HMA

HEALTH MANAGEMENT ASSOCIATES

An Analysis of Treatment Coverage for Children with Autism Spectrum Disorder in South Dakota

PREPARED FOR THE
STATE OF SOUTH DAKOTA
DEPARTMENT OF LABOR AND REGULATION AND
DEPARTMENT OF HUMAN SERVICES

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Research and Consulting in the Fields of Health and Human Services Policy, Health Economics and Finance, Program Evaluation, Data Analysis, and Health System Restructuring

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Introduction

In June 2014, Health Management Associates (HMA) was engaged by the South Dakota Department of Labor and Regulation and Department of Human Services to develop an autism study for the Governor and State Legislature. HMA is an independent, national research and consulting firm with expertise in financing of healthcare and related services for vulnerable populations. HMA sub-contracted with NovaRest Actuarial Consulting for the cost analysis; NovaRest is a firm with extensive experience conducting similar cost analyses related to insurance coverage for the treatment of children with Autism Spectrum Disorder (ASD.)

Coverage of services for the treatment of children with ASD in the private insurance market as well as in State Medicaid Programs is a complex issue. Misinformation may persist related to efficacy of treatment options; there may be conflicting assumptions related to treatment costs, savings and their implications; and relevant state and federal laws remain open to some level of interpretation. The purpose of this report is to clarify what is known from the literature on treatment efficacy, assess the level and cost of current coverage, provide clarification on relevant federal and state law, project the cost of coverage for treatment that is not widely covered but shown to be effective for children with ASD, and to share the outcomes of other states' deliberations to form public policy on this issue.

We thank the State of South Dakota's Department of Labor and Regulation, the Department of Human Services, the Department of Education, the Department of Social Services and the Governor's Office for assistance in identifying relevant state data and helping us hone in on the questions most relevant to stakeholders. We also thank the many ASD treatment providers for sharing information about the services they provide and their current capacity, and the four domestic insurance carriers for providing critical information on coverage, claims and costs. Finally, we thank the parents of children with Autism Spectrum Disorder who shared their stories of hope and sacrifice to obtain services to support their children in being able to live the most productive and independent lives possible.

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Executive Summary

Autism Spectrum Disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. A diagnosis of ASD includes several conditions that were previously diagnosed separately: Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (usually referred to as PDD-NOS), and a more mild form of the disorder known as Asperger Syndrome. Although ASD varies significantly in character and severity, it occurs in all socioeconomic and ethnic groups and affects every age group.[1] Experts estimate about one in 68 children in the United States has been identified with ASD.[2]

During the 2014 legislative session, the State of South Dakota passed Senate Bill 108 – an Act to require a study of services and insurance coverage for the treatment of ASD for children. The primary purpose of the study is to ensure that policy makers have the information needed to make informed decisions related to ASD insurance coverage.

HMA conducted a literature search and identified credible research reviews on ASD treatments and their outcomes conducted in the last five years. In Section I of the report, we summarize findings from the most recent and comprehensive reviews -- Comparative Effectiveness Reviews -- which rate treatment outcomes for children with ASD based on evidence. The treatments with the greatest evidence-base include: Intensive Behavioral Intervention Services (IBIS) including Applied Behavioral Analysis and Early Start Denver Model for improving cognition and language/communication; play or interaction-based joint attention interventions to improve joint attention; and cognitive behavioral therapy to reduce anxiety. Specific medication therapies -- Aripiprazole and Risperidone -- have the greatest evidence base for reducing challenging behaviors though they both have potential adverse side effects. Each of the reviews included the caveat that universal improvements for individuals with ASD cannot be assumed. It was also noted that the data are scarce or missing altogether on the efficacy of interventions for adolescents with ASD.

In Section II of the report, we summarize state law and regulation as well as requirements of selected national certifying boards regarding the licensing and certification of providers to screen, diagnose and treat children with ASD in South Dakota. We collected and present publicly available data from the State Department of Education on the types and intensity of direct or contracted services provided to children with Autism through 18 years of age in the public schools. Schools are providing services -- an average of between 0.5 and 0.75 hours per

[1] National Institute of Neurological Disorders and Stroke, Autism Fact Sheet, April 2014.
[2] Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. Surveillance Summaries, March 2014.

week of speech therapy, occupational therapy and physical therapy -- to the sub-set of children with Autism deemed to require these services.

We developed and conducted surveys of the primary ASD direct provider organizations in the State and interviewed these providers to better understand their survey responses and related issues. As described in Section III, these providers offer varying levels of service intensity based on the assessed needs of the child; however, lack of access in some areas of the State, limited insurance coverage and a lack of awareness of treatments for ASD influence the extent to which children with ASD receive effective treatment.

We researched current State expenditures for children with ASD through 18 years of age, and present a breakdown of State costs which total over $18.5 million annually through the Department of Education, the Medicaid State Plan, the CHOICES Medicaid Waiver and Family Support Medicaid Waiver, the State Health Insurance Plan, and a grant to the University of South Dakota Center for Disabilities for the ASD Program.

In Section IV, based on our research and legal interpretation of the Affordable Care Act, federal and state Mental Health Parity laws, and the Center for Medicaid and Medicare Services 2014 clarification of Medicaid benefits for ASD services, we conclude that insurance carriers, including Medicaid, are not required under current law to provide coverage for IBIS in South Dakota.

To estimate the short and long-term premium impact of an insurance mandate that covers IBIS, we conducted research to inform assumptions and developed a cost model. The methodology for development of these estimates is provided in Section V of the report.

We estimate that starting in 2016 and in the short-term, the additional premium cost for covering IBIS for children through 18 years of age is approximately $0.50 per insured member per month. This number reflects a provider network that is currently not adequate to serve the potentially eligible population of children. With provider network adequacy requirements, we estimate the longer term or “ultimate” premium impact as a range that includes low-level, moderate-level and high-level assumptions. The ultimate premium impact may be as much as $2.50 per member per month using the high-level assumptions outlined in the report. In addition to current State expenditures for children with ASD, the State would be responsible for a portion of the cost of a commercial insurance mandate; we estimate this to be an ultimate amount of $2.98 million annually. Further costs would be incurred to the State if the State were to expand the Employee Health Plan and Medicaid coverage to include IBIS for children with ASD.

In Section VI, we summarize the experience of six states that border South Dakota; four of these states mandate coverage of IBIS for children with ASD in the State Employee Health Plan, and at least three require some level of commercial insurance coverage for IBIS. We explore the

costs of maintaining the status quo in Section VIII and identify research that demonstrates a return on investment for IBIS.

To ensure input from key stakeholders – parents and families affected by ASD, providers, insurance carriers, policy makers and others – four public forums were held: in Rapid City, Pierre, Aberdeen, and Sioux Falls. While several themes were identified, an overarching theme is that families whose children receive IBIS typically have insurance coverage; the cost of intensive services without insurance coverage is out of reach for the vast majority of middle class families in South Dakota.

Section I. Accepted ASD Treatment Protocols and Associated Outcomes

Treatment protocols are a set of specific interventions designed to achieve specific outcomes when implemented as described. Treatment protocols should be supported by a strong evidence-base of effectiveness. Numerous studies of the effectiveness of specific treatments for ASD have been conducted to identify whether or not the interventions lead to improvements in functional capacity, such as language use and social skills. We present the results of recent, systematic research reviews of the literature related to ASD treatment efficacy and provide a brief analysis and summary as it relates to the treatment of children with ASD.

Four research reviews were consulted in the development of this section of the report. These include Comparative Effectiveness Reviews (2014 and 2011), the Autism Spectrum Disorder Services: Final Report on Environmental Scan (2010), and the National Autism Center's National Standards Report (2009.)

The most recent and comprehensive reviews of the literature published at this time are the two Comparative Effectiveness Reviews (CERs) commissioned by the national Agency for Healthcare Research and Quality (AHRQ). A CER is a systematic review of existing research on the effectiveness, comparative effectiveness, and harms of different treatment interventions. These reports are designed to accurately and transparently summarize a body of literature with the goal of informing real-world health care decisions for patients, providers, and policymakers. This section will draw heavily on these CERs. The literature review in Appendix A summarizes findings of effective treatment protocols identified in the other reviews as well.

The first CER, published in 2011, focuses on therapies for children 0-12 years old with ASD. Included in this review are studies relevant to treatment for ASD that were published in English from January 2000 to May 2010. Searches retrieved 4,120 citations. The vast majority were excluded for reasons detailed in the review. A total of 183 articles representing 159 unique studies were included in the review.

Since the 2011 review, several additional research studies to test the efficacy of early intensive behavioral interventions have been published, and the quality of these studies has improved. Therefore, an update to the 2011 review was undertaken and published in August 2014. The authors included studies of behavioral interventions for ASD published in English through December 2013. Searches retrieved 2,639 newly published citations and abstracts. Again, the vast majority were excluded for reasons detailed in this review. A total of 79 publications, comprising 65 unique studies met criteria for inclusion.

The researchers of these reviews organized the array of ASD treatments into five categories: behavioral interventions, educational interventions, medical and related intervention, allied health interventions, and complementary and alternative medicine (CAM) interventions.

Sound research methods -- outlined in the Methods Guide for Comparative Effectiveness Reviews -- help to ensure the scientific rigor of the CERs. To give decision-makers a comprehensive evaluation of the evidence, and a sense of how much confidence they should place in the evidence, a "strength of evidence" score is provided for each treatment. The strength-of-evidence system takes into account many factors. These factors include but are not limited to study design, presence or absence of bias, quality of evidence, and consistency of evidence. [3]

The authors of these reviews assign one of four grade levels for "strength of evidence" to each type of treatment. The grade reflects the researchers' confidence of the estimated effect of the treatment's benefit or harm. It also takes into account their assessment of the likelihood that future research might affect the level of confidence. The strength of evidence scores are defined as follows:

- High: researchers have high confidence that the evidence reflects the true effect. Further research is very unlikely to change our confidence in the estimate of effect.
- Moderate: researchers have moderate confidence that the evidence reflects the true effect. Further research may change our confidence in the estimate of effect and may change the estimate.
- Low: researchers have low confidence that the evidence reflects the true effect. Further research is likely to change the confidence in the estimate of effect and is likely to change the estimate.
- Insufficient: researchers have determined evidence either is unavailable or does not permit a conclusion.

Of the five types of intervention categories reviewed – behavioral, educational, medical and related, allied health, and complementary and alternative medicine (CAM) -- there were two intervention categories that were found to have interventions of "moderate" or "high" evidence of effectiveness.

Table 1 summarizes treatment interventions for which the literature indicates demonstrated improvements in ASD symptoms with a strength of evidence grade that is either "moderate" or "high" as defined by the most recent AHRQ-sponsored Comparative Effectiveness Reviews (CER).

[3] Owens DK, Lohr KN, Atkins D, et al. Grading the strength of a body of evidence when comparing medical interventions. In: Agency for Healthcare Research and Quality, Methods Guide for Comparative Effectiveness Reviews [posted July 2009] Rockville, MD. http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?productid=328&pageaction=displayproduct

Table 1: Interventions and Treatment Outcomes with a Moderate or High Strength of Evidence of from the Comparative Effectiveness Reviews

Intervention	Treatment Outcomes	Strength of Evidence
Behavioral Interventions		
Intensive Behavioral Intervention Services	Applied Behavior Analysis and Early Start Denver Model improved cognitive and language/communication	Moderate
Play or Interaction-Based	Joint attention interventions may demonstrate positive outcomes in preschool-age children with ASD when targeting joint attention skills	Moderate
Interventions to Ameliorate Symptoms	Effects of Cognitive Behavioral Therapy on anxiety reported positive results in older children with IQs greater than or equal to 70	High
Medical and Related Interventions		
Aripiprazole and Risperidone	Ability to affect challenging behaviors:* 1. Aripiprazole 2. Risperidone	 1. High 2. Moderate

*Both medications have high strength of evidence for adverse side effects.

Analysis and Summary

ASD treatments focus on improving core deficits in social communication, as well as addressing challenging behaviors to improve functional engagement in developmentally appropriate activities. Treatment is also provided for difficulties associated with the disorder such as anxiety, attention difficulties, and sensory difficulties.

Intensive Behavioral Intervention Services (IBIS) have the strongest evidence of effectiveness at this time. Established treatments such as Applied Behavior Analysis (ABA) and Early Start Denver Model (ESDM) have moderate evidence of effectiveness; however, all research reviews considered indicated that universal improvements cannot be expected to occur for all individuals on the autism spectrum. Individual treatment goals vary for different children and a combination of therapies may be necessary to achieve substantial gain.

