



NEW MEXICO SENATE BILL 197

A Study of Autism Spectrum Disorders Services, Systems and Financing

December 2007



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A STUDY OF AUTISM SPECTRUM DISORDERS SERVICES, SYSTEMS, AND FINANCING

EXECUTIVE SUMMARY

During the 2007 legislative session, the New Mexico Legislature recognized that many New Mexicans with autism spectrum disorders (ASD) and their families are facing a crisis in the fragmentation of their systems of care. Senate Bill 197 charged the New Mexico Human Services Department (HSD) to appoint a comprehensive group to: study ASD services; study the current systems that serve this population; and determine the most appropriate funding mechanisms. Membership consisted of representatives from various state agencies, including HSD, the New Mexico Department of Health (DOH), the New Mexico Children, Youth and Families Department (CYFD), commercial insurance carriers, service providers, content experts, and adult and family consumers.

Prior to convening the workgroup, HSD, through the Medical Assistance Division (MAD) conducted a study of the infrastructures in place in other states and how they funded ASD services and how these other states addressed ASD needs. MAD learned, and shared with the group, that other states used various methods including but not limited to, insurance mandates, state and federal Medicaid options, and state general funds. Some states created an "Autism Council" to continue to address ASD comprehensive services and systems. MAD provided members with detailed workbooks of the options used in other states at the outset of SB 197 meetings. The large SB 197 group was then divided into four workgroups: (1) funding; (2) intensive behavioral interventions (services); (3) statewide capacity (systems); and (4) adult infrastructure. Through these workgroups, meetings with the larger SB 197, and use of consultants, SB 197 Study Group has determined the following findings:

SB 197 STUDY GROUP FINDINGS

1. The Centers for Disease Control (CDC) has placed the prevalence of ASD at 1 in 150 of the 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.
2. 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.
3. 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
4. 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.
5. Individuals with ASD requiring services affect virtually every state agency; however, each department views ASD differently, such as a behavioral health disorder or a physical health disorder or developmental disability, and each has different points of entry for obtaining services.
6. 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.
7. 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.
8. 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.
9. 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 and communication abilities and inflexibility in changes in daily living.

SUMMARY OF RECOMMENDATIONS

1. 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 ASD specific treatment services, including intensive behavioral interventions services, for Medicaid eligible recipients and the \$1.0 million for DOH would support expanded diagnostic and ASD specific treatment services 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.
2. Support the Secretary of the Higher Education Department in a plan to work with its four-year institutions to develop ASD specific pre-service and continuing education opportunities for a wide variety of professional disciplines in the amount of \$1.0 million.
3. 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.
4. 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.
5. Support the Behavioral Health Purchasing Collaborative in the development of a flex-funding program for the ASD population in the amount of \$1.0 million.
6. Support the Department Secretaries of Public Education, Health, and Human Services thru 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.
7. Support the extension of Senate Bill 197 Study Group's charge to continue 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 representation 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.
8. 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.

9. 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 individual school districts.

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.



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NEW MEXICO **SENATE BILL 197 –**

A STUDY OF AUTISM **SPECTRUM DISORDERS** **SERVICES, SYSTEMS, AND** **FINANCING**

BACKGROUND

The New Mexico Human Services Department (HSD) was directed by the New Mexico Legislature to “conduct a study of autism spectrum disorders services, study the systems that serve the population affected by autism spectrum disorders and determine the most appropriate funding mechanisms, including health insurance, state disability insurance, developmental disability waivers, or autism waivers.”¹ The Secretary of HSD directed the Medical Assistance Division (MAD) the task of gathering information and convening a study group of consumers, state agency representatives, providers, and insurance companies to develop a report of the work group’s findings and recommendations to be presented to the Legislative Finance Committee.

WHAT ARE AUTISM SPECTRUM DISORDERS (ASD)?

Autism Spectrum Disorders (ASD), also known as Pervasive Developmental Disorders (PDD), cause severe and pervasive impairment in thinking, feeling, and the ability to relate to others. ASD are complex neurological disorders of development that onset in early childhood. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorders (through a number of different subtypes), to a much

milder form, Asperger’s syndrome.² ASD affect the functioning of the brain to cause mild to severe difficulties, including language delays, communication problems, limited social skills, and repetitive and other unusual behaviors.

Nationally, ASD now affects an estimated one in every 150 children across all racial, ethnic, and socioeconomic backgrounds.³ ASD is more prevalent in males and affects one in every 94 boys.⁴ The spectrum of ASD represents the fastest growing serious developmental disability in the United States. ASD is more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined.⁵

Although the etiology of ASD is unknown, experts believe there is more than one cause of ASD.⁶ Genetics appear to play a role, and there is growing scientific evidence about the role of environmental influences. Today, research continues to investigate the extent genetic and environmental factors contribute to ASD.

There is no known cure for these disorders. Experts agree that treatment should be tailored to address the needs of the individual, and no single intervention is best for every person with ASD. There is also widespread agreement that it is important for

¹ Senate Bill 197

² National Institute of Public Health

³ Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report, Surveillance Summaries*, vol. 56, no. SS-1, U.S. Department of Health and Human Services, Atlanta, Georgia, February 9, 2007.

⁴ Ibid.

⁵ Autism Speaks, 2006 Annual Report, page 4

⁶ National Institute of Child Health and Human Development, “Autism Overview: What We Know,” U.S. Department of Health and Human Services, May 2005, www.nichd.nih.gov.

children with ASD to receive intensive interventions during early childhood. Research indicates that some interventions have a high degree of efficacy for treating certain symptoms of ASD in some children.⁷ Given intensive behavioral interventions, half of the individuals with ASD are more likely to live at a high level of independence, as an adult with minimal help from their families or other support systems.⁸ Efforts are underway to better define for the field effective interventions for ASD and specific program elements of interventions so they can be replicated successfully in the home, at school, and in other community settings.

ASD may seem like a modern disorder, but it is not. Some of the earliest published descriptions of behavior similar to autism date back to the 18th century. The disorders, however, did not have a name until the middle of the 20th century.

ASD are a lifetime disorder. Although some individuals may mature and with interventions, move out of the ASD diagnosis, they will retain some elements of the overall interactions that are ASD-like. Today, hundreds of thousand children and adults continue to live with ASD.

WHAT MAKES ASD UNIQUE?

The three core deficit areas that comprise a diagnosis of ASD create challenges in all life areas. These three areas are: (1) social interaction; (2) verbal and nonverbal

communication; and (3) exhibit repetitive behaviors or interests. Functional or adaptive behaviors are difficult for an individual with ASD to acquire because of a lack of social understanding, delayed and disordered communication abilities, and rigid behaviors. Individuals with ASD often process sensory information differently than individuals without these disorders. Typical environmental sights and sounds are often overwhelming for a person with ASD and trigger behavioral outbursts or shutdown. Emotional regulation can be of concern. Families with autistic children report that their children experience difficulties falling and staying asleep. These core impairments in the social, communication, and behavior areas combined with sensory processing differences, difficulty with emotional regulation and sleep deprivation create untenable stress for individuals with ASD and their families.

As children with ASD mature, community support becomes critical. ASD will affect most of our basic service systems. For example, planning for involvement of persons with ASD with the law enforcement/court/corrections systems as victims, witnesses, or perpetrators of crime is critical. When approached by a law enforcement officer, an individual with ASD may engage in self-injurious behaviors, walk away from sirens, flashing lights, avoid eye contact, and not respond to repeated commands. This could lead to tragic outcomes for all concerned and training is necessary to avert these potential consequences.

Despite a large body of research looking at an individual with ASD's quality of life, an individual's ability to achieve independence cannot often be predicted because every individual with ASD is unique. Similarly, each individual with ASD responds differently to interventions. This creates challenges in designing systems of care and support due to complexity of the task.

⁷ Rogers, Sally J. and Laurie A. Vismara, "Evidence Based Comprehensive Treatments for Early Autism," *Journal of Child and Clinical Psychology*, University of California, Davis, M.I.N.D. Institute.

⁸ Howlin, P. Goode, S.I. Hutton, Jane, Rutter, M, "Adult Outcome for Children with Autism," *Journal of Child Psychology and Psychiatry*, 45, pp. 212-229, 2004.



WHAT ARE THE NUMBERS?

Over the years, statistics regarding ASD have fluctuated given changes in the definition of “what is ASD?”⁹ This has

⁹ The definition changes that have occurred are:

1956 - Kanner criteria: lack of affective contact; desire for sameness; fascination with objects; mutism or non-communicative language before 30 months of age;

1978 - Rutter criteria: emphasized delayed and unusual social and language development and early onset and unusual behaviors;

1980 - DSM III: differentiated autism from schizophrenia (not a psychotic disorder, but developmental);

1987 - DSM III-R: concept of PDD continued; autism and PDD-NOS defined;

1992 - ICD-10: greatly expanded PDD concept – autism; atypical autism; Rett syndrome; other childhood disintegrative disorder; overactive disorder; associated with MR and stereotyped movements; Asperger’s syndrome; other PDDs; PDD unspecified;

1994 - DSM IV and DSM IV-TR: also expanded PDD concept – autistic disorder; Asperger’s syndrome; Rett syndrome; CDD; PDD-NOS

caused confusion and has hampered states from gathering useful and identifiable information. To further complicate the matter, as the definition of ASD has changed, individuals that are now adults may not have qualified for an ASD diagnosis when they were children. In addition, many pediatricians and special education professionals were not familiar with ASD diagnoses and often incorrectly diagnosed children. Currently, the American Academy of Pediatrics (AAP) recognizes that its professionals may still be operating under the wrong assumptions about ASD. AAP has developed a “tool kit” for its members to provide the knowledge and information to correctly diagnose children.¹⁰ Great care must be taken in the selection of the interdisciplinary team called to determine an ASD diagnosis.

