations within reason, using the SB 197 \$9 million dollars as a minimum to adequately fund medically necessary services for the ASD population. The creation of an Office of ASD allows for the planning, policy, standards, and oversight to implement SM 20 –HM 44. Furthermore, the legislature and the executive should work together to see that all insurance plans in NM include treatment for autism spectrum disorders.

SM 20 – HM 40 Recommendation List in Order of Importance

(Total funding \$9 million, the same amount recommended in 2007 through SB 197)

- **Create an Office Of Autism Spectrum Disorders that will be responsible for coordination of all autism initiatives in New Mexico - \$1.0 million**
- **Pass legislation to cover ASD treatment in all insurance plans, and work with the Public Regulations Commission on reasonable co-payment regulations**
- **Increase the HSD budget for Medicaid to include Adaptive Skill Building Services for children over the age of five as well as develop additional innovative ASD specific services through Centennial Care - \$3.0 million**
- **Increase the DOH budget by \$2.0 million to further fund diagnosis for children and adults, and to expand parent training programs.**
- **Appropriate \$1.0 million to HSD to create and develop model programs for adults with ASD who do not meet developmental disability criteria**

- **Appropriate \$1.0 million to the Public Education Department for professional development in ASD and implementation of the 11 IEP Considerations.**
- **Support the Office of Autism Spectrum Disorders with \$1.0 million to establish and implement a flex- fund program.**

Supporting Documents Included:

Autism Oversight Team Report to Linda Roebuck-Homer, September 2011

PED 11 Considerations, July 29, 2011

Issues Brief: Autism Services in New Mexico Travis Goldman, DDSD – DOH, June 2010

New Mexico Senate Bill 197 Report, December 2007

Memorandum to all State agencies and State contractors involved in service delivery and service coordination to individuals with Autism Spectrum Disorders, June 26, 2007

Addresses for Additional Supporting Documents:

“Collaborating for Effective Services for Children with Autism Spectrum Disorder in New Mexico; Summary of Findings & Recommendations”, April 2004, University of New Mexico – Center for Development and Disability:

http://www.chcs.org/usr_doc/NM_policy_paper.pdf

“New Mexico Adults with Autism State Plan: Needs Assessment and Best Practices Review”, New Mexico Developmental Disabilities Planning Council, November 2010:

<http://www.nmddpc.com/uploads/NMDDPC%20Adults%20with%20Autism%20State%20Plan%20Final.pdf>

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