The research is currently insufficient to determine the characteristics of children for which treatment may be most effective. Therefore, each child's treatment should be monitored closely for effectiveness in meeting the treatment goals.

There are several other treatment modalities in current practice that are described in the literature beyond those identified in the table above. While many of these treatments are generally accepted components of a comprehensive treatment program for ASD, there may not be a sufficient number of well-designed, published studies to have confidence in the estimated effect of the treatment's benefit or harm. The omission of these treatments in this analysis is not to be interpreted as a lack of endorsement. Rather it is to focus on the purpose of this

section, which is to provide an overview of accepted treatment protocols with a strong evidence-base of effectiveness.

Many of these evidence-based and other generally accepted treatment modalities are offered in the marketplace in South Dakota. Utilization of these services is limited primarily due to lack of insurance coverage for selected treatments, geographic distribution of providers in the State, and parental awareness of effective treatment modalities which is discussed in subsequent sections of this report.

A description and evidence-base for the range of interventions included in the Comparative Effectiveness Reviews are summarized below.

Behavioral Interventions

Intensive Behavioral Intervention Services draw from principles of applied behavior analysis (ABA), with differences in methods and setting. Two intensive interventions that have published treatment manuals were included in the research review; these are the University of California, Los Angeles/Lovaas model and the Early Start Denver Model (ESDM). Also included in this intervention category are those interventions that apply intensive ABA principles using a similar approach to the UCLA/Lovaas model. An additional set of interventions included in this category use ABA principles to focus on teaching pivotal behaviors to parents rather than on directed intensive intervention.[4]

Treatment Outcomes: Evidence from the original report and the update suggests that early Intensive Behavioral Intervention Services (IBIS), based on the principles of Applied Behavior Analysis, delivered using a comprehensive approach (i.e., addressing numerous areas of functioning) and in an intensive manner (greater than or equal to 15 hours per week), can positively affect a subset of children with ASD. Across intervention approaches, children receiving early IBIS demonstrate improvements in language, cognitive, adaptive and ASD impairments compared with children receiving eclectic non-ABA based interventions and low-intensity interventions. (The strength of evidence was moderate for cognitive and language/communication; and low for adaptive behavior, symptom severity and social skills/social behavior.)[5]

Social Skills Interventions focus on facilitating social interactions and may include peer training and social stories.

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[4] Vanderbilt Evidence-Based Practice Center. *Effective Health Care Program Comparative Effectiveness Review, Number 26. Therapies for Children with Autism Spectrum Disorder.* Agency for Healthcare Research and Quality. April 2011.

[5] Vanderbilt Evidence-Based Practice Center. Effective Health Care Program Comparative Effectiveness Review, Number 137. Therapies for Children with Autism Spectrum Disorders: Behavioral Interventions Update. Agency for Healthcare Research and Quality. August 2014. P. ES-11

Treatment Outcomes: Social skills interventions varied in scope and intensity and showed some positive effects on the social behaviors for older children in small studies. (The strength of evidence is low for positive effects on social skills.)[6]

Play- or Interaction-Focused Interventions use interactions between children and parents or researchers to affect outcomes, including imitation, joint attention skills, or children's ability to engage in symbolic play.

Treatment Outcomes: Studies on play and interaction-based approaches reported that joint attention interventions may demonstrate positive outcomes in preschool-age children with ASD when targeting joint attention skills (strength of evidence is moderate.) Data on the positive effects of such interventions in other areas such as play skills, language and social skills were limited (The strength of evidence is low.)[7]

Interventions to Ameliorate Symptoms are designed to lessen symptoms commonly associated with ASD such as anxiety. Techniques used include cognitive behavioral therapy (CBT) as well as parent training focused on other challenging behaviors. Additional interventions for sleep disorders include techniques such as sleep workshops.

Treatment Outcomes: Studies examining the effects of CBT on anxiety reported positive results in older children with IQs greater than or equal to 70. (The strength of evidence is high.) Smaller short-term studies of other interventions reported some improvements in areas such as sleep but sufficient data were unavailable to assess their overall effectiveness.[8]

Educational Interventions

Educational interventions focus on improving educational and cognitive skills. They are intended to be administered primarily in educational settings. While some interventions in educational settings are based on principles of ABA and may be intensive, no interventions in this category used the UCLA/Lovaas or ESDM treatment protocols.

Treatment Outcomes: Researchers identified 15 unique studies of educational interventions meeting inclusion criteria. Most of the research was on the TEACHH Program -- Treatment and Education of Autistic and Communication-related Handicapped Children -- and was conducted prior to the date cutoff for the review. Newer studies continue to report improvements among children in motor, eye-hand coordination, and cognitive measures. There is not sufficient evidence, however, to draw conclusions about the efficacy of the TEACHH Program and other

[6] Vanderbilt Evidence-Based Practice Center. *Effective Health Care Program Comparative Effectiveness Review, Number 26. Therapies for Children with Autism Spectrum Disorder*. Agency for Healthcare Research and Quality. April 2011.
[7] IBID
[8] Vanderbilt Evidence-Based Practice Center. *Effective Health Care Program Comparative Effectiveness Review, Number 26. Therapies for Children with Autism Spectrum Disorder*. Agency for Healthcare Research and Quality. April 2011.

broad-based educational programs as there are too few studies and those studies have inconsistencies in outcomes measured.[9]

Medical and Related Interventions

Medical and related interventions are those that include the administration of external substances to the body to treat symptoms of ASD. These include a variety of pharmacologic agents, including antipsychotics, psycho-stimulants, and serotonin reuptake inhibitors (SRIs), and modalities such as nutritional or hormonal supplements, therapeutic diets, immunoglobulin, chelating agents, and hyperbaric oxygen.

Treatment Outcomes: Forty-two unique studies in the medical literature were reviewed, of which 27 were Randomized Control Trials (RCTs). Although no current medical interventions demonstrate clear benefit for social or communication symptoms, a few medications show benefit for repetitive behaviors or associated symptoms. The clearest evidence suggests the use of medications to address challenging behaviors. The antipsychotics Aripiprazole and Risperidone each have at least two RCTs demonstrating improvement in challenging behavior as reported by parents. A parent-reported noncompliance and hyperactivity measure also showed significant improvement. Both medications reduced repetitive behavior as well.

Significant side effects were seen with both medications including weight gain, sedation, and risk of side effects such as muscle stiffness or tremor. Due to side effects, researchers indicated that these drugs should be limited to patients with severe impairment or risk of injury. (The strength of evidence is moderate for the ability of Risperidone to affect challenging behaviors, high for Aripiprazole's effects on challenging behaviors, and high for the adverse effects of both medications.)[10]

Allied Health Interventions

Allied health interventions include therapies typically provided by speech/language, occupational, and physical therapists. These interventions also include auditory and sensory integration, music therapy, and language therapies (e.g., Picture Exchange Communication System).

Treatment Outcomes: The allied health interventions assessed included 17 unique studies. All studies of music therapy and sensory integration were of poor quality, and two fair-quality studies of auditory integration showed no improvement associated with treatment. Language and communication interventions (Picture Exchange Communication System, and Responsive Education and Pre-linguistic Milieu Training) demonstrated short-term improvement in word

[9] IBID

[10] Vanderbilt Evidence-Based Practice Center. *Effective Health Care Program Comparative Effectiveness Review, Number 26. Therapies for Children with Autism Spectrum Disorder*. Agency for Healthcare Research and Quality. April 2011.

acquisition, and should be studied further. No other allied health interventions had adequate studies to assess the strength of evidence.[11]

Complementary and Alternative Medicine (CAM) Interventions

CAM interventions include acupuncture and massage. Evidence for CAM interventions is insufficient for assessing outcomes.[12]

Treatment Modifiers

Researchers conducting these reviews also assessed studies of treatment modifiers (factors that can alter the outcomes of treatment) to determine whether the magnitude of the effect of a treatment differed depending on other factors. There were few studies that were designed to identify modifiers of treatment effect. Examples of potential modifiers with currently conflicting data that warrant further investigation include pre-treatment IQ and language skills, and age of initiation of treatment (with earlier age potentially associated with better outcomes). Imitation skills and social responsiveness may also correlate with improved treatment response in UCLA/Lovaas treatment.[13]

[11] IBID
[12] Vanderbilt Evidence-Based Practice Center. *Effective Health Care Program Comparative Effectiveness Review, Number 26. Therapies for Children with Autism Spectrum Disorder*. Agency for Healthcare Research and Quality. April 2011.
[13] IBID

Section II. Provider Licensure, Certification and Availability

In South Dakota, as in other states, anyone who performs screening, diagnosis and treatment must be licensed and/or certified by the state. Health care professionals are licensed in accordance with South Dakota statutes, Title 36. These requirements are not specific to ASD – they apply to screening, diagnosis and treatment for any condition that may be treated under a health care professional's license.

State licensure requirements are displayed in Table 2. Detailed descriptions of each provider type are provided in Appendix B.

Table 2: Requirements for Providers Who Screen, Diagnose or Treat Individuals – Licensure

Services	Provider Type	South Dakota Statutes Licensure Requirements – Title 36
Counseling Services	Marriage and Family Therapist Licensed Professional Counselor-Mental Health	36-33
Occupational Therapy	Occupational Therapist Occupational Therapy Assistant	36-31
Psychological Services	Psychologist	36-27A
Physical Therapy	Physical Therapist Physical Therapy Assistant	36-10
Physician Services	Psychiatrist Physician (e.g. Pediatrician)	36-4
Speech Therapy	Speech-Language Pathologist, Provisional Speech-Language Pathologist, and Limited Speech-Language Pathologist Speech-Language Pathology Assistant	36-37 36-37-17 36-37-19 36-37-18

Source: South Dakota Codified Laws

Providers who deliver Intensive Behavioral Intervention Services (IBIS) such as Applied Behavioral Analysis (ABA) and the Early Start Denver Model (ESDM) in South Dakota may be certified by a national certifying body. ABA providers may be certified by the Behavior Analyst Certification Board® Inc.; and ESDM providers may be certified by the University of California, Davis Continuing and Professional Education.

Table 3: National Certification for Providers of Applied Behavioral Analysis and Early Start Denver Model Practitioner Functions

Practitioner Functions	Practitioner Type	National Certification Body
Applied Behavioral Analysis		
Behavioral assessments, interpretations and interventions	Holds at a minimum a master's degree in behavior analysis or other natural science, education, human services, engineering, medicine or a field related to behavior analysis and is a Board Certified Behavior Analyst (BCBA, BCBA-D)	Behavior Analyst Certification Board
With technical supervision of a BCBA, conducts behavioral assessments, interpretation and interventions	Holds a bachelor's degree in education, clinical, counseling, or school psychology, clinical social work, occupational therapy, speech language therapy, engineering, medicine or other field related to behavior analysis and is a Board Certified Assistant Behavior Analyst (BCaBA)	Behavior Analyst Certification Board
With supervision of a BCaBA, implements plans developed by supervisor, collects data, and conducts certain assessments	Has a minimum of a high school diploma or national equivalent and is a Registered Behavior Technician (RBT)	Behavior Analyst Certification Board
Early Start Denver Model (ESDM) Practitioner Functions		
Conducts developmental assessment, develops individualized teaching objectives, implements ESDM teaching practices with fidelity, maintains data	Psychologist, behaviorist, occupational therapist, speech and language pathologist, early intervention specialist or developmental pediatrician and is a Certified ESDM Therapist	University of California, Davis Continuing and Professional Education

While some states specifically certify providers of these services, others rely on national certification to help ensure appropriate and effective delivery of Intensive Behavior Intervention Services. Practitioner functions, type and related national certifying organizations are presented in Table 3.

All categories of providers described in Tables 2 and 3 practice in South Dakota and provide services to children with ASD. Many of these professionals work in the schools while others work in community private practices or Universities.

School Services

Currently, families of children with ASD report they rely on the school system to provide allied health services (speech, occupational and physical therapy) as private therapies are financially out of reach for many families. Services provided in the schools are limited in terms of their intensity and do not generally include intensive behavioral services. Table 4 provides a snap

shot of the percent of children and median hours per week of therapy/service provided to children with an Autism diagnosis as defined by the DSM IV – the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. In the 2013-2014 school year, the South Dakota public school system served 835 children 3 through 18 years of age with this diagnosis.

Table 4: Allied Health and Counseling/Psychology Service Intensity for Children Aged 3-18 with Autism Diagnosis in the South Dakota Public School System, 2013 -2014 School Year

Therapy/Service	Number (Percent) of Children Receiving the Therapy/Service (N=835)	Median Hours Therapy/Service Received Per Week
Speech Therapy	644 (77.1%)	0.75
Occupational Therapy	300 (35.9%)	0.50
Physical Therapy	80 (9.6%)	0.50
Counseling Services	47 (5.6%)	0.40
Psychological Services	3 (0.36%)	0.30

Schools are charged with providing a free appropriate public education with a focus on educational goals and issues related to functioning in the school setting. Additionally, while school professionals may meet State licensure or certification requirements for their profession, they need training and support to work effectively with children with ASD.