The adult world is vastly different from the children’s and riddled with inconsistencies. Many physicians are unaware that a number of their patients fit the current definition of ASD. The process of determining if an adult has ASD requires a verifiable childhood history of ASD behaviors before age 21. Physicians that are unfamiliar with ASD often tell their patients, “you can’t have ASD; you can talk and hold a job.” The stigma of always equating the disability of mental retardation with ASD is simply not correct. Though a number of individuals with ASD have co-occurring mental retardation, many do not and are able to function in society, for example, by holding down a job and attending post-secondary institutions.

See generally,
www.cdc.gov/ncbddd/autism/overview_changes_diagnostic.htm

¹⁰ www.aap.org Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians, \$79.95 non-members; \$69.95 members

Gathering effective information or the surveillance of ASD has become an international dilemma. Attempting to find some way to estimate the number of adults that have ASD to determine if the prevalence rate has truly increased does not exist. Information in school or other medical charts yield little insight in determining the number of unidentified ASD using “historical” information. This lack of information presents challenges in designing a system of care for adults, as the “correct” number of ASD individuals is presently unknown. For both children and adults, the knowledge base about the disorders and lack of available qualified professionals able to diagnose ASD continues to cause us to rely upon estimates rather than verified numbers.

The Centers for Disease Control and Prevention (CDC), through its surveillance system, has what is considered the most accurate picture of the prevalence rate of individuals living in the United States with ASD.

The CDC estimates that 1 in 150 children is thought to have an autism spectrum disorders. Other estimates show the alarming rate and projections of ASD:

- 1 in 150 children are diagnosed with autism today, compared to 1 in 10,000 in 1993;
- Autism is the fastest-growing serious developmental disorder in the United States;
- 1 in 94 boys is on the autism spectrum;
- Boys are four times more likely to have autism than girls;
- 67 children are diagnosed each day;
- A new case is diagnosed almost every 20 minutes;
- Autism receives less than 5% of the research funding of many less prevalent childhood diseases;
- More children are diagnosed with autism than with pediatric AIDS,

juvenile diabetes, and childhood cancer, combined;

- Autism costs the nation over \$90 billion per year, a figure that is expected to double in the next decade;
- There is no medical detection or cure for autism¹¹

New Mexico does not have the infrastructure in place to either support or negate the findings of the CDC. Using the 1 in 150 statistic and the New Mexico Public Education Department’s (NMPED) 2006-2007 child counts, New Mexico can anticipate on an annual basis, over 850 ASD diagnosed cases from birth to 5 years of age and 2,100 ASD diagnosed children, K-12th grade. Therefore, approximately 3,000 children will be diagnosed with ASD from birth to 18 years of age. The NMPED, Special Education records the following children’s count percentages for the special education exceptionality of autism as follows:

2004-2005 to 2005-2006

3 – 5 year olds	25% increase
6 – 21 year olds	19% increase

COMPARING 2005-2006 DATA TO 2003-2005

3 – 5 year old	78% increase
6 – 21 year olds	38% increase

Based on these growth percentages, the State can forecast an additional 400 children with a diagnosis of ASD each school year.

WHAT ARE OTHER STATES DOING?

MAD, through its Benefits Services Bureau, began researching other states that cover or are proposing to cover through state

¹¹ Autism Speaks, 2006 Annual Report and citations therein.

legislation, or mandated autism spectrum disorders health insurance. Concurrently, a study began to review the types of autism spectrum disorders services offered by states, through a variety of funding mechanisms.

Across twenty-two (22) states researched, there were few common factors.¹² States do not share consistent terminology for autism spectrum disorders. At least six (6) different terms are used or combinations of terms are used to define what each state considers “autism spectrum disorders.”¹³ Added to this, autism is classified as a developmental disability by some, a severe or disabling mental illness by others, and referred by other states as a neurological disorder. In addition, terms change depending on the age of the individual seeking or receiving services.¹⁴ The inconsistency in terminology has, at times, been used as ways for individuals to access health benefit services. These terms speak to the philosophy of the state’s system of care and delivery of services to individuals with ASD. To that end, states house their ASD services in a multitude of departments, from education to mental health.¹⁵ The Funding Work Group’s

¹² Alabama, California, Connecticut, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Minnesota, Mississippi, Montana, New Jersey, New York, Oregon, Pennsylvania, South Carolina, Tennessee, Virginia, Wisconsin

¹³ Mental and Nervous Conditions, Biologically-based Developmental Disability, Neurological Disorder, Biologically-based Mental Illness, Pervasive Developmental Disorders, Chronic Neurodevelopmental Disorder, Mentally Disabled, Serious Emotional Disorders-children, Severe Mental Illness-adults

¹⁴ Montana separates children from adults by listing ASD under Serious Emotional Disorders for children and Severe Mental Illness for adults

¹⁵ Department of Social and Rehabilitation Services, Department of Health and Family Services, Department of Education, Department of Public Aid, Department of Health and

efforts were placed ‘on hold’ with the release of Governor Richardson’s proposed health care reform – Health Solutions New Mexico. The 2008 State Legislature and Governor Richardson will debate and provide direction around issues of mandated health coverage in a variety of areas, including ASD coverage. Senate Bill 197 Study Group proposed to continue the Funding Work Group’s efforts into 2008.

EVIDENCE-BASED PRACTICES ARE THE KEY FOR TREATMENT OF AUTISM SPECTRUM DISORDERS

There is no cure for autism. The closest science has come to combating the core symptoms of autism is a cross-section of behavioral-based interventions that address the specific needs of each individual. Many of these interventions have a range of scientific backing supporting their validity and efficacy for individuals with ASD; however, no one is certain how individuals will respond to which of these interventions. Extensive research conducted in behavioral therapies demonstrates that they are effective and are commonly referred to as “evidence-based practices.”

Evidence-based practices are founded in applied behavioral analysis and positive behavioral supports. These evidence-based practices include, but are not limited to: naturalistic learning approaches; incidental teaching; positive behavioral supports; assistive technology; social skills training; and the use of visual structure and functional routines.¹⁶ Regardless of the setting (school,

Welfare, Department of Public Welfare,
Department of Human Services, Family and
Social Services Administration

¹⁶ Lord, Catherine and James McGee, eds. “Educating Children with Autism”, Chapter 16 Conclusions and Recommendations, pp. 211-229, National Academy of Sciences Committee on Educational Interventions for Children with

home, or community), the research supports the implementation of a range of evidence-based practices.¹⁷ Moreover, the scientific data supports a complex approach to the treatment of individuals with ASD. Based on this research, it is clear that professionals must treat not just one specific aspect of autism (i.e., social, communication or sensory deficits, challenging behaviors or restricted, repetitive behaviors), instead treatment must affect other areas of autistic deficits and the individual's overall skill development.¹⁸

One of the cornerstones to evidence-based treatments is the use of applied behavioral analysis (ABA) which allows professionals to measure the effectiveness of their interventions, track the progress of the individual to obtain established goals, and to provide accountability for treatment systems. Therefore, the treatments of autism spectrum disorders for individuals at any age are complex and necessitate a highly trained and skilled practitioner to develop comprehensive treatment approaches that utilize a range of evidence-based practices to maximize the efficacy of intensive behavioral intervention (IBI) programs. Given such a comprehensive approach, that includes family members and caregivers as primary team members, intensive behavioral interventions are highly effective in addressing the core deficits of ASD, improving adaptive skills, and improving the individual's and family's quality of life.

The Senate Bill 197 Study Group has created a draft "Adaptive Skills Building (ABS)" service definition designed with these evidence-based practices. See, ABS

Autism, National Academy Press, Washington, D.C., 2001

¹⁷ Rogers, 1998. "Empirically supported comprehensive treatments for young children with autism." *Journal of Clinical Child Psychology*. 27. 168-179

¹⁸ Rogers, 1998.

Definition, **Appendix A.** The service definition is for children 21 years of age or younger. Due to the lack of research and development of evidence-based practices, it is recommended that further study be contemplated for an adult service definition for ABS.

EARLY IDENTIFICATION AND INTERVENTION ARE THE KEY COMPONENTS TO BUILDING A SUCCESSFUL MODEL OF CARE

Autism spectrum disorders are complex disorders with variable and fluctuating manifestations. Nevertheless, progress made in early detection techniques now allows for earlier diagnosis of these disorders, frequently before a child's second or third year of life.¹⁹ Typically full spectrum autism can be diagnosed earlier than other types of ASD, such as Asperger's syndrome and Pervasive Developmental Disorder, Not Otherwise Specified.

Despite these advances, it is estimated that, in the United States, only fifty percent (50%) of children with ASD are diagnosed before they enter kindergarten, which is typically at age five.²⁰ Further, there is

¹⁹ Strock, Margaret, "Autism Spectrum Disorders (Pervasive Developmental Disorders), NIH Publication no. NIH-04-5511, National Institute of Mental Health, National Institutes of Health, U.S. Department of Health and Human Services, Bethesda, Maryland, 2004; and Koegel, R.L. and L.K. Koegel, "Pivotal Response Treatments," Baltimore, Maryland, Paul H. Parks Publishing Company, 2006.

²⁰ Strock, Margaret, "Autism Spectrum Disorders (Pervasive Developmental Disabilities), NIH Publication no. NIH-04-5511, National Institute of Mental Health, National Institutes of Health, U.S. Department of Health and Human Services, Bethesda, Maryland, 2004; and Centers for Disease Control and Prevention, "Can Developmental Screening Provider Early Detection?," U.S. Department of Health and

evidence that late diagnosis occurs more frequently among children of low socioeconomic status, children in rural communities, Hispanic and African American children.²¹

Current best practices indicate that effectively screening all children across a wide range of developmental domains is crucial to the early detection of children with ASD. Both the American Academy of Pediatrics (AAP) and the American Academy of Neurology recommend that developmental surveillance, using validated screening instruments, should occur at well-child visits for children from birth through school-age.²² Experts indicate, “good screens make a correct decision at least 70 percent to 80 percent of the time.”²³ These screens are intended to identify children who should receive further evaluation for ASD and/or other developmental problems.