Organizations Providing Treatment Services to Children with ASD

HMA worked with the State Department of Human Services, Division of Developmental Disabilities to identify the providers of services for children with ASD. We developed and administered electronic provider surveys and conducted provider interviews to obtain the information in this section. While there are many other direct providers of ASD services in the State as well as those dedicated to providing information and referral, the six organizations identified in Table 5 below provide the majority of treatment services for children with ASD.

According to providers, Intensive Behavioral Intervention Services for ASD have been available in South Dakota for about the past six years. These services have been used mainly by families in or around the Sioux Falls metropolitan area as this is where the majority of providers are based, and to families with out-of-state insurance carriers as most in-state carriers do not provide this coverage.

Table 5: Direct Service Providers That Serve Children with ASD

Service	Autism Behavioral Consulting (Sioux Falls)	Accelerate Center for Intensive Early Intervention (Sioux Falls)	Behavior Care Specialists (Sioux Falls, Aberdeen)	Black Hills Special Services Coop (Sturgis)	Lifescape (Sioux Falls)	USD Center for Disabilities (Sioux Falls)
Diagnostics	✓		✓	✓	✓	✓
Intensive Behavioral/ Developmental Intervention		✓ (ESDM)	✓ (ABA)		✓ (ABA)	
Speech Therapy	✓	✓		✓	✓	
Occupational Therapy		✓		✓	✓	
Physical Therapy					✓	
Psychological Services			✓	✓	✓	✓
Psychiatric Services					✓	✓

To ensure that we captured the major organizations providing IBIS, we researched the number of certified behavioral analysts residing in the state through the Behavior Analyst Certification Board. As of July 2014, there were 16 certified behavioral analysts in South Dakota.[14] These behavior analysts were either employed by one of the organizations in the table above, or in private practice providing consultation to school districts, teachers, and parents. One of the behavior analysts recently left the state and one could not be located.

The Department of Education provided a list of 81 school psychologists to facilitate study of whether any of these professionals may be providing or supervising intensive behavioral interventions in private practice outside the school setting.

HMA developed and administered electronic surveys to these individuals and organizations to collect information on the number of full time equivalent staff providing these services to children with ASD, provider qualifications, the number of hours of service provided, maximum number of hours of service that could be provided by the organization if demand increased, referral sources to identify any other organizations providing these services, and information required for the cost analysis. We also met face to face with leadership of most of these

[14] Searchable database of nationally certified ABA therapists. http://www.bacb.com/index.php?page=100155&by=state.

organizations to clarify survey responses and better understand the roles of their organizations in supporting children and families with ASD.

We received eighteen completed surveys from the list of 81 school psychologists; none indicated that they provide intensive behavioral intervention. We received seven completed surveys from 8 identified organizations; three indicated that they provide direct Intensive Behavioral Intervention Services as indicated in Table 5.

These three organizations – Behavior Care Specialists, Lifescape (formerly Children's Hospital and School), and Accelerate Center for Intensive Early Intervention (formerly Theratime) -- employ a total of approximately 50 full-time equivalent direct service staff to provide Intensive Behavioral Intervention Services to children with ASD.

Leadership from Behavior Care Services indicated it is their goal to continue to build capacity across the state expanding to Pierre, Rapid City, Mitchell, Watertown and Brookings so that all children in South Dakota needing and qualifying for ABA have access to high quality services by trained professionals. Similarly, leadership from Lifescape indicated interest in expanding to provide in-home ABA therapy to children with ASD. Leadership from Accelerate Center for Intensive Early Intervention indicated that if reimbursement methodologies were changed, they would be interested in increasing capacity to expand service provision as well.

Organizational leaders were generally optimistic about the ability to ramp up to meet a potential increase in demand for Intensive Behavioral Intervention Services in the State. While those providing ESDM are typically licensed professionals that enroll in a distance certification program through the University of California at Davis, one of the most significant barriers for the provision of ABA therapy is not having an in-State training program for Applied Behavior Analysis. Currently, individuals seeking this certification must go out of State to receive this training and some trainees don't return to the State. Another option is to register for an on-line ABA training program.

Section III. State of South Dakota Spending for Treatment of Children with Autism Spectrum Disorder

In State Fiscal Year 2014 (SFY 2014), the State of South Dakota spent over $18 million in state funds for treatment of children with ASD, primarily through the educational system, Medicaid and the State Health Insurance Plan. This amount does not include spending for vocational rehabilitative services, for which data were not available by fiscal year. It also does not include spending for potentially high-cost services that may be related to a child's ASD, such as emergency department visits or inpatient admissions, and pharmaceutical costs.

Table 6 illustrates the current annual costs to the State as well as the federal funds accessed in the form of matching dollars for services funded by the State and Federal government for the treatment of ASD in children. These funds support the following services:

1) Diagnostic services
2) Speech therapy
3) Occupational therapy
4) Physical therapy
5) Counseling
6) Service coordination
7) Residential supports
8) Day habilitation
9) Pre-vocational
10) Nursing
11) Specialized medical services, equipment, and drugs
12) Respite care
13) Companion care
14) Nutritional supplements
15) Vocational rehabilitation

Table 6: Total Annual Cost for ASD-Related Services SFY 2014

Program	State Share	Federal Share	Total Expenditure
Department of Education	$12,060,991*	-	$12,060,991
Medicaid (Non-waiver)	$112,918	$133,628	$246,546
Medicaid - CHOICES Waiver	$5,822,851	$6,890,798	$12,713,650
Medicaid - Family Support Waiver	$275,181	$325,651	$600,832
State Health Insurance Plan	$27,106	-	$27,106
Other - grant	$112,500	-	$112,500
Total Annual Cost[15]	**$18,411,547**	**$7,350,077**	**$25,761,625**

*State and local contribution.

Department Of Education

The following services are currently provided for students with Autism who are eligible for educational services by the Department of Education (DOE):

1) Diagnostic services
2) Speech therapy
3) Occupational therapy

[15]This figure does not include the rehabilitative costs because the available data reflects the total costs of rehabilitative services over the entire period during which the individual received services, not an annual amount.

4) Physical therapy
5) Counseling

The South Dakota statute with respect to the Special Assistance and Related Services--Title 13--provides for the allocation of funds to the Department of Education (DOE) to support students with disabilities based on their "level" of disability. This level is defined in the statute and ranges from a "level one disability" which is defined as "mild disability" to a "level six disability" which is defined as requiring "prolonged assistance."[16] The statute defines autism as a "level four disability."[17] The allocation for each student with a level four disability for the school fiscal year beginning July 1, 2014, is $14,008.12.[18] The statute also states that, "For each school year thereafter, the allocation for a student with a level four disability shall be the previous fiscal year's allocation for such child increased by the lesser of the index factor or three percent."[19] The index factor is defined as, "the annual percentage change in the consumer price index for urban wage earners and clerical workers as computed by the Bureau of Labor Statistics of the United States Department of Labor for the year before the year immediately preceding the year of adjustment or three percent, whichever is less."[20]

According to a DOE report, there are currently 912 individuals under the age of 22,[21] diagnosed with Autism and eligible for educational services in South Dakota using the designation of Autism in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). Eight hundred and sixty one (861) are children under the age of nineteen. Using the annual per-student allocation figure listed above, these 861 individuals would represent spending in the amount of $12,060,991 in SFY 2014. The most recent administrative rule effective September of 2014 has expanded the categorization of ASD beyond the definition of Autism in the DSM-IV, which will increase the number of children identified as having ASD.

Medicaid

Medicaid provides therapeutic services (as well as waiver services described later in this section) to children with an ASD diagnosis. The majority of these services are provided through school based services. These services include:

1) Diagnostic services
2) Speech therapy
3) Occupational therapy
4) Physical therapy

[16] http://legis.sd.gov/Statutes/Codified_Laws/DisplayStatute.aspx?Type=Statute&Statute=13-37-35.1. Accessed September 17, 2014
[17] IBID
[18] IBID
[19] IBID
[20] IBID
[21] On July 1st after their 21st birthday children are transferred to adult programs.

5) Counseling services
6) Audiology services

Tables 7 and 8 display the annual Medicaid expenditure for these services for the past two fiscal years for children birth through 18 years of age with an ASD diagnosis. Medicaid services are also provided to children with other developmental disorders that may in fact be ASD or may eventually result in a diagnosis of ASD; they were not included in the table below.

Table 7: State Fiscal Year 2013 Medicaid Expenditure for ages 0-18 with ASD Diagnosis

Age Group	Recipients with ASD Diagnosis	Recipient Months	State Costs	Federal Costs[22]	Total Cost	Average Cost Per Recipient Per Month
0-5	91	921	$16,035.14	$21,195.27	$37,230.41	$40.42
6-13	396	4,370	$79,444.19	$105,009.46	$184,453.65	$42.21
14-18	184	2,022	$24,941.30	$32,967.46	$57,908.76	$28.64
Total	**671**	**7,313**	**$120,420.63**	**$159,172.19**	**$279,592.82**	**$38.23**

Source: Data provided by the Department of Social Services

Table 8: State Fiscal Year 2014 Medicaid Expenditure for ages 0-18 with ASD Diagnosis

Age Group	Recipients with ASD Diagnosis	Recipient Months	State Costs	Federal Costs[23]	Total Cost	Average Cost Per Recipient Per Month
0-5	59	755	$13,507.08	$15,984.36	$29,491.44	$39.06
6-13	399	4486	$73,182.55	$86,604.68	$159,787.23	$35.62
14-18	251	2509	$26,228.44	$31,038.90	$57,267.34	$22.82
Total	**709**	**7,750**	**$112,918.07**	**$133,627.94**	**$246,546.01**	**$31.81**

Source: Data provided by the Department of Social Services

Medicaid Waivers

The State provides funding for the following waiver programs to provide services to residents with intellectual and developmental disabilities including children with ASD:

- CHOICES Medicaid waiver
- Family Support 360 Medicaid waiver

The CHOICES waiver program, which stands for "Community, Hope, Opportunity, Independence, Careers, Empowerment, Success,"[24] is designed to "provide for the health and

[22] Blended SFY13 Title XIX FMAP: Federal Share: 56.93%, State Share: 43.07%. Title XIX costs represent 98.42% of total expenditures.
[23] Blended SFY14 Title XIX FMAP: Federal Share 54.20%; State Share: 45.80%. Title XIX costs represent 98.41% of total expenditures.
[24] CHOICES application for a 1915(c) Home and Community-Based Service Waiver.

developmental needs of South Dakotans with intellectual/developmental disabilities who would otherwise not be able to live at home or in a community-based setting and would require institutional care."[25] Services included in the CHOICES waiver include:

- Service coordination
- Residential supports
- Day habilitation
- Pre-vocational
- Supported employment
- Nursing
- Specialized medical services, equipment, and drugs.

South Dakota does not operate a Medicaid home and community-based services (HCBS) waiver specifically for children or adults with autism.

The table below shows the expenditure for children with a primary or secondary diagnosis of ASD under the CHOICES Waiver for the state fiscal years 2013 and 2014.

Table 9: CHOICES Waiver

	Total Expenditure	Total Federal	Total State	Average per Person Total	Average per Person Federal	Average per Person State
SFY 13	$13,030,174.58	$7,418,078.39	$5,612,096.19	$35,797.18	$20,379.34	$15,417.85
SFY 14	$12,713,649.53	$6,890,798.05	$5,822,851.48	$34,927.61	$18,930.76	$15,996.84

The Family Support 360 Waiver was originally approved on October 1, 1998 as a flexible program serving people with disabilities.[26] The Family Support 360 Waiver utilizes family support coordinators who create customizable programs which utilize informal support systems such as: extended family members, friends, neighbors, church congregations, community organizations and formal support programs such as: Child Care Assistance Program, Children's Miracle Network, Energy Assistance, Children's Special Health Services, Home-Based Services, Independent Living Centers, etc.[27] Services included in Family Support 360 waiver include:

- Service coordination
- Respite care
- Companion care
- Environmental accessibility
- Vehicle modification
- Specialized Medical Adaptive Equipment and Supplies

[25] IBID
[26] Family Support 360 Application for a 1915(c) Home and Community-Based Service Waiver.
[27] Family Support 360 Application for a 1915(c) Home and Community-Based Service Waiver.

- Nutritional supplements

Table 10 details the expenditures for children with a primary or secondary diagnosis of ASD under the Family Support 360 waiver for the state fiscal years 2013 and 2014.