Human Services, Atlanta, Georgia, October 29, 2004.

²¹ Mandell, D. and others, “*Pediatrics*, vol. 116. No. 6, December 2005, pp. 1480-1486; McCook, A., “Autism Diagnosis Comes Later for Blacks than Whites,” Reuters News Center, November 22, 2002; Mandell, D. and others, “Race Differences in Age at Diagnosis Among Medicaid-eligible Children with Autism,” *Journal of Academy of Child and Adolescent Psychiatry*, December 2002, vol. 41, pp. 1447-1453.

²² American Academy of Neurology and the Child Neurology Society, “Practice Parameter: Screening and Diagnosis of Autism,” *Neurology*, 2000, vol. 55, pp. 468-479; and American Academy of Pediatrics, “Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening,” *Pediatrics*, July 2006, vol. 116, no. 1, pp. 405-420.

²³ Glascoe, F. “Commonly Used Screening Tools,” <http://www.dbpeds.org/>.

Pediatricians have a critical role in the detection of children with ASD and other developmental problems. Research has shown that the pediatrician’s appraisal of a child’s developmental status may be inaccurate without the use of a standardized developmental screening tool. Surveys of pediatricians and parents show that most pediatricians do not use screening tools to assess children for developmental problems. According to a 2002 survey by AAP, over seventy percent (70%) of pediatricians reported using only clinical observation (without a screening instrument) to identify children with developmental delays. Only twenty-three percent (23%) of pediatricians reported using a standardized developmental screening tool.²⁴

Effective child-focused questionnaires (screening tools) are available to evaluate children between 18 months-to-24 months of age for signs of ASD. Experts caution that ASD screening tools do not identify all children with ASD, and in some cases detect possible signs of ASD that are not substantiated by further evaluation.²⁵ Researchers continue to refine these tools, as well as other diagnostic procedures, such as early language development, facial processing, and eye-tracking movements, to improve their accuracy and implementation,

²⁴ American Academy of Pediatrics, Division of Health Policy Research, “Periodic Survey of Fellows #53: Identification of Children Under 36 Months At Risk for Developmental Problems and Referral to Early Identification Programs,” as cited by Earls, M. and S. Shackelford Hay, “Setting the Stage for Success: Implementation of Developmental and Behavioral Screening and Surveillance in Primary Care Practice – the North Carolina Assuring Better Child Health and Developmental Project,” *Pediatrics*, vol. 118, no. 1, July 2006, pp. 183-188.

²⁵ Medscape, “The Diagnosis of Autism: An Expert Interview With Catherine Lord, Ph.D,” *Medscape Psychiatry and Mental Health*, vol. 10., no. 2, July 11, 2005.

including their sensitivity for use among children of different racial and ethnic groups.²⁶

The American Academy of Pediatrics recommends that a targeted screening tool for ASD be administered to all children at the 18-month visit.²⁷ The evidence-based best practices for early detection of ASD are described by AAP in, “ASD Best Practice Guidelines for Screening, Diagnosis, and Assessment.” The recommendations are intended for parents, healthcare professionals, regional centers, local education agencies, and others working with-in the ASD field.

Once a child is identified through screening as having indicators of ASD, the child is referred for a comprehensive diagnostic ASD evaluation. Since there are no medical tests for ASD, diagnosis involves a series of diagnostic evaluations across multiple domains of functioning to differentiate ASD from other disorders. Multi-disciplinary evaluation teams are necessary to provide an initial diagnosis of the disorder and to detect changes in a child’s condition over time.

Early identification and intervention for ASD is critical for children to reach their full potential and reduce their level of disability and dependence. Generally, research shows that some children with ASD who receive intensive interventions early in life may have reduced symptoms, improved functioning, and better outcomes. Research further suggests that benefits of

interventions diminish, as children get older, indicating that there is a crucial window of opportunity for early intervention.²⁸

Children with ASD who have improved functioning as a result of early intervention services may have less intensive and costly service needs for the rest of their lives, thereby reducing hardships on families and costs for services of care to serve these individuals during adulthood. For this reason, investments in early identification and intervention services are considered an important, cost-effective approach for society.

One study published in 2006 attempted to document the total costs of autism to U.S. society. The study reported, “It can cost society about \$3.2 million to care for a person with autism over his or her lifetime and about \$35 billion (in direct medical, direct non-medical, and lost productivity costs) to care for all individuals with autism over all of their lifetimes.”²⁹ However, the study also indicated that the total annual costs, “could range from \$13 billion to \$76 billion,” depending on underlying assumptions, and that “these are highly conservative estimates” of the true societal costs because certain types of costs, such as some family out-of-pocket expenses, are not included in the estimates.³⁰

²⁶ Autism Expert Working Group, “Autism Spectrum Disorders Roadmap, Presented to Interagency Autism Coordinating Committee,” May 16, 2005.

²⁷ American Academy of Pediatrics, “Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening,” *Pediatrics*, July 2006, vol. 118, no. 1, pp. 405-420.

²⁸ Mars, A. and others, “Symptoms of Pervasive Developmental Disorders as Observed by Prediagnostic Home Videos of Infants and Toddlers,” *Journal of Pediatrics*, 1998, 132, pp. 500-504, as cited by Mandell, D. and others, “Factors Associated with Age of Diagnosis among Children with Autism Spectrum Disorders,” *Pediatrics*, vol. 116, no. 6, December 2005, pp. 1480-1486.

²⁹ Ganz, M., “The Costs of Autism,” *Understanding Autism: From Basic Neuroscience to Treatment*, S. Moldin, J.L.R. Rubenstein, eds., CRC Press, 2006, pp. 475-502.

³⁰ Ibid.

Taking these numbers and applying them to New Mexicans with ASD, the costs become astronomical. If approximately 3,000 children birth to 21 years of age have ASD, at a cost of \$3.2 million for each person's lifetime, the total cost expectancy is \$9.6 billion.

Clearly, the state must provide needed early screening and intensive interventions in order to be cost-effective.

IMPROVING ACCESS TO SERVICES AND SYSTEMS OF CARE FOR INDIVIDUALS WITH ASD

As a result, the rise in reported cases of individuals with autism spectrum disorders and subsequent media coverage, there is generally more awareness of the occurrence of ASD.³¹ However, there are still gaps in public awareness of the early signs and symptoms, the importance of early identification and intervention, and the programs and services available for diagnosis and treatment. The main area of concern is that individuals with ASD require treatment across multiple disciplines through-out their lifetimes.³²

³¹ It is estimated that in the United States, a child is diagnosed with autism every 20 minutes and there are more than 24,000 new cases of ASD diagnosed each year. The Help Group, Sherman Oaks, California, 2007.

³² For example, typically an ASD evaluation includes a medical examination and an examination by a psychologist, speech pathologist, and an occupational therapist. Other types of evaluations may be necessary based upon an individual's symptoms and circumstances. These may be performed by neurologists, psychiatrists, audiologists, immunologists, gastroenterologists, and geneticists.

Individuals with ASD require ongoing care by a wide array of other health care professionals, including speech and language, physical and occupational, behavioral specialists and mental health professionals. Several years of intensive speech and language therapy are often recommended for treatment of ASD.³³ Many children with ASD have difficulties with balance, coordination, and the appropriate use of fingers, hands, and other muscles. Studies have documented that, in some children, these problems can be improved or overcome with prolonged, intensive, skilled physical, behavioral, and/or occupational therapy.³⁴ There is also compelling evidence that many children with ASD can respond to and improve with intensive behavioral modification therapy. A significant number of ASD individuals require mental health interventions during stressful or life-altering events.³⁵

The duration and mix of services depends on each ASD individual. For example, research shows that most children with ASD will require early intensive behavior intervention for a minimum of several years, as well as

³³ Lord, Catherine and James McGee, eds., "Educating Children with Autism", Chapter 16 Conclusions and Recommendations, pp. 211-229, National Academy of Sciences Committee on Educational Interventions for Children with Autism, National Academy Press, Washington, D.C., 2001.

³⁴ Sallows, G. and T. Graupner, "Intensive Behavioral Treatment for Children with Autism; Four-year Outcome and Predictors," *American Journal of Mental Retardation*, vol. 110, pp. 417-438, 2005.

³⁵ Lovaas, O., and others, "Behavioral Treatment and Normal Intellectual and Educational Functioning in Autistic Children," *Journal of Consulting and Clinical Psychology*, 55, 1987, pp. 3-9.

ongoing interventions and supports throughout their lifetimes.³⁶

The Statewide Capacity Building & Maximizing Existing Resources Work Group of the SB 197 Study Group prepared an extensive matrix of New Mexico Services/Resources, Limitations/Gaps, and Recommendations for the following age groups: (1) Children Birth-to-Three with ASD; (2) Children with ASD Age Three-to-Five; (3) Children with ASD in Elementary School; (4) Children with ASD in Middle School; (5) Youth in High School; (6) Youth 18-21 if No Longer in High School; and (7) Adults 21 and Older. See, **Appendix B**.

Many of the work group's recommendations involve training individuals about autism and how to navigate the complex service delivery systems. For example, for children birth-to-three with ASD, it is recommended that materials be developed for health care providers as to how/where to refer children suspected of having ASD for high quality multidisciplinary evaluations. Overall recommendations include strengthening transition supports between each age group. With regard to NMPED's work with ASD children, there is a need to promote the use of parents and other family members as trainers to assure a family-centered approach.