Table 10: Family Support 360

	Total Expenditure	Total Federal	Total State	Average per Person	Average per Person Federal	Average per Person State
SFY 13	$430,461.31	$245,061.62	$185,399.69	$2,020.95	$1,150.52	$870.42
SFY 14	$600,831.80	$325,650.84	$275,180.96	$2,820.81	$1,528.88	$1,291.93

Vocational Rehabilitation Services

The federal government and the state of South Dakota provide funds for vocational rehabilitation services for individuals with ASD aged nineteen years or younger on the date of their application. Services can extend beyond age 19. Table 11 provides state expenses based on data related to individuals whose primary cause of vocational impairment is identified as autism. Figures include what was spent over the entire period during which the individual received services.

Table 11: Vocational Rehabilitation Expenditures for Individuals with ASD through 19 Years of Age

	Number Served	Total Expenditures	Total Federal (78.7%)	Total State (21.3%)	Average expenditures per person	Per Person Federal (78.7%)	Per Person State (21.3%)
Closed in SFY 13	34	$187,943.04	$147,911.17	$40,031.87	$5,527.74	$4,350.33	$1,177.41
Closed in SFY 14	26	$131,916.90	$103,818.60	$28,098.30	$5,073.73	$3,993.02	$1,080.70
Remain open	42	$362,481.73	$285,273.12	$77,208.61	$8,630.52	$6,792.22	$1,838.30

State Health Insurance Plan

The State Employee Health Plan also provides services to members with ASD. The State Employee Health Plan had 42 child members with a diagnosis of Autism at the time of our survey in September of 2014. The Health Plan covers diagnosis, therapies and psychiatric and psychological services, but specifically excludes Applied Behavioral Analysis (ABA) therapy. Table 12 shows the current costs associated with various services for members with ASD. These figures were based on 25,657 total members enrolled with the State Health Insurance Plan.

Table 12: State Employee Health Plan Cost of Services SFY 2014

	Claim Cost PMPM[28]	Total Annual Claim Cost[29]
Diagnosis	$0.044	$13,553
Speech Therapy	$0.022	$6,911
Occupational Therapy	$0.015	$4,668
Psychological Care	$0.003	$837
Psychiatric Care	$0.004	$1,137
Total	**$0.088**	**$27,106**

Other

The Division of Developmental Disabilities grants a total of $112,500 annually to the University of South Dakota Center for Disabilities, Autism Spectrum Disorders Program.

[28] This is the per-member-per-month cost or the average monthly claim cost of individuals covered by the State employee health plan

[29] This is the total cost for all 42 children diagnosed with ASD

Section IV. Federal Policy and Insurance Coverage for ASD Treatment

The passage of the federal Mental Health Parity and Addiction Equity Act (MHPAEA) and the Patient Protection and Affordable Care Act (referred to as ACA) were designed to provide greater access to health care, including mental health care and, potentially, coverage of treatments for ASD. However, for the reasons discussed later in this section, these provisions do not provide access to IBIS for children with ASD in South Dakota. The following summarizes the requirements of federal and state policies as they relate to the coverage of Autism Spectrum Disorder services.

- MHPAEA does not require insurers to provide treatment and services for mental health conditions. Rather it requires group health plans and health insurers that do cover mental health conditions to ensure that financial requirements and treatment limitations are no more restrictive than those applied to medical/surgical benefits.
- ASD is defined as a developmental disorder not a mental health condition by independent standards of medical practice. Therefore, unless states or health plans define ASD as a mental health condition, MHPAEA does not apply to ASD.
- South Dakota's mental health parity law requires health plans to provide coverage for the treatment and diagnosis of a set of biologically-based mental health diagnoses, which does not include ASD.
- The ACA expands the reach of MHPAEA to include the individual health insurance market and Qualified Health Plans (QHPs – health plans that meet ACA requirements).
- The ACA requires Essential Health Benefit (EHB) packages to cover mental health and substance use disorder services, including behavioral health treatment, as defined by state benchmark EHB plans. ASD services are not required as part of the EHB, unless a state law mandates those services be covered or the state's benchmark plan includes these services. South Dakota does not mandate ASD services, nor does the state's benchmark plan include these services.
- The ACA requires that rehabilitative and habilitative services and devices be included in the EHB package. States have broad latitude to define habilitative services or allow insurers to determine how these services will be defined and the coverage policies that dictate the services provided.

Federal regulations allow insurers to substitute the provision of habilitative services for children with a more robust offering of rehabilitative services for adults. While states may bar substitution, South Dakota has adopted regulation allowing insurers to substitute within an EHB benefit category. Mental Health Parity

Mental health parity protections do not extend to children with ASD in South Dakota at present because ASD is not included in the State's definition of a mental illness. In addition, mental health parity is complicated by various other federal and State provisions as described below.

Mental Health Parity and Addiction Equity Act of 2008

The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) was enacted on October 3, 2008. MHPAEA supplements prior provisions under the Mental Health Parity Act of 1996, which required parity with respect to aggregate lifetime and annual dollar limits for mental health benefits.

MHPAEA originally applied to group health plans and group health insurance coverage and was amended by the Patient Protection and Affordable Care Act, as amended by the Health Care and Education Reconciliation Act of 2010 (collectively referred to as the "Affordable Care Act" (ACA)) to also apply to individual health insurance coverage. While MHPAEA does not apply directly to small group health plans, its requirements are applied indirectly in connection with the ACA's Essential Health Benefit requirements as described below.

Key changes made by MHPAEA include the following:

- Group health plans and health insurance issuers must ensure that financial requirements (such as co-pays and deductibles) and treatment limitations (such as number of visits or days of coverage) applicable to mental health or substance use disorder benefits are no more restrictive than the predominant requirements or limitations applied to substantially all medical/surgical benefits.
- Mental health/substance use disorder benefits may not be subject to any separate cost-sharing requirements or treatment limitations that only apply to such benefits.
- If a group health plan or health insurance coverage includes medical/surgical benefits and mental health and substance use disorder benefits, and the plan or insurer provides for out-of-network medical/surgical benefits it must provide for out-of-network mental health/substance use disorder benefits.
- Standards for medical necessity determinations and reasons for any denial of benefits relating to mental health/substance use disorder benefits must be disclosed upon request.

Although MHPAEA provides protections to participants in group health plans and health insurance coverage, it is important to note that MHPAEA does not mandate that a plan provide mental health or substance use disorder benefits. Rather, if a plan provides medical/surgical and mental health/substance use disorder benefits, it must comply with the MHPAEA's parity provisions.

The changes made by MHPAEA are generally effective for plan years beginning after October 3, 2009. The final regulation was effective January 13, 2014 and generally applies to plan years (in the individual market) beginning on or after July 1, 2014.

South Dakota's Mental Health Parity Law

On September 24, 2014, the South Dakota Department of Labor and Regulation, Division of Insurance proposed rules to amend its mental health parity law, ARSD 20:06:40, in order to be consistent with the MHPAEA final regulation.[30]

Some states include ASD as a covered mental illness under their mental health parity law. South Dakota's mental health parity law, SDCL 58-17-98 and 58-18-80, requires individual, small group, and large group health insurance policies to provide coverage for the treatment and diagnosis of biologically-based mental illness and do so with the same dollar limits, deductibles, coinsurance factors, and restrictions as for other covered illnesses. The statute defines biologically-based mental illness as schizophrenia and other psychotic disorders, bipolar disorder, major depression, and obsessive-compulsive disorder. Therefore, the state's mental health parity law does not include ASD.

According to MHPAEA, existing state mental health laws that are contrary to the federal requirements and therefore prevent the application of the new federal requirements are preempted and no longer apply. South Dakota law does not prevent the application of the federal requirements; therefore, it continues to apply.

Applicability of Mental Health Parity to Autism Spectrum Disorder

The MHPAEA final regulation defines "mental health benefits" as benefits with respect to items or services for mental health conditions. Plans are permitted to define "mental health conditions", taking into account any applicable state or federal law such as those mandating coverage for serious mental illness or biologically-based mental illness. In the absence of state law, any condition defined by the plan or coverage as being or as not being a mental health condition must be defined in a manner that is consistent with generally recognized independent standards of current medical practice.[31] The independent standards of current medical practice are:

- The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), [32] which includes Autism Spectrum Disorder (299.00) as a Neurodevelopmental Disorder.

[30] South Dakota Register Vol. 41 available at http://legis.sd.gov/docs/Rules/Register/09292014.pdf
[31] 26 CFR 54.9812-1(a)
[32] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

- The ninth edition of the International Classification of Diseases, Clinical Modification (ICD-9-CM), which classifies ASD as a pervasive developmental disorder. ICD-10-CM, which will replace the current ICD-9-CM on October 1, 2015, categorizes pervasive developmental disorders as disorders of psychological development.

Based on these two independent standards of current medical practice, ASD is categorized as a developmental disorder. A plan or coverage that does not define ASD as a mental health condition would be consistent with independent standards in compliance with the MHPAEA regulation. Therefore, MHPAEA would only apply to ASD if a state or plan defined it as a mental health condition.

Affordable Care Act

The Affordable Care Act and its implementing regulations, building on the MHPAEA, expanded coverage of mental health and substance use disorder benefits and federal parity protections in two distinct ways:

1) by including mental health and substance use disorder benefits in the Essential Health Benefits
2) by applying federal parity protections to mental health and substance use disorder benefits in the individual and small group markets

Essential Health Benefits

Beginning in 2014 under the ACA, all new small group and individual market plans, including plans providing insurance to previously uninsured individuals through the Health Insurance Exchange are required to cover the following ten Essential Health Benefits (EHB): ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.[33] In South Dakota, eligible individuals may purchase insurance through the federal Health Insurance Exchange. Self-insured and large-group (generally companies with more than 100 employees) health plans are not subject to EHBs, although most offer these EHBs.[34]

Extending Mental Health Parity

The ACA extended MHPAEA to apply to the individual health insurance market and QHPs in the same manner and to the same extent as it applies to health insurance issuers and group health

[33] The Essential Health Benefits, Actuarial Value and Accreditation Final Rule was released February 20, 2013. http://www.gpo.gov/fdsys/pkg/FR-2013-02-25/pdf/2013-04084.pdf

[34] "Health Policy Brief: Essential Health Benefits," *Health Affairs*, Updated May 2, 2013. http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_91.pdf

plans. As a result, Americans accessing coverage through non-grandfathered plans in the individual and small group markets will be able to receive mental health and substance use disorder coverage that is comparable to their general medical and surgical coverage. The protections of mental health parity only apply to ASD services where states and/or health insurers define Autism Spectrum Disorder as a mental health condition.

Essential Health Benefits Benchmark Plan

The federal government has long emphasized the role of states in the regulation of insurance. In keeping with that approach, the U.S. Secretary of Health and Human Services (HHS) has elected to delegate the power to define EHBs to both states and, in special cases insurers, at least in the initial implementation years.

Essential health benefits, according to the Centers for Medicare & Medicaid services (CMS), should be equal in scope to a typical or "benchmark" employer health plan selected by the state. [35]QHPs are required to offer plans with benefits "substantially equal" to those found in a state's benchmark plan. South Dakota's EHB benchmark plan for 2014-2015, Wellmark of South Dakota Blue Select, is the largest small group product in the state.[36]

EHB Packages and Services for Individuals with ASD

Two of the ten EHBs could be interpreted to cover ASD treatment services – mental health and substance use disorder services and rehabilitative and habilitative services and devices. Advocates for the coverage of Autism services contend that the history and construction of the ACA provides the context to promote a broad interpretation of the category "mental health and substance use disorder services, including behavioral health treatment". The language "including behavioral health treatment" was not in the original bills and was added by the Menendez Amendment (Amendment) by both chambers of Congress. Advocates point to the amendment as intending to expand coverage to include behavioral services for individuals with ASD.

The Congressional Budget Office (CBO) reviews legislation and determines a cost score for a bill using current federal law as a basis for its assumptions. When the CBO scored the Amendment, it concluded that the Amendment clarified rather than expanded the original language requiring mental health and substance use disorder services. Therefore, unless states mandate the coverage of ASD services, federal law does not explicitly require the coverage of these services as part of mental health and substance use disorder services in the EHB package.

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[35] States were required to choose from a range of health insurance plans to serve as an EHB benchmark plan. States selected from the three largest small group health insurance products (default), the three largest state employee health plan options, the three largest federal employee health plan options, or the largest commercial HMO plan sold in the state.

[36] The State's benchmark plan may change in 2016, but at this time no federal guidance has been provided on how that selection will take place.