Critical to the needs of New Mexicans with ASD is the proposed "Adaptive Skill Building Service." See, **Appendix C**. ASB is defined as:

³⁶ Cohen, H., and others, "Early Intensive Behavioral Treatment: Replication of the UCLA Model in a Community Setting," *Developmental and Behavioral Pediatrics*, vol. 27, S145-S155, 2006; and Seltzer, M., and others, "The Symptoms of Autism Spectrum Disorders in Adolescence and Adulthood," *Journal of Autism and Developmental Disorders*, vol. 33, pp. 565-581, 2003.

Adaptive Skill Building services (ASB) are provided to children, adolescents, and young adults with a diagnosis of an autism spectrum disorder (ASD) who need intensive intervention to develop skills necessary to function successfully at home and in the community. ASB services utilize applied behavioral analysis approaches to develop a comprehensive intervention plan, to implement the intervention plan, to monitor the plan for ongoing progress, and to teach individual socially purposeful activities. This service includes use of basis Applied Behavior Analysis techniques, which are provided as part of a comprehensive approach to the treatment of Autism Spectrum Disorders. Similarly, ASB services are family-focused, and services will incorporate a multi-disciplinary approach.

Essential to the proposed service is adequate funding. HSD, in its expansion request, is seeking an additional \$2.9 million which, when added with federal funds, would total \$10 million for certain eligible individuals under the State's Medicaid program. This increase in funding should be seen as a cost-effective approach to provide necessary complex services to this population.

EMPOWERING OTHERS THROUGH EDUCATION AND TRAINING ABOUT AUTISM SPECTRUM DISORDERS

One of the key components to an effective ASD system is education and training about autism spectrum disorders. From educators and other school personnel to first responders and law enforcement officers, encounters with individuals with ASD can be challenging. Performing outreach and training can provide these professionals with the tools necessary for positive interactions.



The federal Individuals with Disabilities Education Act and related state laws place responsibility on the state and local school boards for providing specialized educational and related services to children ages three-to-twenty-two who have disabilities, including autism, so they may benefit from a free and appropriate public education, and in the least restrictive environment. However, these laws do not prescribe specific educational entitlements for certain special education services. School personnel are asked to evaluate a child's disability and needs for educational programming, develop an individualized education program to meet that child's needs, and provide services according to the child's program. The ideal is that the program is developed by a team, including parents, clinicians, school personnel, teachers, and other experts or

advocates. In reality, there is little consistency between school districts in truly incorporating a family-centered approach to individual educational plans for children with ASD.

Regardless of the setting in which they are educated, all children with ASD are entitled to qualified teachers and other educational service providers who understand their unique cognitive, behavioral, and social skills needs and are able to provide effective educational interventions to meet those needs. Therefore, teachers of general education and special education, teacher aides, speech and language therapists, school administrators, school psychologists, and other staff who serve children with ASD must be properly trained with the competencies to deliver effective educational interventions for ASD. An in-depth study is recommended, in collaboration with qualified school personnel, to develop programs to meet the needs of New Mexico children with ASD. Included in this study is the need to develop a more comprehensive approach by NMPED towards including time away from school as an integral piece of children's individual education plans. Children with ASD struggle at school to minimize their ASD symptoms, only to have breakdowns at home when parents are assisting their children with schoolwork. Learning occurs outside of the walls of a school and parents must be provided by professionals the tools and skills to promote their children's learning in the community and home.

It is similarly true that focused training on ASD is needed for law enforcement officers and emergency first responders. Persons with ASD may be very concerned about their ability to accurately communicate with those around them during highly stressful events. Compounding this, some of the behavioral characteristics of persons with ASD may be read as hostile or uncaring. Many persons with ASD, especially those who require substantial care and supervision and have limited language skills, can

become victims of unscrupulous people who prey on the vulnerable; people with ASD are particularly disadvantaged because many are unsuccessful in accessing help when they need it from the police, courts, and others. The police, emergency responders, and the courts are similarly frustrated at the lack of specialized services and supports they have available as referral sources for individuals with ASD. The system of care is fragmented or in some cases, non-existent for individuals with ASD.

It is essential to address this problem by formulating ways of educating first responders as well as persons with disabilities who need to develop skills to function effectively in a community. As New Mexico's 3,000 ASD children grow into adulthood, the state will need to provide particular attention and accommodations to adult service systems.

**MORE STUDY IS NEEDED FOR
SERVICES AND SUPPORTS FOR
ADULTS WITH AUTISM
SPECTRUM DISORDERS**

Presently, the state's system of care for adults with disabilities has not been

designed o adequately serve persons with ASD. The state needs to review both the design and adequacy of its programs for employment, adult and higher education, supportive housing, self-direction, and long-term support systems.

Every person with ASD transitioning into adulthood needs a life-plan that addresses their educational, social, residential, and employment supports and is developed with the person, family, friends, and community supporters. It was brought to the Study Group's attention that parents of ASD children fear for their adult children when they, as parents, age and can no longer care for them.

State service programs for persons with disabilities respond to crises when maintenance of functional level is often the critical goal. Rather than offering access to services to prevent deterioration, current public programs often offer nothing until something goes wrong. Services should not be predicated on a model that is offered only in time of crisis. Rather, efforts should be made to focus on maintaining stability and providing effective resource management for adults with ASD.



WHAT ARE THE NEXT STEPS?

The Senate Bill 197 Study Group had several barriers to contend with in meeting the charges from the State Legislature. Funding was not allocated, so membership was comprised from the Albuquerque and Santa Fe areas. The Study Group had limited time to address the bill's charges. Yet, even with these barriers, the Study Group came to a consensus that although the complexities were difficult to grasp, some effective steps could be taken to address the Legislature's desire to develop viable, sustained and dynamic systems of care for its ASD citizens.

The Study Group proposes a combination of approaches for consideration by the New Mexico Legislature:

- (1) Recommendations that require legislative action;**
- (2) Recommendations requiring action through the proposed Health Care Authority; and**
- (3) Recommendations to be resolved within existing systems.**



RECOMMENDATIONS TO THE NEW MEXICO LEGISLATURE

- (1) *The New Mexico Legislature support expansion funding for the Department of Health in the amount of \$1 million and the Human Services Department request of \$2.9 million. DOH funding will be used to provide Applied Skills Building services to non-Medicaid eligible ASD recipients. HSD funding will be used to provide Applied Skills Building services for Medicaid eligible ASD recipients. The Study Group endorses the Children, Youth and Families proposed expansion of funds to provide ASD services to non-Medicaid eligible children.*

RATIONALE:

The ASD prevalence rate of 1 in 150 females and 1 in 94 males requires the State to take specific action to develop the infrastructure and services to meet the needs of New Mexicans with ASD. The National Institute of Mental Health states, “One point that most professionals agree on is that early intervention is important; another is that most individuals with ASD respond well to highly structured, specialized programs.”³⁷

Developing an Adaptive Skills Building service will be the centerpiece to the development of a comprehensive system of care for individuals with ASD. These services will focus on evidence-based practices that have shown to be highly effective at mitigating the effects of the core deficits of ASD. These services have the potential to maximize an adult’s potential to live independently with improved quality of life as the ASD individual ages. Currently, New Mexico has a gap in its system of care to meet the needs of individuals with ASD, and these requests for funds for services will help bridge that gap while being proactive in the treatment of ASD as a new health crisis.

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- (2) *The New Mexico Legislature should direct the Secretary of the Higher Education Department to work with its four-year institutions to develop ASD specific pre-service and continuing education modules for instructional use by a wide variety of professionals who will be increasingly interacting with individuals with ASD in their home communities.*

RATIONALE

Using the CDC’s number of the growing incidence of ASD, New Mexico's state, counties, municipalities, and tribal communities will experience increasing interactions with the ASD population. By training qualified professionals, the State will support the increased independence of ASD individuals and provide governmental staff the skills and knowledge to more effectively and efficiently plan for and work with this population.

³⁷ www.nimh.gov/health/publications/autism/treatment.shtml.

Governmental personnel must provide opportunities for full inclusion and protection as individuals with ASD become engaged citizens of their home communities.

- (3) ***The New Mexico Legislature should provide funding in the amount of \$200,000 to the Department of Health for the creation and implementation of a statewide ASD surveillance and registration program. The Department of Health will coordinate these efforts with the Centers for Disease Control and Prevention and Autism Speaks International efforts of the Autism Epidemiology Network for surveillance and registration.***

RATIONALE:

There is no doubt that the number of children and adults diagnosed with ASD will continue to grow in New Mexico. For the State to provide and maintain services, the State Legislature must have New Mexico-specific accurate and current rates of prevalence, and information on the utilization rates for cost analysis and budget development.

- (4) ***The New Mexico Legislature should support the Behavioral Health Collaborative in its efforts to convene the appropriate departments and agencies necessary to develop, if appropriate, adequate and appropriate systems, service definition, policies and licensing standards for New Mexico-based residential treatment center facilities for ASD individuals requiring this intensive level of care. Seed money in the amount of \$350,000 is recommended to establish this service, after which it will be self-sustaining through existing billing structure.***

RATIONALE:

New Mexico fully embraces keeping disabled individuals in their home communities; however, there will always be a need for some form of institutional care. By nature of the disorders, there will be individuals with ASD that need a highly structured facility and staff, such as residential treatment centers (RTC). The average annual cost for an individual with ASD in an out-of-state residential treatment center is \$300,000. New Mexico presently lacks the professional expertise to provide services to individuals with ASD needing residential treatment care settings. In-state providers have not developed the qualified infrastructure. This may be due to the current reimbursement rate of \$350-per day, while out-of-state residential treatment centers receive anywhere from \$500 to \$800-per day. The Legislature should support the Behavioral Health Collaborative's efforts to review and develop community-based programs, including the development of an ASD-specific infrastructure as outlined herein. The Study Group, however, believes that certain individuals with ASD may need such intensive therapies that an RTC setting may be the most appropriate setting.