Rehabilitative and habilitative services and devices include services helpful to children with ASD such as speech-language, occupational, and physical therapy. However, the federal government does not define habilitative services specifically and defers to the state law or in the absence of state law to the health insurance industry defined scope of coverage. However, there is no generally accepted definition of habilitation among health plans.

The federal rule provided insurers two options for defining habilitative services: 1) use a "parity" approach and elect to cover the same range of physical, mental, cognitions, and other therapies available through rehabilitative coverage or 2) on a transitional basis decide which habilitative services to cover and report coverage to HHS. Because South Dakota does not define habilitation in state law or administrative rule, habilitative services coverage is defined by Wellmark's Blue Select interpretation. Wellmark Blue Select covers "habilitative services driven by congenital disorders/developmental delays. Exclusions include therapies rendered primarily for job training and therapy services related to general conditioning of the patient."[37]

Under federal regulation[38] and South Dakota state regulation[39], insurers are permitted to engage in substitution within benefit categories. The substituted benefit must be actuarially equivalent to the EHB. For example, under substitution insurers may opt to offer rehabilitative services in lieu of habilitative services. States have the option to bar substitution.

Federal Requirements for Medicaid Coverage of Services for Children with ASD

The Centers for Medicare and Medicaid Services' (CMS) July 7, 2014 Bulletin and September 24, 2014 Question and Answer document clearly indicate that states are not mandated to provide specific ASD services. Rather, CMS provided guidance to states regarding the various authorities that could be used if states opt to provide specific ASD services. As noted in CMS guidance, CMS does not mandate any specific therapy such as ABA therapy for ASD treatment, and the South Dakota Medicaid State Plan does cover a range of services included in the State Plan, but does not cover this type of therapy.

On July 7, 2014, CMS released an Informational Bulletin[40] to clarify Medicaid's coverage of services to children with Autism. A variety of federal authorities provide states the ability to reimburse for ASD services: section 1905(a) of the Social Security Act, which includes services such as therapy services and rehabilitative services, section 1915(i) that permits coverage of state plan Home and Community-Based Services (HCBS), section 1915(c) that permits coverage

[37] EHB Benefits Provided by Wellmark for Potential Benchmark Major Medical Plan. Provided by the South Dakota Division of Insurance.
[38] 45 CFR § 156.115. Insurers are not permitted to substitute a prescription drug benefit.
[39] ARSD 20:06:56:05
[40] CMCS Informational Bulletin, Clarification of Medicaid Coverage of Services to Children with Autism available at http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf

of HCBS under a waiver, and section 1115 that permits wide scale coverage reform or research and demonstration programs. In addition, Section 1905(r) requires states to arrange for and cover any Medicaid coverable service listed in section 1905(a)[41] of the Act that is determined to be medically necessary to correct or ameliorate any physical or behavioral conditions for Medicaid eligible children under the age of 21 whether or not the state specifically includes the service in its Medicaid state plan. This requirement is known as Early and Periodic Screening, Diagnostic and Treatment services (EPSDT), also known as the Well-Child Program in South Dakota.

Children enrolled in Medicaid must receive EPSDT screenings designed to identify health and developmental issues, including ASD. EPSDT also requires medically necessary diagnostic and treatment services. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for medically necessary diagnosis and treatment.

While not going into detail on specific treatments, the bulletin identified the category of Intensive Behavioral Intervention Services including ABA as one form of treatment, but also acknowledged that there are other recognized and emerging treatment modalities for children with ASD. On September 24, 2014, CMS published a follow-up Frequently Asked Questions document[42] which stated, "CMS is not endorsing or requiring any particular treatment modality for ASD. State Medicaid agencies are responsible for determining what services are medically necessary for eligible individuals." While questions about the coverage of ABA and other ASD-related services under Medicaid still remain for States, many are in the process of reviewing their coverage practices and program policies to determine if changes are needed to existing state regulations, policy, and/or the Medicaid state plan to ensure compliance with the EPSDT program and CMS guidance.

[41] Three Section 1905(a) authorities under which services to address ASD may be covered include: Section 1905(a)(6) (Other Licensed Practitioner Services); Section 1905(a)(13)(C) (Preventive Services); and Section 1905(a)(11) (Therapy Services).

[42] CMCS, Medicaid and CHIP FAQs: Services to Address Autism available at http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/FAQ-09-24-2014.pdf

Section V. What Would It Cost to Cover Intensive Behavioral Intervention Services for Children with ASD in South Dakota through Private Insurance?

South Dakota could mandate coverage of services to children diagnosed with ASD from birth until their 19th birthday through private insurance.

- Insurance premiums would increase to the extent that services not currently covered by the policy would be paid for by the carrier. The primary uncovered service category is Intensive Behavioral Intervention Services (IBIS) such as ABA or ESDM.
- There would be administrative costs associated with processing additional claims for these services.
- The actual premium impact would be determined by the carriers' estimates of the hours of services that will be provided and the estimated average cost per hour. NovaRest's estimate is based on the assumptions described in this section of the report, but pricing actuaries for the carriers may be more conservative in developing premiums. It is worth noting that the rates for the 2015 policy year have been filed and therefore NovaRest does not anticipate a rate impact until 2016.
- NovaRest estimates the initial premium impact would be approximately $0.50 per insured per month, and the potential ultimate impact as high as $2.50 per insured per month. The difference between the initial and potential impact is that initially there will not be sufficient providers to meet the demand. Ultimately it is possible sufficient providers will fill the gap in the demand. It is impossible to say how long it will take to recruit and train providers.
- The increased cost of coverage could be offset in whole or part by savings that result from reduced costs for other services, discussed in Section VII of this report.

NovaRest's estimates of insurance premium impact are based on current information and several assumptions, these include: current service coverage, the estimated number of children with ASD in South Dakota, age and dollar limits of coverage, hours of service utilization by age, reimbursement rates, projected health insurance premiums and membership. The following sections detail the assumptions that form the basis of the estimates.

Current Service Coverage

Some of the services that could be required by a mandate are currently covered by insurance providers and therefore would have no effect on insurance premiums, unless the mandated coverage increased the scope of coverage. Insurance carriers surveyed for this report indicated that they currently cover the following services:

1) Diagnostic services

2) Speech therapy
3) Occupational therapy
4) Physical therapy
5) Psychological care
6) Psychiatric care

Only one carrier had restrictions on the number of therapy services covered, reporting that the number of services were limited in a calendar year unless otherwise authorized. There would be no additional cost associated with these services under a mandate if there were no increase in the utilization of the services. However, some additional costs could arise if IBIS were covered and the IBIS practitioners recommended additional therapies or services during the course of a child's treatment.

The following services are currently provided for students with Autism in schools:

1) Diagnostic services
2) Speech therapy
3) Occupational therapy
4) Physical therapy
5) Counseling

Table 13 indicates current provision of and coverage for ASD-related services from the Department of Education (DOE) and four commercial insurance carriers surveyed.

Table 13: Extent of Current Insurance and DOE Coverage for ASD-Related Services

Service	Covered	Partially Covered
Diagnostic services	DOE* & 3 Carriers	One Carrier has some limitations**
Speech therapy	DOE & 3 Carriers	One Carrier has some limitations**
Occupational therapy	DOE & 3 Carriers	One Carrier has some limitations**
Physical therapy	DOE & 3 Carriers	One Carrier has some limitations**
Psychological care	DOE & 3 Carriers	One Carrier has some limitations**
Psychiatric care	DOE & 3 Carriers	One Carrier has some limitations**
IBIS - Applied Behavior Analysis (ABA)		One Carrier covers ABA with some limitations***

* DOE is the Department of Education and represents services provided in the schools
** One carrier reported 30 therapy sessions were covered a calendar year unless authorized for additional sessions
***One carrier requires authorization based on criteria such as continued improvement in the child

Estimated Number of Children with ASD in South Dakota

The Department of Education reports State-level data from districts for children with Autism using the DSM IV definition (rather than the broader ASD category in the current DSM V published in 2013.) We will use "children with Autism" or "children with ASD" depending on the data that is being referenced. The DOE recently started to use the broader definition of ASD in September 2014 in accordance with a new administrative rule.

Table 14: Current Estimate of Children with Autism in South Dakota

Age Group[43]	Children
0 to 6	112
6 to 14	529
14 to 19	220
Total	861

Source: South Dakota Department of Education, 2013-2014 school year

The available data on children with ASD is likely to be an underestimate particularly for children under the age of 6. Although children under the age of 6 with ASD or other developmental delays are eligible for the Department of Education's "Birth-to-3" and "Early Childhood" programs, some children are not diagnosed with ASD early on. The Centers for Disease Control and Prevention estimates that in general the occurrence of ASD may be underestimated by as much as seventeen percent. Older children will be less likely to go undiagnosed, but it is possible that a small percent of children with ASD remain undetected.[44]

Using CDC's underestimates of diagnosis, the Table 15 represents the potential population of children in South Dakota with Autism, based on the current number of identified children adjusted for the potential underestimate.

Table 15: Current Estimate of Children with ASD in South Dakota Adjusted for Under-Reporting

Age Group	Children
0 to 6	136
6 to 14	575
14 to 19	231
Total	942

While the data in Table 15 may be a closer estimate to the actual number of children with ASD in South Dakota, NovaRest did not use the adjusted data for its modeling since it is unknown to what extent undiagnosed individuals will request and receive services. The current estimate of children with an Autism diagnosis was therefore used in the modeling.

Premium Impact of IBIS

NovaRest used a range of assumptions to model our estimate of the impact of IBIS on premiums. Our assumptions were primarily developed using information gained from interviews with providers of ABA services as well as the literature to confirm and/or augment our assumptions.

[43] Age groupings end on the birthdate of the child's age, i.e., "6 to 14" indicates from age 6 through 14th birthday.
[44] Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report, Surveillance Summaries/Vol. 63/No. 2 March 28,2014

We assumed that a South Dakota mandate would not have restrictions on the annual claims cost or on the utilization of services based on past proposed legislation though some states have age or dollar limits as described for South Dakota's neighboring states in Section VI.

The initial cost of covering IBIS will be low due to the limited number of qualified providers of those services. NovaRest estimated the initial cost assuming that 2016 would be the first full year of the mandate, if a mandate passed in 2015. We included assumptions such as the number of providers in each certification category, the number of hours for each category that the practitioner would spend providing the services, and the hourly rate for each category. The doctorate and masters level practitioners would have more limited time to spend with patients due to administrative duties and the time required to supervise junior staff.

The ultimate cost of a possible mandate will depend on the number of children with ASD, the percentage of those children that would benefit from the services, the percentage of children that actually receive services based on insurer medical necessity decisions as well as parental decisions, and the number of hours of services received.

It may take a number of years for the supply of providers to meet the ultimate demand for these services.

Utilization

Utilization of IBIS varies significantly from child to child, with hours per week varying between five and forty. According to South Dakota ABA providers, younger children benefit most from twenty to forty hours per week for as long as four years, though hours per week often decrease after two years. School-age children with ASD are often in traditional or special education classes all or part of the week and therefore fewer hours of IBIS need be provided at these times.

Oliver Wyman, a global management consulting firm, developed a cost model in order to analyze and estimate the impact of insurance benefits for ASD. Oliver Wyman assumed that once a child reaches school age, the hours utilized drop by approximately fifty percent for the children who are not fully assimilated into traditional classrooms.[45] Based on our discussions with ABA providers in South Dakota, NovaRest agrees with Oliver Wyman's assumption.

In some cases, the IBIS therapist will actually provide services in the classroom if that is where the behavioral issues are being observed. According to South Dakota ABA providers, for children aged fourteen to nineteen the average number of service hours utilized drops even further. Once IBIS are available for more children at a younger age, some children will not

[45] Marc Lambright, Actuarial Cost Estimate: Nebraska Legislative Bill 1129, http://www.autismspeaks.org/sites/default/files/docs/gr/ne.wyman_2.6.2012.pdf

require ABA services as older children while others will need ABA for specific behaviors as they occur.

Some children, though, are not considered good candidates for IBIS or are determined to not be good candidates after services are shown to be ineffective. Even children that receive significant benefit from IBIS will eventually plateau in their improvement. That is to say that additional services do not produce additional benefits at some point in a child's treatment and therefore the services are discontinued. Insurers can use medical management to limit the availability of services to children that can benefit from IBIS and to current patients that will benefit from additional IBIS.

Taking into account all of the above-stated assumptions concerning the variation in utilization by age, the appropriateness of IBIS for some children and not others, and the plateauing of effectiveness, Table 16 shows NovaRest's estimate of the percentage of ASD-diagnosed children in South Dakota (using the DSM IV definition) that would receive IBIS by age, if there were a mandate.

Table 16: Assumption of the Percentage of Children with ASD that would Receive IBIS in South Dakota

Age Group	Number of Children with ASD	Percent of Children with ASD to Receive IBIS[46]	Number of Children with ASD to Receive IBIS
0 to 6	112	70%	79
6 to 14	529	21%	114
14 to 19	220	2%	5

Assuming that children will only receive services for fifty weeks a year, allowing for missed sessions due to vacation and illness, NovaRest used the following assumption for hours of service per year for the children that would receive services. (See Table 17.) The assumptions are based on our literature review and interviews with South Dakota providers.

Table 17: Assumption of Hours per Week per Child of IBIS Services that would be Received in South Dakota

Age Group	Low	Med	High
0 to 6	20	30	40
6 to 14	10	15	20
14 to 19	5	8	10

Table 18 shows NovaRest's assumptions for average annual hours of IBIS for children with ASD in South Dakota, based on our literature review and interviews with South Dakota providers.

[46] These percentages are rounded to the nearest percent.

Table 18: Assumptions for Average Annual Hours of IBIS

Age Group	Low	Med	High
0 to 6	1,000	1,500	2,000
6 to 14	500	750	1,000
14 to 19	250	400	500

Reimbursement Rates

The hourly rate charged for IBIS depends on the type of service and the certification category of the practitioner. Based on the current providers in South Dakota, estimated hours per week for each provider category, and fees for each category, the current average hourly rate is approximately $70.

Based on the current number of board certified providers in South Dakota and interviews with these and other providers, Table 19 shows an approximate number of IBIS providers in South Dakota in 2016 and their estimated hourly rate by category of certification.

Table 19: Estimated Providers and Hourly Rates in 2016

Certification Category[47]	Number of providers	Hourly Rate
BCBAD	4	$120
BCBA	10	$98
BCaBA	5	$78
RBT	18	$47
Start Denver Model (ESDM)	2	$50
Total	37	Avg. $70

On the other hand, once services are covered by insurance providers, hourly rates may increase. Providers that charge on a sliding scale based on parent finances will not continue to reduce fees when services are covered by insurance. These fee increases may be offset by carriers contracting with specific preferred providers for reduced fees.

NovaRest assumed that as more providers receive their certification or are attracted to South Dakota, the time provided by the more senior level staff will be leveraged by the use of more RBTs with senior staff in a supervisory capacity. This will eventually reduce the average cost of services. Therefore, we estimated that after all of the fee pressures and redistribution of the categories of providers, average hourly rates will be between $50 and $60 per hour.

[47] Refer to Appendix B for educational requirements for each certification category.

Table 20: Assumption of Number of Projected Providers

Category	Number of providers
BCBAD	5
BCBA	13
BCaBA	5
RBT or ESDM*	135
Total	158

*RBTs and ESDM Certified professionals are consolidated here as they have similar billing rates.

Prevalence of Children with ASD in the Population

The increase in health care costs and therefore the premium impact will depend on the percentage of the insured population receiving services.

Table 21 shows the percentage of the South Dakota population with ASD by age.

Table 21: Percent of Population 0-18 with ASD in South Dakota

Age Group	Number of Children	Percent of Population
0 to 6	112	0.16%
6 to 14	529	0.59%
14 to 19	220	0.39%
Total	861	0.40%

Source: South Dakota Department of Education

NovaRest assumes that the rates of children diagnosed with ASD in the insurer survey are low because the services covered by insurers, such as allied health therapies, are currently being provided by the school system.

Parents of children with ASD that believe IBIS will benefit their children will seek insurance coverage for these services. Parents that are uninsured, or whose health plan does not cover IBIS, will likely become insured or move to health plans that do cover IBIS. This move could be accomplished by purchasing child only coverage in the individual insurance market or could require changing employers to move to a company that offers policies that cover IBIS. Also, as implied above, not all parents will believe that IBIS will benefit their children or for personal reasons may decide not to seek IBIS for their children with ASD. Reasons for not seeking such treatment may include the time commitment required of the parents and/or lack of access to appropriate providers in specific areas of the State.

Premiums will increase by an amount equal to the health care costs that are paid by the insurer. NovaRest assumed, based on our experience and consultation with other health exchange experts, that parents of children with ASD who have a choice of plan (i.e., purchase coverage through the Exchange) will select a plan with the lowest out-of-pocket costs. Of

course, not all parents will have a choice, including parents who have employer insurance where the employer determines the richness of the plan. Insurer survey responses indicate that the current average percentage of benefit cost paid for ABA is 90 to 96 percent leaving 4 to 10 percent paid by deductibles and other cost sharing. NovaRest used an assumption of 90 percent in our modeling.

In addition to the cost of the services, the cost of premiums will increase with the administrative cost of paying claims for those services. The cost of paying these claims is approximately three percent of the total health care cost. NovaRest used the five percent of cost figure, which approximates the actual cost of services, although a pricing actuary may add as much as 25 percent of the incurred claims cost to cover administrative costs. The difference is that the pricing actuary is using an average percentage that includes marketing cost for example, and we are only considering the added cost for administering this one benefit.

Projected Health Insurance Premiums and Membership

NovaRest used the 2013 Supplemental Health Care Exhibits (SHCE) filed with the National Association of Insurance Commissioners by South Dakota insurers to determine current premium levels in South Dakota. These exhibits provide total premiums and member months for individual, small group, and large group markets. Premiums were trended up by 7 percent a year for three years from the 2013 premiums to the projected 2016 premiums.

The SHCEs along with carrier survey results were used to determine total membership. The small group membership was adjusted for the change in definition of small group from 50 employees to 100 employees required by ACA in 2016. The 2013 Medical Expenditure Panel Survey (MEPS) data was used to adjust for self-insured prevalence in the larger groups and the membership for groups between 50 and 100 employees.[48]

Short Term Premium Impact with Coverage of IBIS

Assuming that more RBTs will be trained and more senior practitioners will be recruited in 2016, NovaRest estimated the number of providers and the total number of hours available to children with ASD in 2016. This is presented in Table 22.

Table 22: Assumption of Practitioners and Hours available in 2016

	Providers	Total Hours Available a Year
BCBAD	4	4,000
BCBA	10	12,500
BCaBA	5	8,750
RBTs	18	25,200
ESDM certified	2	3,500
Total	39	53,950

[48] IBID

The total capacity of 1,079 hours per week at an estimated 2016 average hourly rate of $70 combined with the other assumptions concerning the percentage of that figure covered by insurance and the associated additional administrative costs, equates to additional billed charges of approximately $3.8 million using assumptions of:

- Total provider hours available (Table 22)
- Average hourly fee of $70

Billed charges are then adjusted for the ratio of paid claims to billed charges, administrative costs and other assumptions such as the percent of uninsured resulting additional premium cost would be approximately $0.50 per insured member per month (PMPM). For ACA-compliant policies the State will have to cover the cost of the mandate, which will have additional administrative cost to coordinate with the carriers. Using an assumption of 10% administrative cost, the state would be responsible for approximately $2.00 PMPM.

Table 23: Initial Premium Increase for Mandate for 2016

	Individual		Small Group Employer		Large Group Employer
	Non-ACA Compliant	ACA Compliant	Non-ACA Compliant	ACA Compliant	N/A
Total Member Months	227,764	562,599	185,408	648,232	1,088,613
Average Projected 2016 Premium PMPM	$302		$445		$455
Premium Increase Dollars PMPM	$0.50	$0.51	$0.50	$0.51	$0.50
Total Additional Premium	$113,882	N/A	$92,704	N/A	$544,307
Total Additional Cost to State	N/A	$286,925	N/A	$330,598	N/A

Long Term Premium Impact with Coverage of IBIS

The long term impact of a mandate regarding coverage of IBIS is made substantially more complicated with the use of many more assumptions. NovaRest used a range of assumptions to arrive at low, medium, and high estimates for the long term costs of a potential mandate.

Table 24 shows the estimated ultimate hours of IBIS per year in the low, medium and high categories for children receiving services.

Table 24: Assumptions of Ultimate Average Hours per Year per Child of IBIS Services Received

Age Group	Children Projected to Receive Services	Annual Hours per child -low	Annual Hours per child - Med	Annual Hours per child -High
0 to 6	79	1,000	1,500	2,000
6 to 14	114	500	750	1,000
14 to 19	5	250	400	500

Table 25 shows the estimated ultimate billed cost of IBIS per year in the low, medium and high categories for the children actually receiving services.

Table 25 Assumptions of Ultimate Average Billed Cost per Year per Child of IBIS Services Received

Age Group	Annual Billed Cost per child -Low	Annual Billed Cost per child - Med	Annual Billed Cost per child -High
0 to 6	$50,000	$82,500	$120,000
6 to 14	$25,000	$41,250	$60,000
14 to 19	$12,500	$22,000	$30,000

Assumptions of cost per hour vary between $50 and $60 and average hours per child per week vary between five and forty depending on age. This would result in additional billed charges of approximately $6.9 million to $16.5 million based on the assumptions:

- Average annual hours of IBIS (Table 24)
- Average cost per hour of a low assumption of $50, mid assumption of $55 and high assumption of $60

Billed charges are then adjusted for the ratio of paid claims to billed charges, administrative costs and other assumptions such as the percent of uninsured. This results in an estimate of the ultimate additional premium cost to be between $1.25 and $2.50 PMPM with an estimate of $1.90 PMPM using mid-level assumptions.

For ACA-compliant policies the State will have to cover the cost of the mandate, which will have additional administrative cost to coordinate with the carriers. Using an assumption of 10% administrative cost the state would be responsible for between $1.30 and $2.65 PMPM with an estimate of $2.00 PMPM using mid-level assumptions.

It is impossible to determine when the full demand in South Dakota could be met or if it ever will be met based on the number of qualified providers. Table 26 shows the ultimate dollar cost and cost as a percentage of premium using the 2016 projected premium for the mid-level set of assumptions. These premiums are in 2016 dollars. The projection also assumes that the cost of IBIS will increase at the same rate as other medical costs using 2016 dollars and will result in the same percentage increase in premiums.

Table 26: Ultimate Premium Increase for a Potential Mandate

	Individual		Small Group Employer		Large Group Employer
	Non-ACA Compliant	ACA Compliant	Non-ACA Compliant	ACA Compliant	N/A
Total Member Months	227,764	562,599	185,408	648,232	1,088,613
Average Projected 2016 Premium PMPM	$302		$445		$455
Premium Increase Dollars PMPM	$1.90	$2.00	$1.90	$2.00	$1.90
Percent of Premium	0.63%		0.42%		0.41%
Total Additional Premium	$432,751	N/A	$352,276	N/A	$2,068,366
Total Additional Cost to State	N/A	$1,125,198	N/A	$1,296,464	N/A

Cost to the State

There are three additional costs to the State for a mandate identified below:

1) The cost to the State Employee Health Plan
2) The cost to the State for a new mandate
3) The cost to Medicaid for providing the coverage to children that do not have other insurance

A separate analysis to determine the cost to Medicaid is currently underway. The short term (.50 PMPM) and ultimate cost using mid-level assumptions ($1.90 PMPM) to the other programs are shown in Table 27.

Table 27: Annual Cost to the State for a Commercial Insurance Mandate

	2016 Initial Cost	Ultimate Annual Cost using Mid-Level Assumptions
State Employee Health Plan	$154,000	$585,000
Cost to the State for a New Mandate	$620,000	$2,400,000
Total	$774,000	$2,985,000

Based on this estimate and the current membership of 25,657 and an initial cost of $0.50 PMPM the total annual impact for the State Employees Health Plan would be approximately $154,000 in 2016.

Based on the current membership of 25,657 and a mid-level assumption of $1.90 PMPM the ultimate total annual impact for the State Employees Health Plan would be approximately $585,000 or between $385,000 and $770,000. The bottom of the range is calculated using the low-level assumptions ($1.25 PMPM) and the top of the range is calculated using the high-level assumptions ($2.50 PMPM.)

Under the Affordable Care Act requirements, the State will have to pay the additional cost of any new mandate. The State will have to pay an equivalent of the additional premium for all individuals enrolled in a Qualified Health Plan (QHP) in or outside of the exchange and may have to subsidize the cost sharing for low–income families. Assuming that all members in transitional policies will eventually join a QHP, NovaRest estimates that the premium equivalent in 2016 would be approximately $620,000.

NovaRest estimates that the premium equivalent once market capacity matches the potential demand could be as high as $3.2 million. This calculation uses the high-level assumptions ($2.50 PMPM). It is more likely, however, to be closer to $2.4 million; this calculation uses mid-level assumptions ($1.90 PMPM.) This amount will increase with inflation and as members of grandfathered plans purchase insurance plans from QHPs.