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- (5) ***The New Mexico Legislature should replicate the Behavioral Health Purchasing Collaborative’s flex-funding program with ASD-specific funding of \$1.0 million for respite care, service extension or to address unfunded gaps in service.***

RATIONALE:

Families consistently state the need for services for which there are little if any funds available. Under the current traditional Medicaid program, respite is not a covered service; however, Medicaid home and community-based waiver programs do provide for some respite or environmental modifications. There is a seven (7) year waiting list to move into the Department of Health Developmental Disabilities Waiver program. Unfortunately, for individuals that do not meet Waiver eligibility, there is a critical unmet need for respite and other types of services not covered by Medicaid. Families need environmental safety modifications to protect their ASD family members from harm (e.g., door alarms, plexi-glass windows). ASD children often place themselves in risky situations. The State Legislature has supported the Behavioral Health Collaborative’s flex-funding program as a way to address these gaps in services. It has been effective in providing assistance to families and recipients where no other funding is available. Under current funding levels, the Behavioral Health Collaborative’s flex-fund program exhausts its allocation by mid-year. This fund would be specifically for individuals with ASD.

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- (6) ***The New Mexico Legislature should direct the Division of Vocational Rehabilitation at the Public Education Department, the Developmental Disabilities Support Division at the Department of Health, and the Working Disabled Initiative at the Human Services Department to adopt national guidelines related to vocational supports for adults with ASD.***

RATIONALE:

Youth and adults with ASD require specific approaches and interventions to support them in employment. Traditional vocational education approaches are not appropriate for high-functioning ASD individuals. The various state agencies and departments must work together to design programs that support individuals with ASD so that they can reach their full potential. As the State develops programs and supports to assist individuals with ASD and as these individuals enter their communities, ready to work, it is imperative that systems be in place to facilitate these transitions. Our employment systems must be ready for the aging of our ASD children into adults, so that they too, can be useful and productive members of society.

- (7) *The New Mexico Legislature should extend the charge of Senate Bill 197 Study Group to continue work to enhance collaborative efforts among the 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 representation 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.*

RATIONALE:

As set forth herein, the prevalence of ASD and the impact on existing services and systems requires further study. No other disability or disorder affects so many citizens. Moreover, the complex nature of ASD affects virtually every state agency. ASD research constantly changes the way we plan and serve individuals with ASD, as researchers develop more effective tools to support individuals with ASD. The information the Study Group reviewed demonstrates that our current systems of care for individuals with ASD are too often dead-ends, unnavigable, and lack the bridges between service systems. New Mexico must continue to maintain its focus on the development of service systems and infrastructure development for individuals with ASD, in particular, a concentrated focus on the fragmented and non-existent adult ASD service systems. Specific recommendations entirely focused on autism should be made to the various state agencies, departments, and the Legislature to continue to address this growing health crisis. Minimal funding is requested to offset some of the costs needed to meet statewide, gather the information from all of our citizens, and encourage broad participation. The money requested herein is to provide stipends and to conduct statewide public forums; it does not include any additional money for staffing. Although HSD, Senate Bill 197's lead agency, has requested additional personnel in its September 2007 budget request, the Legislature should be cognizant of the other initiatives, including such intense programs as Coordinated Long-Term Services, that current staff resources are of concern.

- (8) *The New Mexico Legislature should support the Behavioral Health Local Collaboratives request for one-time funding in the amount of \$175,000 to study service needs, service gaps, and the design for ASD high-functioning adults.*

RATIONALE:

The Study Group attempted to design a service definition for high-functioning ASD adults, only to find limited research and recommendations for best practices. As the

number of ASD children mature into adulthood, the State must be prepared with the research to develop appropriate services and supports. ASD adult services must include opportunities and transition planning towards independence, employment, and housing. By developing such services and systems prior to the ever-increasing number of ASD individuals leaving child services and entering into adult services, we support ASD adults to become productive, inclusive members of our communities and of society.

RECOMMENDATIONS TO THE HEALTH CARE AUTHORITY

On October 25, 2007, Governor Richardson unveiled his vision for health care reform, Health Solutions New Mexico. One of the key components of the Governor's proposal was the creation of the Health Care Authority. Study Group members learned of the Governor's proposal at their penultimate meeting when the group was discussing its final recommendations. Should the Legislature support the Governor's proposal, the Health Care Authority (HCA) should be directed to review autism spectrum disorders, potentially creating an Autism Spectrum Disorders Advisory Council and, regardless of the HCA's approach, report to the Legislature on three specific areas: (1) Systems Development and Alignment; (2) Adult Transitions and Supports; and (3) Research Opportunities. These recommendations should encompass public programs and the private sector, commercial insurance products.³⁸

SYSTEM DEVELOPMENT AND ALIGNMENT

The HCA should develop commonality across the various "medically/educationally necessary" definitions for evidence-based practices and accepted services to individuals with ASD into one definition that recognizes the overlapping need for physical health services, behavioral health services and educational services needed during these individuals' lifetimes. At present, an ASD medical diagnosis and the ASD educational diagnosis provide different services that affect the duration, intensity and approved practitioner credentials. The challenge for individuals with ASD is that they can meet both definitions and still have gaps in their service plans. If these two diagnostic protocols could become compatible, services could flow through a seamless set of service plans that meet the comprehensive needs of individuals with ASD.

The HCA should also bridge the gap between the behavioral health and the developmental disabilities systems. The behavioral health system uses "recovery and resiliency" and the developmental disabilities system uses "functional improvement" to classify ASD needs. Consumers, families, providers, and decision-makers understand that ASD is a life-long diagnosis and an individual can experience times of stabilization, as well as crises, and services must be provided along a continuum of care. In addition,

³⁸ The Study Group discussed commercial insurance products currently available in the market and established the new service "Adaptive Skills Building," as a possible benefit; however, given the Governor's proposal of placing a moratorium on any new insurance mandates, the Study Group deferred any recommendation until such time as the Health Care Authority can review and recommend to the Legislature any changes to existing services and systems.

on the physical health side, the focus is on “treatment” and “cure” while on the behavioral health side emphasis is placed on developing a recovery and resiliency plan. Families are forced to navigate these systems facing frustration and lack of service coordination. Common language should be developed and instituted to pull separate systems into one cohesive system for individuals with ASD.

ADULT TRANSITIONS AND SUPPORTS

Individuals with ASD experience periods of time when the need for service stabilization is low or constant. There are other periods of time, due to the disorders themselves, where an individual with ASD must utilize more services, with increases in duration and intensity. Some individuals with ASD face extreme challenges in their functioning stability with life transitions and changes. Parents’ of ASD children often have kept their adult children in their family home. As these parents age, they face their inability to provide the level of care and stability necessary for their ASD adult children. When this ASD adult is forced to move from his known home environment to a new living arrangement, the need for extensive service hours and professional assistance is required to make the transition successful for the parents and their adult child.

The Study Group recommends that the HCA review and develop an adult system of care that encompasses supports for parents of adult ASD children living at home, and supports ASD adults to live independently. Support services must be responsive to address life-changing events that occur in the lives of individuals with ASD. These may include expansion of hours and services for specified periods of time. It is further recommended that the HCA take into consideration that services and supports must be available throughout an individual with ASD’s lifetime.

RESEARCH OPPORTUNITIES

Currently, there are five (5) regional centers of Excellence for Autism research as designated by the National Institute of Health and the Centers for Disease Control and Prevention.³⁹ These centers pursue research and disseminate information out to other professional institutions. The Study Group recommends to the HCA that a separate funding stream be developed around research in New Mexico:

- (1) that identifies research proposals that are unique to the needs of New Mexicans;
and

³⁹ California Department of Health Services, Colorado Department of Health and Environment, Maryland-John Hopkins University, North Carolina-University of North Carolina at Chapel Hill, Pennsylvania-University of Pennsylvania/Children’s Hospital of Philadelphia

- (2) filters information for relevance and validity and disseminates this information to service providers, recipients, families, and state agencies about evidence-based new services, best practices and new knowledge about ASD;

In addition, the Study Group recommends that research be conducted in the following areas:

- (1) the prevalence rate of individuals with ASD experiencing co-occurring incidences of depression, substance abuse, and domestic violence as either perpetrators, victims, and witnesses; and
- (2) best practices for ASD adults in employment, housing and support services.

RESOLUTIONS WITHIN EXISTING SYSTEMS

The Study Group recommends the following:

- (1) Training be provided to all individuals that serve on special education plan development and implementation teams on strategies for family, consumer and communities to be engaged in the Individual Family Service Plan (IFSP) and Individual Education Plan (IEP) process on ASD and to promote the use of parents/family members, and whenever possible ASD children, to assure family-centered approaches to ASD service development and delivery. There is an additional need for the development and support of ASD resource teams at individual school districts.
- (2) Support the efforts of Developmental Screening Initiative that is currently developing screening and referral information for pediatricians and family practitioners to assist in their appropriate referrals to parents of children suspected of having ASD for high quality multidisciplinary evaluations, services and supports. Materials to include information on acquiring the American Academy of Pediatricians *ASDToolkit* and the *Act Early* information from the Centers for Disease Control and Prevention.
- (3) Support and complete efforts underway by the University of New Mexico Center for Development and Disabilities and the New Mexico Autism Society to develop a roadmap tool to assist service coordinators, health professionals, parents, adult consumers, and educators to navigate the systems of care and services for individuals with ASD

ACKNOWLEDGEMENTS

The Study Group acknowledges the heightened awareness of the New Mexico Legislature, Governor Richardson, health care professionals, parents, and others on the growing concerns of autism spectrum disorders. Many states, including California, have done extensive research and provided background material that was used in this report.⁴⁰ As more and more individuals are being diagnosed with ASD, the need to design and utilize comprehensive tools and establish and maintain comprehensive services becomes readily apparent. Therefore, the Study Group would like to acknowledge the hundreds of professionals across the country that are reviewing and addressing these needs. New Mexicans with ASD will benefit from these efforts and the research and hopefully, provide a roadmap for significant change.



⁴⁰ The California Legislature Blue Ribbon Commission on Autism Report, “An Opportunity to Achieve Real Change for Californians with Autism Spectrum Disorders,” September 2007.

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Appendix A

SPAC/SB 197
AN ACT
RELATING TO HEALTH INSURANCE;
REQUIRING A STUDY OF AUTISM
SPECTRUM DISORDER SERVICES AND SYSTEMS.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF NEW MEXICO:

Section 1. TEMPORARY PROVISION--STUDY OF AUTISM

SPECTRUM DISORDER SERVICES AND SYSTEMS.--The human services department, in collaboration with private insurance companies and consumers, shall conduct a study of autism spectrum disorder services, study the systems that serve the population affected by autism spectrum disorders and determine the most appropriate funding mechanisms, including health insurance, state disability insurance or developmental disability waivers or autism waivers. The human services department shall report its findings and recommendations to the legislative finance committee and the appropriate interim legislative committee on or before November 1, 2007.

Appendix B

Statewide Capacity Building and Maximizing Existing Resources Work Group

Senate Bill 197 Study Group

Draft October 13, 2007

Children Birth to Three with Autism Spectrum Disorders (ASD)

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Early Childhood Evaluation Clinic (ECEP) • Autism Programs at CDD (\$500,000/year) • Physicians 	<ul style="list-style-type: none"> • ECEP identified 63 toddlers with ASD in FY07 – ECEP not exclusively for ASD – evaluates infants/toddlers suspected of all types of developmental delays. • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • Challenging to make a diagnosis in this age range – follow up to confirm may be critical. Requires high level of expertise & experience; best practice is a multidisciplinary team. • Physicians may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred especially in this age range. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Family Infant Toddler Program (FIT) • Children’s Medical Services (\$280,000/year from FIT for this age group) • Salud! care coordinators 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • FIT services (including services billed through Medicaid). • Therapy covered by private insurance 	<ul style="list-style-type: none"> • Prior authorization required to exceed 19 hours per month in FIT services • Not all – or even most FIT providers have 	

<ul style="list-style-type: none"> • Therapy through private pay • Behavioral Health through Value Options • Indian Health Services or BIA? 	<p>taken advantage of the opportunity to receive ASD specific training from SET.</p> <ul style="list-style-type: none"> • FIT doesn't currently track children by diagnosis so has no firm numbers with ASD in their system. • FIT funding structure not structured to cover intensity/frequency of intervention recommended for this population. Should numbers with ASD rise significantly this could create a budget crisis for FIT. • Few private insurance plans cover "habilitation" services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services shown to be needed to be effective. • Even with Value Options, insurance coverage or private pay – number of therapists with ASD specific expertise is very limited. • Children typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud! frequently denied due to perception that the therapy need is 	
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	educational rather than medically necessary.	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund (SGF) respite • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. • Family Specialists and Social workers through the Autism Programs at CDD. 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given their annual budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid) 	
<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Project SET at the Autism Programs at CDD provide training to professionals serving this age group. • UNM School of Medicine 19th Annual SW Psychiatric Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered. • Ziggurat model training scheduled through CDD 11/29 & 30/07. • Early Childhood Network at CDD has supported FIT providers to enhance expertise with ASD. Upcoming early childhood conference will focus on ASD. 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of SET opportunities. If they did, could SET meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines • Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> • Promote use of parents/family members as trainers to assure family-centered approach.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • FIT has administrative structure and monitoring process in place. • DOH provides contract oversight for Autism Programs at CDD. 	<ul style="list-style-type: none"> • FIT & other DOH staff with monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect. 	<ul style="list-style-type: none"> • Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.

Children with ASD Age Three to Five

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Early Childhood Evaluation Clinic (ECEP) • Autism Programs at CDD • Physicians including those through Indian Health Services • Public Schools • Individual Private Practitioners 	<ul style="list-style-type: none"> • <i>ECEP for 3 year olds only.</i> ECEP identified 63 toddlers with ASD in FY07 – ECEP not exclusively for ASD – evaluates infants/toddlers suspected of all types of developmental delays. • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • PCPs may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred. • Schools use educational rather than medical lens for identification of ASD. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Children’s Medical Services • Salud! care coordinators • Pre-school teachers 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families • Teachers have limited time and expertise for this function 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • 3 & 4 year old program through local public schools. • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • Intensive Parent Training/Mentoring through Autism Programs at CDD (\$600,000) • Medicaid EPSDT covered benefits • Indian Health Services and/or BIA? 	<ul style="list-style-type: none"> • Not all – or even most preschool teachers have received ASD specific training. • Few districts cover the number of hours per week recommended for ASD. • CDD Intensive Parent Training limited to 120 families/year statewide. • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited 	

	<p>by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective.</p> <ul style="list-style-type: none"> • Even with EPSDT, Value Options, insurance coverage or private pay – number of therapists/counselors with ASD specific expertise is very limited. • Children typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud! frequently denied due to perception that the therapy need is educational rather than medically necessary. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund (SGF) respite • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid expected to start in Dec. 2007) 	
<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Project SET at the Autism Programs at CDD provide training to professionals serving this age group. • UNM School of Medicine 19th Annual SW Psychiatric 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of SET opportunities. If they did, could SET meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other 	

<p>Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered.</p> <ul style="list-style-type: none"> • Ziggurat model training scheduled through CDD 11/29 & 30/07. • CDD also contracted to conduct training with certain school districts, through both their Autism Programs and Preschool Network. 	<p>disciplines</p> <ul style="list-style-type: none"> • Ziggurat training limited to 275 participants 	
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • Public Education Department (PED) has administrative structure and monitoring process in place. • DOH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>PED & DOH staff with monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect.</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Children with ASD in Elementary School

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Autism Programs at CDD • Physicians including those through Indian Health Services • Public Schools • Individual Private Practitioners 	<ul style="list-style-type: none"> • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • Physicians may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred. • Schools use educational rather than medical lens for identification of ASD. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Children’s Medical Services • Salud! care coordinators • Teachers & School Social Workers • CDD if participating in the Adaptive Skill Building Program. 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families • Teachers have limited time and expertise for this function 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • Special Education through local public schools. • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • Adaptive Skill Building Program through Autism Programs at CDD (\$1,850,000) • Medicaid EPSDT covered benefits, including OT, PT, SLP, Personal Care, Private Duty Nursing, Home health aide. • DD Waiver services, including case 	<ul style="list-style-type: none"> • Not all – or even most teachers have received ASD specific training. • Few districts cover the number of hours per week recommended for ASD. • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective. • Even with EPSDT, Value Options, 	

<p>management, community access, personal companion, behavioral support consultation, respite and very limited therapies which don't duplicate EPSDT or school therapy needs.</p> <ul style="list-style-type: none"> • Indian Health Services and/or BIA? 	<p>insurance coverage or private pay – number of therapists/counselors with ASD specific expertise is very limited.</p> <ul style="list-style-type: none"> • Adaptive Skill Building Program currently funded at level to serve just 60 children statewide. • Children typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud! frequently denied due to perception that the therapy need is educational rather than medically necessary. • DD Waiver waiting list is approximately 7 years long. Providers may not have ASD specific training or expertise. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund (SGF) respite • DD Waiver respite. • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. • VSA Saturday Art Program. • Recreational Respite Program (\$61,500) 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid expected to start in Dec. 2007) • Few children this age are on the DD Waiver due to length of waiting list. • VSA Saturday Art Program limited in size and to the Albuquerque 	

	<p>Metro area.</p> <ul style="list-style-type: none"> • Recreational Respite Program hasn't yet gone out for RFP 	
<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Autism Programs at CDD provide training to professionals serving this age group through funding from both DOH and PED (for certain school districts). This includes ADOS training and web-based training. • UNM School of Medicine 19th Annual SW Psychiatric Symposium "Autism Spectrum Disorders Through the Lifespan" 11/1 & 2/07 in Albuquerque. CME and CEU offered. • Ziggurat model training scheduled through CDD 11/29 & 30/07. 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of CDD opportunities. If they did, could CDD meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines • Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> • Mandate basic training/knowledge of ASD for all educators • Promote Applied Behavior Analyst certification for relevant professionals.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • Public Education Department (PED) has administrative structure and monitoring process in place. • DoH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>PED & DOH staff with monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect.</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Children with ASD in Middle School

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Autism Programs at CDD • Physicians including those through Indian Health Services • Public Schools • Individual Private Practitioners 	<ul style="list-style-type: none"> • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • Physicians may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred. • Schools use educational rather than medical lens for identification of ASD. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Children’s Medical Services • Salud care coordinators • Teachers & School Social Workers • CDD if participating in the Adaptive Skill Building Program 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families • Teachers have limited time and expertise for this function 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • Special Education through local public schools. • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • Adaptive Skill Building Program through Autism Programs at CDD – at this age this includes social skills groups (\$1,850,000) • Medicaid EPSDT covered benefits, including OT, PT, SLP, Personal Care, Private Duty Nursing, Home health aide. • DD Waiver services, including case 	<ul style="list-style-type: none"> • Not all – or even most teachers have received ASD specific training. • Few districts cover the number of hours per week recommended for ASD. • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective. • Even with EPSDT, Value Options, insurance coverage or 	