Premium Impact of Non-IBIS ASD Treatments

To this point the cost estimates have focused on IBIS. If non-IBIS services were currently not being covered and would be required under the mandate, there would be additional claim cost and increases to premiums, but all non-IBIS services are covered by carriers and are only restricted by the need for approval by the provider. These services are also often provided without cost to the parents by the school system. Although the utilization of services may increase due to referrals from IBIS practitioners, NovaRest does not believe that the increase will impact premiums to any significant level.

Section VI. Experience with ASD Insurance Reform in Neighboring States

Thirty-seven states, the District of Columbia and the US Virgin Islands have enacted insurance reform laws related to the treatment of Autism Spectrum Disorder.[49] Table 28 provides a summary of these reforms for South Dakota's six neighboring states.

Four of the six states that border South Dakota -- Iowa, Minnesota, Montana and Nebraska -- have enacted reforms requiring the provision of diagnosis and treatment for ASD, including Intensive Behavioral Intervention Services (IBIS) such as Applied Behavioral Analysis (ABA). All four of the state's mandates apply to the State Employee Health Plan, and three require several types of group plans to cover these services. All four of the states have age limits and three of the four have dollar caps. Some of the neighboring states have mental health parity laws that cover ASD treatment.

Three of the four states – Iowa, Montana, and Nebraska – had cost projections of their insurance mandates prepared by Oliver Wyman that are in the public domain. These are presented below in Tables 29 and 30. As detailed in Section V, NovaRest estimated an ultimate annual premium using mid-level cost assumptions would be $1.90 PMPM or $23 per insured annually. NovaRest's estimate is higher than what was projected in these states primarily due to the limitation on benefits in these states and the variance in projected hourly rate for services.

[49] Autism Speaks, State Initiatives, http://www.autismspeaks.org/advocacy/states, accessed 9/27/14

Table 28: ASD Insurance Reform/Mandate and Mental Health Parity Laws Inclusive of ASD for South Dakota's Neighboring States, Current October 2014

State	Reform Legislation: Plans Effected	Services Covered	Age Limits	Dollar Caps	Reference	Mental Health Parity (MHP) laws inclusive of ASD[50]
Iowa	State Employee Health Plan. Effective Jan 1, 2011	Diagnostics, pharmacy, psychiatric, psychological, rehab (e.g., ABA), therapeutic care (e.g., speech, OT, PT)	Limits coverage to individuals under age 21	Coverage treatment maximum annual benefit of $36,000	HF 2531 passed April 29, 2010	No
Minnesota	State Employee Health Plan effective Jan 1, 2016; fully insured large group plans. Effective Jan 1, 2014	Diagnosis, evaluation and multi-disciplinary assessment, early intensive behavioral and developmental therapy (e.g., ABA), neurodevelopmental and behavioral health treatment, speech, OT, PT, medications	Limits coverage to individuals under age 18	None	HF 1233, passed May 23, 2013	Yes, MHP law requires group health policies that provide coverage for mental conditions treated in the hospital must also treat those outside the hospital. May include Autism.
Montana	State Employee Health Plan; individual, fully insured large and small group plans. Effective Jan 1, 2010	Diagnosis, habilitative or rehabilitative care (e.g., ABA), medications, psychiatric or psychological care, therapeutic care (e.g., speech, OT, PT)	Limits coverage to individuals through 18 years of age.	8 years or younger: $50,000 9-18 years: $20,000	SB 0234, passed May 5, 2009	Yes, MHP law covers severe mental illness including ASD
Nebraska	Any individual or group policy or subscriber contract. Includes self-funded employee benefit plan to the extent	Screening, diagnosis and treatment including intensive behavioral interventions, e.g., ABA	Limits ABA coverage to individuals up to age 21	Limits ABA to 25 hours per week	LB 254 passed April 2014	Yes, MHP law specifies that if a plan covers mental illnesses, then it must be covered similar to other medical conditions. Autism is included.

[50] Source: Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD L&M Policy Research. HHSM-500-2006-00009I/HHSM-500-T0002 January 24,2014

State	Reform Legislation: Plans Effected	Services Covered	Age Limits	Dollar Caps	Reference	Mental Health Parity (MHP) laws inclusive of ASD[50]
	not exempted by federal law. Includes State Employee Health Plan.[51] Effective Jan 1, 2015					
North Dakota	None				N.D. Cent. Code §26.1-36-09	Yes, MHP law requires group health insurers to provide the same coverage for the diagnosis and treatment of mental illnesses as other conditions. May include Autism.
Wyoming	None					No

[51] http://nebraskalegislature.gov/FloorDocs/103/PDF/Slip/LB254.pdf

Limitations on ASD Mandates

Statutory limits on mandated coverage reduce the level of coverage that must be provided. These limits are enacted to lessen the premium impact of mandated benefits. Each of the states surrounding South Dakota set their own limits on mandates based on the state legislation. Limits include the amount that is covered per year and the age of children that must receive coverage. Currently, Iowa and Kansas have the lowest statutory limits on the amount spent per year per patient on ABA at $36,000. Montana has the highest limit of the surrounding states at $50,000 up to age nine for all employer groups. From ages nine to eighteen, coverage in Montana is subject to a $20,000 annual maximum. Nebraska took an alternate approach to setting a dollar maximum and instead set a limit on the number of hours that must be covered. Their law requires ABA coverage be limited to 25 hours per week for patients up to 21 years of age.

Projected Cost of ASD Mandates

The projected cost of ASD mandates vary based on mandate limitations and the current status of coverage in the state. Often these are associated with services beyond ABA. Also, projected costs vary by the assumptions used, such as that of the hourly cost of the service. The estimated projected costs are extremely sensitive to these assumptions, especially those related to a provider's hourly rate and utilization. The studies performed by Oliver Wyman were performed over a number of years and included multiple states. Table 29 was developed referencing these studies in order to demonstrate the assumptions variance in surrounding states.

Table 29: Projected Hours and Cost of Intensive Behavioral Interventions by Age in IA, MT, NE

Age	Annual Average Hours Per Child	Iowa	Montana	Nebraska
Average cost per hour of ABA therapy		$39.00	$45.45	$43.00
Ages Under 8	1,500	$58,500	$68,175	$64,500
Ages 8 to 12	671	$26,169	$30,497	$28,853
Ages 13 to 21	401	$15,639	$18,225	$17,243

Oliver Wyman's analysis included scenario testing to develop cost estimates under a range of assumptions. To develop the scenario testing they varied the assumptions that drive cost estimates. The premium increase under the "Low," "Middle," and "High" scenarios are provided in Table 30.

Table 30: Projected Annual Premium Increase per Person to Cover Children with ASD Receiving Intensive Behavioral Intervention Services under Various Assumption Scenarios for IA, MT, NE

Scenario	Iowa	Montana	Nebraska
Low	$9.80	$9.50	$15.60
Middle	$14.60	$12.70	$17.10
High	$21.50	$16.90	$24.90

NovaRest's estimated ultimate middle level annual premium impact of $23 per insured ($1.90 PMPM), as described in Section V, is higher than projected in other states primarily due to limitations on benefits in those states and the projected hourly rate for services. The differences in hourly rate estimates are attributable to inflation and to the fact that South Dakota had a high proportion of Doctorate and Masters-level practitioners with higher fees than the practitioners licensed in other states at the time the projections were done.

Section VII. Long and Short Term Cost of Maintaining the Status Quo

Estimates of the total cost of caring for an individual with ASD over his or her lifetime ranges from $1.4 million[52] to $3.2 million[53], based on the individual's level of dependency. Early Intensive Behavioral Intervention Services (IBIS) can translate into significant cost savings for some individuals. The status quo in South Dakota -- a limited number and distribution of qualified IBIS practitioners and a high cost of treatment -- will continue to deter families from pursuing this course of treatment.

As discussed in Section II of the report, this type of treatment has demonstrated functional improvements for some children. For these children, there may ultimately be a reduction in costs related to special education services, medical services and other lifetime costs, as well as a reduction in the loss of parental income due to caretaking demands. Each of these costs is discussed below.

Costs Related to Special Education Services

There have been multiple studies demonstrating that children who receive early IBIS are more often mainstreamed in school which has significant cost implications for the educational system. Analyses conducted in two states found that providing early IBIS for three years could result in cost savings by reducing further special education costs for some children, and completely eliminating them for others. While IBIS services are costly, they are typically incurred for two to three years in the preschool years. Research on special education costs for untreated individuals suggests that most children with ASD who do not receive early IBIS are likely to remain in an intensive special education classroom up to age 22.[54]

Researchers projected costs savings for the State of Pennsylvania of an average of $187,000 to $203,000 for each child who received three years of early IBIS relative to one who received special education services until age 22. Researchers projected cost savings for the State of Texas of an average of $208,500 in education costs for each student who received three years of early IBIS relative to a student who received 18 years of special education from ages four to 22.[55]

[52] Ariane V.S. Buescher, et al, (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States. http://archpedi.jamanetwork.com/article.aspx?articleID=1879723 . Accessed September 16, 2014

[53] Michael L. Ganz, (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. Arch Pediatr Adolesc Med/Vol 161, April 2007: Page 348.

[54] Report of the Joint Legislative Audit and Review Commission to the Governor and the General Assembly of Virginia. Assessment of Services for Virginians with Autism Spectrum Disorders, p. 15. http://jlarc.virginia.gov/reports/Rpt388.pdf.

[55] IBID

Medical Costs

According to 2003 data, the average medical expenditures for individuals with ASD can exceed those of individuals without ASD by $4,110-$6,200 per year.[56] Over the four-year period between 2000 and 2004, researchers found that the annual medical expenditure for individuals with ASD increased by 20.4 percent when adjusted for inflation.[57] A review of health care utilization of children with ASD experienced three times more inpatient hospitalization and 2.5 times more outpatient hospitalizations than those without ASD.[58]

Other Lifetime Costs

The continuum of medical, social services and housing designed to support the needs of adults living with chronic health problems that affect their ability to perform everyday activities is the largest contributor to the overall lifetime cost for an untreated individual with ASD.[59] According to a study recently published in JAMA Pediatrics, researchers at the Center for Mental Health Policy and Services Research at the University of Pennsylvania estimate that lifetime cost of individuals with ASD and no intellectual disabilities is approximately $1.4 million (in addition to the costs that would accrue with a typically-developing child), and $2.4 million for individuals with intellectual disabilities.

Loss of Parental Income

Parents of children who have been diagnosed with ASD can experience a loss of productivity due to high levels of chronic stress, which researchers have found to be similar to those of soldiers in combat situations. Such high levels of chronic stress can affect the parents' performance in the workplace. Researchers indicate that mothers who have adolescents and adults with ASD were interrupted in one out of every four workdays, compared with one out of every ten days for other mothers.[60] One study indicates that parents with children younger than eighteen with ASD work 7 hours less per week than parents with children who do not have ASD.[61] Another study corroborates these findings and estimates an annual productivity loss for the caregivers of children with ASD to amount to $18,720.[62]

[56] T. T. Shimabukuro, S. D. Grosse, et al. (2008). Journal of Autism and Developmental Disorders 38(3): 546-552.
[57] D. L. Leslie and A. Martin (2007). Archives of Pediatrics & Adolescent Medicine 161(4): 350-5.
[58] L. A. Croen, D. V. Najjar, et al. (2006). Pediatrics 118(4): e1203-11.
[59] Catherine Pearson (2014). Lifetime Costs of Autism Can Exceed $2 Million, Study Says. http://www.huffingtonpost.com/2014/06/09/autism-costs_n_5474061.html. Accessed September 29, 2014.
[60] Michelle Diament. Autism Moms Have Stress Similar to Combat Soldiers. http://www.disabilityscoop.com/2009/11/10/autism-moms-stress/6121/. Accessed September 16, 2014
[61] Ariane V.S. Buescher, et al, (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States. http://archpedi.jamanetwork.com/article.aspx?articleID=1879723. Accessed September 16, 2014
[62] IBID

Conclusion

HMA and NovaRest conclude that Intensive Behavioral Intervention Services (IBIS) as defined in the report are established treatments that have demonstrated improvements in cognitive function, and language/communications skills in some children with ASD. The federal government does not require coverage for this type of treatment, nor does South Dakota state law.

Cost projections for commercial insurance coverage requiring a broad range of ASD treatment including IBIS in South Dakota the ultimate cost could be as high as $2.50 PMPM using high-level estimates. The premium impact estimates are based in part on assumptions which include: current service coverage, the estimated number of children with ASD in South Dakota, age and dollar limits of coverage, hours of service utilization by age, reimbursement rates, projected health insurance premiums and membership.