<p>management, community access, personal companion, behavioral support consultation, respite and very limited therapies which don't duplicate EPSDT or school therapy needs.</p> <ul style="list-style-type: none"> • Indian Health Services and/or BIA? 	<p>private pay – number of therapists/counselors with ASD specific expertise is very limited.</p> <ul style="list-style-type: none"> • Adaptive Skill Building Program currently funded at level to serve just 60 children statewide. • Children typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud frequently denied due to perception that the therapy need is educational rather than medically necessary. • DD Waiver waiting list is approximately 7 years long. Providers may not have ASD specific training or expertise. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund (SGF) respite • DD Waiver respite. • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. • VSA Saturday Art Program • Recreational Respite Program (\$61,500) 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid expected to start Dec. 2007) • VSA Saturday Art Program limited in size and to the Albuquerque area. • Recreational Respite Program hasn't yet gone out for RFP 	

<p>Training/Professional Development:</p> <ul style="list-style-type: none"> Autism Programs at CDD provide training to professionals serving this age group through funding from both DOH and PED (for certain school districts). This includes ADOS training and web-based training. UNM School of Medicine 19th Annual SW Psychiatric Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered. Ziggurat model training scheduled through CDD 11/29 & 30/07. 	<ul style="list-style-type: none"> Not all relevant professionals take advantage of CDD opportunities. If they did, could CDD meet demand? Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> Mandate basic training/knowledge of ASD for all educators Promote Applied Behavior Analyst certification for relevant professionals.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> Public Education Department (PED) has administrative structure and monitoring process in place. DOH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>PED & DOH staff with monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect.</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Youth in High School

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Autism Programs at CDD • Physicians including those through Indian Health Services • Public Schools • Individual Private Practitioners 	<ul style="list-style-type: none"> • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • Physicians may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred. • Schools use educational rather than medical lens for identification of ASD. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Children’s Medical Services • Salud care coordinators • Teachers & School Social Workers • CDD if participating in the Adaptive Skill Building Program 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families • Teachers have limited time and expertise for this function 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • Special Education through local public schools. • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • Adaptive Skill Building Program through Autism Programs at CDD – at this age this includes social skills groups (\$1,850,000) • Medicaid EPSDT covered benefits, including OT, PT, SLP, Personal Care, Private Duty Nursing, Home health aide. • DD Waiver services, including case 	<ul style="list-style-type: none"> • Not all – or even most teachers have received ASD specific training. • Few districts cover the number of hours per week recommended for ASD. • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective. • Even with EPSDT, Value Options, insurance coverage or 	

<p>management, community access, personal companion, behavioral support consultation, respite and very limited therapies which don't duplicate EPSDT or school therapy needs.</p> <ul style="list-style-type: none"> • Schools require Transition Plan. • Indian Health Services and/or BIA? 	<p>private pay – number of therapists/counselors with ASD specific expertise is very limited.</p> <ul style="list-style-type: none"> • Adaptive Skill Building Program currently funded at level to serve just 60 children statewide. • Youth typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud frequently denied due to perception that the therapy need is educational rather than medically necessary. • DD Waiver waiting list is approximately 7 years long. Providers may not have ASD specific training or expertise. • Transition difficult due to extremely limited ASD specific services for adults. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund (SGF) respite • DD Waiver respite. • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. • Recreational Respite Program (\$61,500) 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid expected to start Dec. 2007) • Recreational Respite Program hasn't yet gone out for RFP 	

<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Autism Programs at CDD provide training to professionals serving this age group through funding from both DOH and PED (for certain school districts). This includes ADOS training and web-based training. • UNM School of Medicine 19th Annual SW Psychiatric Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered. • Ziggurat model training scheduled through CDD 11/29 & 30/07. 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of CDD opportunities. If they did, could CDD meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines • Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> • Mandate basic training/knowledge of ASD for all educators • Promote Applied Behavior Analyst certification for relevant professionals.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • Public Education Department (PED) has administrative structure and monitoring process in place. • DOH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>PED & DOH staff with monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect.</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Youth 18-21 if No longer in High School

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Autism Programs at CDD • Physicians including those through Indian Health Services • Individual Private Practitioners 	<ul style="list-style-type: none"> • Autism Programs at CDD currently has operating capacity to evaluate 4 children per week. • Physicians may lack specific expertise to confirm this diagnosis & multidisciplinary approach is preferred. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Children’s Medical Services • Salud care coordinators • CDD if participating in the Adaptive Skill Building Program 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for children with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • Adaptive Skill Building Program through Autism Programs at CDD – at this age this includes social skills groups (\$1,850,000) • Medicaid EPSDT covered benefits, including OT, PT, SLP, Personal Care, Private Duty Nursing, Home health aide. • DD Waiver services, including case management, community access, personal companion, behavioral support consultation, 	<ul style="list-style-type: none"> • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective. • Even with EPSDT, Value Options, insurance coverage or private pay – number of therapists/counselors with ASD specific expertise is very limited. • Adaptive Skill Building Program currently funded at level to serve 	<p>New Mexico state agencies to adopt National Guidelines for Vocational Programs (e.g. DVR, DDSD Supported Employment Programs)</p>

<p>respite and very limited therapies which don't duplicate EPSDT or school therapy needs.</p> <ul style="list-style-type: none"> • Division of Vocational Rehabilitation • Indian Health Services and/or BIA? • Independent Living & Day Habilitation or Supported Employment through DDS State General Fund (SGF) 	<p>just 60 children statewide.</p> <ul style="list-style-type: none"> • Youth typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • OT & SLP thru Salud frequently denied due to perception that the therapy need is educational rather than medically necessary. • DD Waiver waiting list is approximately 7 years long. Providers may not have ASD specific training or expertise. • SGF services extremely limited in number. • Extremely limited ASD specific services for adults; only occurs when DD Waiver and/or SGF providers have taken advantage of opportunities for staff training. • DVR counselors need ASD training. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund SGF respite • DD Waiver respite. • Behavioral Respite through Value Options • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. • Recreational Respite Program (\$61,500) 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF limited by each provider depending upon local demand given budget. • Value Options limited to 24 hours/week and for non-Medicaid eligible also limited to 100 hours/year for first 75 families (\$150,000 total available for non-Medicaid expected to start Dec. 2007) • Recreational Respite Program hasn't yet gone out for RFP 	

<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Autism Programs at CDD provide training to professionals serving this age group through funding from both DOH and PED (for certain school districts). This includes ADOS training and web-based training. • UNM School of Medicine 19th Annual SW Psychiatric Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered. • Ziggurat model training scheduled through CDD 11/29 & 30/07. 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of CDD opportunities. If they did, could CDD meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines • Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> • Promote Applied Behavior Analyst certification for relevant professionals.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • DOH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>DOH has monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to address this aspect.</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Adults 21 and Older

Services/Resources	Limitations/Gaps	Recommendations
<p>Identification/Diagnosis:</p> <ul style="list-style-type: none"> • Physicians including those through Indian Health Services • Individual Private Practitioners 	<ul style="list-style-type: none"> • Physicians may lack specific expertise to confirm this diagnosis. Multidisciplinary evaluation preferred. 	<ul style="list-style-type: none"> • Identify strategies to successfully obtain 3rd party payment for evaluations from Medicaid and insurance in order to expand evaluation capacity. • Develop materials for physicians as to where/how to refer children suspected of having ASD for high quality multidisciplinary evaluation. • Develop method to track children identified with ASD, by all relevant programs/parties.
<p>Service Coordination:</p> <ul style="list-style-type: none"> • Salud care coordinators • Case manager if on DD Waiver 	<ul style="list-style-type: none"> • Many may need training specific to ASD • See limitations in ASD specific services below to which service coordinators can link families 	<ul style="list-style-type: none"> • Strengthen transition supports between each age group. • Develop a “how to navigate the system for adults with ASD” tool for service coordinators, health professionals, parents, etc.
<p>Intervention/Treatment:</p> <ul style="list-style-type: none"> • Therapy covered by private insurance • Therapy through private pay • Behavioral Health through Value Options • DD Waiver services, including case management, community access, personal companion, behavioral support consultation, respite and very limited therapies which don’t duplicate EPSDT or school therapy needs. • Division of Vocational Rehabilitation • Indian Health Services and/or BIA? • Independent Living & Day Habilitation or Supported Employment through DDS State 	<ul style="list-style-type: none"> • Few private insurance plans cover “habilitation” services for children with developmental disabilities such as ASD. • Private pay is limited by family income – very few NM families have sufficient financial resources to pay for intensity of services needed to be effective. • Adults also typically need services from both physical health and behavioral health systems – which need to be coordinated and sometimes even performed together. Does not occur well currently. • DD Waiver waiting list 	<p>New Mexico state agencies to adopt National Guidelines for Vocational Programs (e.g. DVR, DDS Supported Employment Programs)</p>

<p>General Fund (SGF)</p>	<p>is approximately 7 years long. Providers may not have ASD specific training or expertise.</p> <ul style="list-style-type: none"> • SGF services extremely limited in number. • Extremely limited ASD specific services for adults; only occurs when DD Waiver and/or SGF providers have taken advantage of opportunities for staff training. • DVR counselors need ASD training. 	
<p>Respite/Family Support:</p> <ul style="list-style-type: none"> • Department of Health (DOH) state general fund respite • DD Waiver respite. • NM Autism Society, Parents Reaching Out, Parents of Behaviorally Different Children can all provide parent to parent support. 	<p>Number of respite hours per family limited:</p> <ul style="list-style-type: none"> • SGF respite limited by each provider depending upon local demand given budget. 	
<p>Training/Professional Development:</p> <ul style="list-style-type: none"> • Autism Programs at CDD provide training to professionals serving this age group through funding from both DOH. This includes ADOS training and web-based training. • UNM School of Medicine 19th Annual SW Psychiatric Symposium “Autism Spectrum Disorders Through the Lifespan” 11/1 & 2/07 in Albuquerque. CME and CEU offered. • Ziggurat model training scheduled through CDD 11/29 & 30/07. 	<ul style="list-style-type: none"> • Not all relevant professionals take advantage of CDD opportunities. If they did, could CDD meet demand? • Psychiatric symposium costs \$245 for physicians and PhD, D.Ed; \$195 for all other disciplines • Ziggurat training limited to 275 participants 	<ul style="list-style-type: none"> • Promote Applied Behavior Analyst certification for relevant professionals.
<p>Infrastructure/Quality Assurance:</p> <ul style="list-style-type: none"> • DOH & PED provide oversight for respective contracts with Autism Programs at CDD. 	<p>DOH has monitoring & oversight responsibilities need training in what quality looks like for ASD. May need to adjust monitoring tools to</p>	<p>Establish a representative Autism Advisory Council to advise state agencies and provide external review of effectiveness of the system.</p>