In addition to the State's current $18.5 million in expenditures for children with ASD, the State would be responsible for a portion of the cost of a commercial insurance mandate up to approximately $2.98 million per year. Further costs would be borne by the State should the State choose to expand the Employee Health Plan and Medicaid coverage to include IBIS for children with ASD.

Appendices

Appendix A: Additional Literature Reviews on Treatment Efficacy

Autism Spectrum Disorder Services: Final Report on Environmental Scan. 2010.
Funder: Centers for Medicare and Medicaid Services
Conducted by IMPAQ International, LLC

This review describes in detail the evidence base for interventions for individuals with ASD across the age span. It takes a broader perspective on interventions than the National Autism Center report (described below) but comes to similar conclusions. In essence, there is growing and encouraging support for behavioral interventions for young children with autism. Data are scarce or missing altogether, however, on the efficacy of interventions for adolescents with ASD.

The report identified fifteen "Level 1 Evidence-based interventions" which is the highest rating based on rigor of evidence of the intervention's efficacy and effectiveness. These include, in alphabetical order: antecedent package, behavioral package, cognitive-behavioral intervention package, comprehensive behavioral treatment for young children, joint attention intervention, multi-component package, naturalistic teaching strategies, peer training package, Picture Exchange Communication System (PECS), schedules, social communication intervention, social skills package, story-based package, structured teaching, technology-based treatment.

The National Autism Center's National Standards Report. 2009.
Primary funder: State of California Department of Developmental Disabilities
Conducted by the National Autism Center

In 2009, the National Autism Center produced the National Standards Report which is a systematic review of the behavioral and educational peer-reviewed treatment literature involving individuals with ASD under the age of 22. The Report was intended, in large part, to provide the strength of evidence supporting behavioral and educational treatments that target the core characteristics of Autism Spectrum Disorder and offer recommendations for evidence-based practice for treating ASD.

The report identified eleven Established Treatments from the literature. "Established" is defined as "sufficient evidence is available to confidently determine that a treatment produces beneficial treatment effects for individuals on the autism spectrum. That is, these treatments are established as effective." These include, in alphabetical order: antecedent package, behavioral package, early intensive behavioral intervention, joint attention intervention, modeling, naturalistic teaching strategies, peer training package, pivotal response treatment, schedules, self-management, and story-based interventions.

Appendix B: Provider Requirements

Provider Requirements for the Provision of Autism Treatment – Licensure

In accordance with South Dakota Codified Laws, the Autism treatment providers set forth below must meet specific licensure requirements:

Counseling Services

Marriage and Family Therapist: An individual who has received a master's or doctoral degree which consists of the requisite number of semester credit hours in marriage and family therapy from a program accredited by the Commission on Accreditation for Marriage and Family Therapy Education, or has completed a program that provides specialty training in marriage and family counseling or therapy that is accredited by the Council for Accreditation of Counseling and Related Educational Programs, or has earned a graduate degree from a regionally accredited educational institution and equivalent course of study that meets national standards, and also has the requisite supervised marriage and family therapy work experience, completed a post-graduate practicum, and passed a written or oral examination (or both), as required by the State Board of Examiners.

Licensed Professional Counselor – Mental Health: An individual who has completed a master's, specialist, or doctoral degree with an emphasis in mental health counseling from a counseling program approved by the Council for Accreditation of Counseling and Related Educational Programs as listed in the Directory of Accredited Program or an equivalent program as demonstrated by studies in select areas.[63] After receiving a master's degree, the individual must have accumulated two years of clinical experience and supervision under an appropriately licensed mental health professional, and passed an examination approved by the State Board of Examiners.

Occupational Therapy

Occupational Therapist: An individual who has completed the academic requirements of an educational program in occupational therapy that is accredited by the committee on allied health education, and the American Medical Association in collaboration with the American Occupational Therapy Association, has completed the requisite supervised fieldwork and any occupational therapy (OT) specialty-specific experience required, and has passed an examination approved by the State board of licensure.

Occupational Therapist Assistant: An individual who has completed the academic requirements of an Occupational Therapist Assistant program approved by the American Occupational Therapy Association, has completed the requisite supervised fieldwork and any

[63] See SDCL 36-32-42 (2) (a-f) for a description of the select areas of study.

OT specialty-specific experience required for licensure, and has passed an examination approved by the State board of licensure.

Psychological Services

Psychologist: An individual who holds a doctoral degree (i.e. Ph.D, Psy.D or Ed.D) from a regionally accredited university or professional school of psychology in the United States (or an individual who is recognized by the Association of Universities and Colleges of Canada as a member in good standing), has completed a supervised psychology internship amounting to the requisite number of hours, has engaged in a supervised postdoctoral psychology practicum for one year, and has successfully passed the licensing board mandated national examination for psychology.

Physical Therapy

Physical Therapist: An individual who has graduated from a physical therapy curriculum accredited by the U.S. Department of Education, passed an exam administered by the State Board of Examiners (Board) to test the individual's knowledge of subjects related to physical therapy to ascertain fitness to practice. The Board may in its discretion, without examination, issue a license to an individual who has passed a national examination recognized by the Board with a sufficient score.

Physical Therapist Assistant: An individual who has completed an accredited physical therapist assistant education program recognized by the State Board of Examiners (Board), and has passed a written examination approved by the Board which tests the individual's knowledge of subjects related to physical therapy.

Physician Services

Physician/Psychiatrist: An individual who holds a diploma from a medical or osteopathic college approved by the State Board of Medical and Osteopathic Examiners (Board), passes a licensing examination required by the Board, has successfully completed the requisite internship/residency in a hospital approved by the Board, and committed no act for which disciplinary action may be justified.

Speech Therapy

Speech-Language Pathologist: An individual who holds a masters or doctoral degree from an institution accredited by the American Speech-Language-Hearing Association (ASHA) and from an educational institution approved by the US Department of Education, has completed supervised clinical practicum, has completed supervised postgraduate professional experience, has passed a written national examination for speech-language pathology, and has committed no act for which disciplinary action may be justified.

Provisional Speech-Language Pathologist: An individual who holds a masters or doctoral degree from an institution accredited by the accrediting agency of ASHA and from an educational institution approved by the U.S. Department of Education, has completed supervised clinical practicum, has passed a written national examination for speech-language pathology, and is working under the mentorship of a licensed speech-language pathologist to complete the postgraduate professional experience needed to be licensed as a speech-language pathologist. Individuals must have committed no act for which disciplinary action may be justified. The term of a provisional license is 24 months and may be renewed only one time.

Limited Speech-Language Pathologist: An individual who holds a bachelor's degree in communication disorders or speech-language pathology and a speech-language pathologist certificate from the South Dakota Department of Education as of July 1, 2012. Individuals must have committed no act for which disciplinary action may be justified. Individuals with a limited license may provide speech-language services as employees of public or private school districts or State departments that provide educational services, but may not perform non-medical endoscopy, or evaluate or treat swallowing disorders.

Speech-Language Pathology Assistant: An individual who holds an associate's degree in speech-language pathology assisting or a bachelor's degree in speech-language pathology or communication disorders from an accredited academic institution, has completed a supervised clinical practicum of at least 100 clock hours as a speech-language pathology assistant, and has committed no act for which disciplinary action is justified. The speech-language pathology assistant works under the direct supervision of a licensed speech-language pathologist.

Provider Requirements for the Provision of Early Intensive Behavioral and Developmental Interventions

Certifications of the Behavior Analyst Certification Board

Board Certified Behavior Analyst: Individuals who have either a master's degree (BCBA) or a doctoral degree (BCBA-D), and are certified by the Board.

- **BCBA:** This certification may be obtained by an individual who has a master's degree in behavior analysis (BA) or other natural science, education, human services, engineering, medicine or a field related to BA that was received from an institution of higher education accredited by the U.S. Accrediting Organizations, or an institution of higher education recognized similarly accredited by Canada, or an equivalent institution outside the U.S. and Canada. The individual must pass the BACB certification examination, complete the requisite coursework at the graduate level OR have held a full-time, one-year college/university teaching appointment, and in all cases must have documented supervised experience in the field of BA.

- **BCBA-D:** To receive this certification from the BACB, an individual must first become and remain actively certified as a BCBA, and earn a doctoral degree from a program accredited by the Association for Behavioral Analysis International, or complete behavior analytic coursework and publish a BCBA-approved dissertation.

Board Certified Assistant Behavior Analyst (BCaBA): This certification may be obtained by an individual who has earned a bachelor's degree from an institution of higher education accredited by the U.S. Accrediting Organizations, an institution of higher education recognized similarly accredited by Canada, or an equivalent institution outside the U.S. and Canada, has completed the requisite BA coursework, obtained documented supervised experience, and has passed the BCaBA certification examination.

Registered Behavior Technician (RBT): This is a relatively new BACB entry-level certification that may be obtained by individuals who have a high school diploma or national equivalent, complete a BACB RBT training program, pass an RBT competency assessment, and submit to a criminal background check.

Details on training qualifications and the certification process can be found at this link. http://www.bacb.com/

We recommend maintenance of and adherence to the national certification standards and processes established by the Behavior Analyst Certification Board. The Board was created in 1998 to meet professional credentialing needs of these practitioners; it is accredited by the National Commission for Certifying Agencies.

Certifications of the University of California, Davis – Continuing and Professional Education

Certified Early Start Denver Model (ESDM) Therapist: An ESDM therapist may be a psychologist, behaviorist, occupational therapist, speech and language pathologist, early intervention specialist or developmental pediatrician with ESDM training and certification. Qualified professionals attend a training workshop and then submit videotapes and other materials demonstrating ability of the provider to implement ESDM techniques reliably and according to high standards.

Details on training qualifications and the certification process can be found at this link. http://extension.ucdavis.edu/unit/autism_spectrum_disorders/esdm_certification.asp

Appendix C: Stakeholder Engagement

Autism Study: Public Forum Themes

Public forums to obtain input on the Autism Study were held in Rapid City, Aberdeen, Pierre, and Sioux Falls the week of August 18, 2014. A total of 125 individuals signed in as participants, though several attendees did not sign in. The majority of those that signed in were parents or family members of children with autism. There were several providers of services for persons with autism and other developmental disabilities, state representatives both from the house and senate, and representatives of three insurance companies.

The study authors presented a brief overview of the background on the autism-related bills from the 2014 legislative session, the scope of services of the Autism Study, data collection processes for the study, and a timeframe for completion. The authors discussed opportunities for interested parties to be kept apprised of progress on the study and ways in which individuals could provide input throughout the duration of the study. Public input was audiotaped and themes were identified.

The following themes emerged:

1. Anecdotes of significant and sometimes dramatic improvements in children receiving early intensive behavioral interventions were provided by parents, grandparents, teachers, and pediatricians among others.
2. Families whose children receive intensive behavioral intervention typically have insurance coverage; the costs of intensive behavioral interventions are out of reach for the vast majority of middle class families in South Dakota.
3. Grief, exhaustion and outrage expressed by parents that have young children with autism with behavioral problems that do not have insurance coverage/ability to pay to for intensive therapy.
4. Parents with older children with autism that require behavioral supports are also not able to access them due to lack of coverage/ability to pay.
5. School staff and therapists need supplemental autism-specific training and support; several mentioned speech therapists in the schools that they perceived did not have the expertise required to work with children with autism.
6. Primary barriers to building capacity in South Dakota for the provision of intensive behavioral interventions (e.g., ABA): lack of a regulatory body, lack of an in-state training program, and lack of insurance coverage; each of these issues can be overcome.

7. Insurance companies either concurred with the need for coverage for comprehensive autism treatment including ABA conducted by certified therapists with clear treatment protocols, or questioned any form of mandate due to ongoing research on treatment.

Note: Some parents lacked awareness of what constitutes a comprehensive treatment program for children with autism; school personnel and healthcare providers are not consistently discussing or referring.

Autism Study: Selected Provider Interviews

West River Autism Team: Rhonda Fetrl, Director; Shirly Hauge, Speech Language Pathologist; Jennifer Negrette, School Psychologist. August 19, 2014

Behavior Care Specialists: Alison Kringstad, MA, Owner and Clinical Supervisor; Tracy Stevens, PhD, BCBA-D, Clinical Psychologist and professional staff. August 21, 2014

ABC Consulting: Brittany Schmidt, MA-CCC/SLP, Speech Language Pathologist. August 21, 2014

Lifescape: Kimberly Marso, RhD, BCBA-D, Chief Operating Officer. August 21, 2014

University of South Dakota, Sanford School of Medicine, Center for Disabilities: Eric Kurtz, PhD, Director, Leadership Education in Neurodevelopmental and Related Disabilities. August 21, 2014