Appendix C

**Skills Training and Development, per 15 minutes
(Adaptive Skill Building)**

DRAFT Service Requirements and Utilization Guidelines

**Adaptive Skill Building
for individuals with Autism Spectrum Disorders**

Service Definition: Adaptive Skill Building services (ASB) are provided to children, adolescents, and young adults with a diagnosis of an autism spectrum disorder (ASD) who need intensive intervention to develop skills necessary to function successfully at home and in the community. ASB services utilize applied behavioral analysis approaches to develop a comprehensive intervention plan, to implement the intervention plan, to monitor the plan for ongoing progress, and to teach individual socially purposeful activities. This service includes use of basic Applied Behavior Analysis techniques, which are provided as part of a comprehensive approach to the treatment of Autism Spectrum Disorders. Similarly, ASB services are family focused, and services will incorporate a multidisciplinary approach.

Criteria	
Source of Funding	HSD or authorized agency
Target Population	<p>Children, adolescents, and young adults (individuals under age 22) who:</p> <ul style="list-style-type: none"> • Have a documented diagnosis of Autism Spectrum Disorder (i.e., Autistic Disorder, Asperger’s Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified) and • Require adaptive skill building services due to challenging behaviors, and • Require specialized therapeutic services in acquiring or maintaining adaptive behavior skills, and/or • Need intensive adaptive behavioral interventions in order to live in their home and community.
Program Requirements	<p>ASB services provide:</p> <ul style="list-style-type: none"> • Utilize applied behavior analysis as defined by the following standards: <ol style="list-style-type: none"> 1. utilize behavioral modification techniques (e.g., operant conditioning) to teach socially relevant behaviors, 2. Use of positive behavioral supports and functional behavioral analysis in developing developmentally appropriate interventions, 3. Uses careful behavioral observation, objectively defined behavior measurement and data collection to monitor behavioral change and inform clinical decisions,

	<p>4. Individualized intervention plans based on applied behavioral analysis are designed to assist in the acquisition and maintenance of social, behavioral, and living skills necessary to function successfully within an individual’s home and community settings</p> <ul style="list-style-type: none"> • Interventions designed to build upon existing individual and family strengths; • Assistance and training for parents, family, and/or guardians to support and maintain the adaptive skills development for the identified individual. Services can be provided to parents, family, and/or guardians without patient present; <p>Clinical assessment requirement:</p> <ul style="list-style-type: none"> • Services are based on the a clinical assessment that guides the development of an individualized Skills Building Plan • Clinical assessment must be completed by a independent licensed Level 2 or 3 ASB provider • The Level 2 and/or 3 ASB provider must conduct one clinical assessment per year to determine the clinical need of ABS services <p>Skills Building Plan:</p> <ul style="list-style-type: none"> • The plan must be included as part of a comprehensive treatment plan which addresses an integrated program of therapeutic services for Autism Spectrum Disorder. • The plan must identify all adaptive skills that are to be addressed by the Adaptive Skills Building specialist(s) • The ASB specialist is responsible for implementation of the Skills Building Plan through applied behavior analysis techniques and teaching, training, and coaching activities. • The family and treatment team will develop an individual’s service or treatment plan. The treatment team will provide a recommended intensity and duration of ABS services.
Provider Requirements	Services must be delivered by an organization that is a legally recognized entity in the US, qualified to do business in NM, and must meet standards established by the State of NM or its designee to provide services to individuals on the DD Waiver.
Staffing Requirements	<p>All clinical services and supervision by licensed practitioners must be in accord with their respective licensing board regulations.</p> <p>Levels of Adaptive Skill Building Specialist:</p> <ol style="list-style-type: none"> 1. Level 1: Providers will need to have a high school diploma or equivalent and extensive interests in autism spectrum disorders. These providers will need ongoing coaching, mentoring and supervision by a Level 2 or 3 provider. Providers will need to meet the knowledge and skill requirements as a specified Level 1 certificate. 2. Level 2a: BA, BS, BABC, MEd, MA, MS, or BCBA, plus specialized training in applied behavioral analysis approaches and specialized interventions for individuals with autism spectrum disorder. These providers will need ongoing supervision by a Level 3 provider. Providers will need to meet the knowledge and skill requirements as a specified Level 1 and Level 2 certificate.

	<p>3. Level 2b: MA, MS, PsyD, PhD, plus specialized training applied behavioral analysis approaches and specialized interventions for individuals with autism spectrum disorder. These providers will be independent licensed by the appropriate state agency or licensing board. Providers at this level (most likely ancillary therapists like speech language pathologists, occupational therapists, or physical therapists) can provide direct services as deemed appropriate by the treatment team with being in the direct line of supervision.</p> <p>4. Level 3: MA, MS, BCBA, PsyD, PhD or MD with extensive knowledge and previous experience developing and supervising adaptive skills building programs. Providers will need to meet the knowledge and skill requirements as a specified Level 1, Level 2, and Level 3 certificate. These providers will need to be independently licensed by the appropriate state agency or licensing board.</p> <p>All Adaptive Skills Building Specialists must:</p> <ol style="list-style-type: none"> 1) Be at least 18 years of age, and 2) Successfully pass a criminal background check, and 3) Demonstrate the ability to independently implement and document goals, measurable objectives, interventions, and outcomes as defined in the individualized Skills Building Plan, 4) Receive at least 80 hours of training including but not limited to: <ul style="list-style-type: none"> • health training to include but not limited to safety, basic first aid, CPR, and emergency protocols • specialized training regarding working with children and youth with Autism Spectrum Disorders • specialized training regarding applied behavioral analysis • training on working with families/primary caregivers of individuals with Autism Spectrum Disorders • training on the Incident Management System, including requirements to report incidents of abuse, neglect, and exploitation 5) Receive a minimum of 4 to 8 hours of supervision monthly, based on the specialist's experience and caseload needs and issues 6) Receive an ASB certificate from the overseeing agency document additional training and supervision has been completed. All providers must obtain an ASB certificate within 6-months of providing services. <p>Clinical Supervision:</p> <ul style="list-style-type: none"> • Must be provided by an independently licensed practitioner with a minimum of 2 years of directly related experience • Level 2 and Level 3 provider will take clinical, legal and ethical responsibility for each ASB program they supervise • Level 2 and Level 3 providers must provide clinical supervision to Level 1 and Level 2 providers
Documentation Requirements	<p>The child, youth, or young adult records documentation requirements include:</p> <ul style="list-style-type: none"> • Documentation of activities as required by the ASB agency and the standards under

	<p>which it operates, including documentation of all contact/services provided</p> <ul style="list-style-type: none"> • Incident reports of any serious incidents, including incidents of abuse, neglect, and exploitation
Service Exclusions	<p>This service may not be billed in conjunction with the following services:</p> <ul style="list-style-type: none"> • Residential and/or inpatient services • The professional services rendered by a psychiatrist may be billed for medication management; as well as, assessments and diagnostic evaluations by an appropriately licensed mental health providers
Admission Criteria	<p><i>All of the following criteria are necessary for admission:</i></p> <ol style="list-style-type: none"> 1. The child, youth, or young adult have Autistic Disorder, Asperger's Syndrome, or Pervasive Developmental Disorder-Not Otherwise Specified consistent with a DSM-IV-TR (AXES I-V) diagnosis 2. The child, youth, or young adult requires specialized therapeutic services in acquiring or maintaining adaptive behavior skills
Psychosocial, Occupational, and Cultural and Linguistic Factors	<p>There is unbiased knowledge of the child, youth, or young adult's culture and language which is an integral part of all efforts to deliver services. Beliefs and practices are identified which include but are not limited to beliefs and practices; family organization and relational roles (traditional and non traditional); an understanding of ethnically related stressors such as poverty, discrimination, and beliefs related to mental health/health care, spirituality and history of help-seeking and treatment.</p> <p>The service must support a recovery and resiliency model with consideration for the longer-term nature of stabilization for the individual with an ASD diagnosis.</p>
Exclusion Criteria	<p><i>Any of the following criteria is sufficient for exclusion from this level of care:</i></p> <ol style="list-style-type: none"> 1. The child, youth, or young adult exhibits severe suicidal, homicidal or acute mood symptoms/thought disorder, which requires a more intensive level of care. 2. The child, youth, or young adult's parent or Guardian is not capable/willing to give consent to participate in ASD services or consent is not given by the State if in custody. 3. The child, youth, or young adult has access to and availability of other funding sources that can provide similar services and supports (i.e. DD Waiver services, ICFMR)
Admission/Service Criteria	<p><i>This service requires prior authorization</i></p>
Continuing Service Criteria	<p><i>Measurable progress towards acquisition of adaptive skills</i></p>
Service Authorization Period	<p><i>Services will be authorized for a maximum of 1 year</i></p>

Benefit Limits	The maximum allowable length of this service is 3 years (36 months) ASD is reimbursed in 15 minute units, not to exceed: <ul style="list-style-type: none">• For ages 0-3 years, 80 units per week (20 hours)• For ages 3-4 years, 60 units per week (15 hours)• For ages 5-22 years, 40 units per week (10 hours)• An individual may qualify for additional ABS services by the following: