AUTISM SPECTRUM DISORDERS: A NEW SERVICE MODEL

BY HOWARD SAVIN, PH.D, MEL SMITH, Th.M., M.S.W., and DAVID PANKOTAI, M.A., L.P.C.

DEFINITION AND PREVALENCE OF AUTISM SPECTRUM DISORDERS (ASD)

Autism is a neurobehavioral syndrome resulting from a dysfunction of the central nervous system that leads to disordered development. According to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), published by the American Psychiatric Association (1994, pp.70-71), the onset of symptoms in autism occurs within the first three years of life and includes three general categories of behavioral impairment common to all persons who have autism:

- Qualitative impairments in social interaction
- Qualitative impairments in communication
- Restricted, repetitive and stereotyped patterns of behavior, interest and activities

In recent years, the conceptualization and criteria defining the condition called "autism" have evolved significantly. The definition of autism has broadened so that autism is now seen as a spectrum disorder. The terminology of "Autism Spectrum Disorder" (ASD) and "Pervasive Developmental Disorder" (PDD) includes the disorders commonly diagnosed as Autism, Asperger Disorder, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). The majority of specialists believe that the boundaries along the continuum overlap to a large degree.

The characteristics of ASD are varied but the following are usually present to one degree or another:

- *Poor understanding of social relationships.* People with autism usually have poor eye contact and limited play and social interactions. They may prefer being alone. It is hard for them to understand social cues — such as facial expressions and body language — and the feelings of other people.
- *Significant language and communication problems*. Studies show that about 40% of people with autism do not speak. For those who do, language is slow to develop and may include unusual speech patterns and repetitive phrases, questions and topics. People with autism often have difficulty understanding instructions or language out of context. They often need extra time to think about the words they have heard or said and to act on them. It may be hard for them to communicate their needs.
- *High need for sameness, predictability.* People with autism may become upset with changes in the environment, schedules and the people around them. They are easily confused and often develop elaborate rituals — such as lining up objects — to organize themselves. They usually have a limited number of interests and activities.
- *Impaired thinking abilities.* To one degree or another, most people with autism have problems with judgment and understanding the meaning of things. They usually focus on details and are unable to see the whole or how the parts fit together. It is hard for them to separate what's important from what's not. Making choices can be troublesome. Generalization is often a challenge: for example, a child may be able to tie his or her shoes at home but not at school. People with autism typically find it very difficult to grasp abstract concepts such as clean-vs.-dirty.
- *Organizational problems*. People with autism usually have difficulty with beginnings and endings. They may not know where to start an activity or understand what "finished" looks like. Many individuals have trouble putting tasks in order and figuring out what comes next.
- *Sensory and perception problems.* People with autism often have inconsistent and unusual sensory responses. They can be both over-reactive and under-reactive — seemingly deaf to a siren but distressed by the vacuum cleaner. They may stare at lights, lick or smell things, and be attracted to or repelled by certain textures, especially in food. Their pain threshold is often high. In general, they are distracted by sensory information and are unable to filter out the unimportant details.

- *Uneven pattern of development.* Typically, the skills of a person with autism are scattered. They may do some things well and others not at all. A child may be able to read, for example, but unable to talk.

Language and social skills are the biggest challenges for most people with autism. Even the most mildly affected people with autism struggle with the complexity and abstraction of language. A person with severe autism may not understand the purpose of language — that people talk to communicate with each other. Social situations also confuse individuals with autism because of the many subtle cues and personal judgments involved in personal interactions.

Autism may be more common than previously realized, particularly if the broader definition of autism as a spectrum disorder is used to determine the number of cases. Earlier studies suggested that the prevalence of autism is about three to four individuals in 10,000, but more recent studies have suggested higher rates for the general class of ASD/PDD, up to or greater than sixty in 10,000. The higher estimated rates reflect inclusion of the broader range of autism, including milder subtypes on the spectrum (PDD-NOS and Asperger Disorder). The apparent increase may also be a result of improved diagnosis, but a real increase in prevalence cannot be absolutely ruled out.

The most recent Center for Disease Control and Prevention (CDC) prevalence estimates for Autism Spectrum Disorder (ASD) is 8.3 per 1,000 (1 in 120). However, the prevalence varies by state and in New Jersey, for example, it is much greater with an estimate at 1 in 94 residents being affected. These estimates are more than ten-fold higher than just two decades ago, and raise critical concerns about what the future holds for the increasing number of persons with ASD.

CURRENT STATE OF SERVICE PROVISION FOR AUTUSM SPECTRUM DISORDERS

There is no cure. Some individuals have made remarkable gains in language and social development and can function relatively well in society but they still have autism. Behaviors may fade or change as the child grows and treatments may relieve specific symptoms but the brain dysfunction does not ever go away. Because experts know so little about what causes autism, even less is known about possible cures. However, research is going on in many areas including genetics, the auto-immune system, possible drug treatments and brain function.

Autism is treatable. With careful instruction and support, most people with autism can learn to function at home and in the community. Many lead happy and fulfilling lives. It's very hard to predict. Having opportunities to learn can help to prepare your child for a meaningful and productive adult life. Like everyone else, people with autism learn and grow throughout their lives. Their skills, interests and strengths may change — and even improve significantly — but they will not outgrow autism.

The impact on multiple spheres of functioning has led to three distinct and often separate approaches, to the care of persons with ASD. The educational sphere assesses the ability to communicate verbally and non-verbally and interact socially. Deficits are addressed in an Individual Educational Plan (IEP). The medical sphere will focus on language, social and behavioral difficulties with early identification of co-morbid conditions. Sleep, nutrition, seizures and accidental injuries are assessed. A Treatment Plan will utilize pharmacological and complementary medicine options. The behavioral sphere relies on an Applied Behavioral Analysis to develop an Individual Support Plan (ISP). This permits systematic development of critical self-help, social, communication, educational and or vocational skills. The aim of most interventions is to bridge the gap, as early and rapidly as possible, between the persons' chronological age and their developmental age and enable mainstream adjustment to the extent achievable. To insure that appropriate services are delivered in a non-redundant fashion, and that steady progress is being made, care should be coordinated across all settings of care.

The combination of intense advocacy by impacted families, the increased demand for autism services, the lack of readily accessible integrated evidenced based practices, and the aging out of children with ASD has resulted in legislative action in twenty three (23) states that mandates inclusion of ASD in insurance based plans of care. (See Appendix A for Chronology of Autism Advocates Successes) States and insurance carriers are struggling to meet the requirements to insure that ASD benefits are made available in an effective and efficient manner. This volatile environment also provides a challenge to the behavioral providers of autism care and the health insurance plans. They are each facing a new reality of working with one another. In addition advocacy has led to a process for filing an appeal when a family feels they have been wrongly denied services, (See Appendix B).

Care for those with autism spectrum disorder is a varied, often uncoordinated, and limited in scope. The multiple spheres affected by the disorder are seldom addressed with a unified plan of care. Several professional groups claim expertise and skills needed to treat the disorder. To complicate matters the availability of treatment resources are limited and access is a challenge for families. The dramatic increased prevalence, as yet unexplained, adds to the volatility and confusion. The arena is challenged with demands it cannot meet, lack of credentialing of professionals, extreme variability in cost of care, and an array of treatment responses often not supported by evidence based practices. If there ever was a need for a new service model, the time is now.

THE NEW SERVICE MODEL: AN AUTISM SPECTRUM DISORDER BENEFITS MANAGER

Utilize Evidence Based Care – Applied Behavioral Analysis (ABA)

Behavior analysis is a scientific approach to understanding behavior and how it is affected by the environment. The science of behavior analysis focuses on principles about how behavior works and how learning takes place. Through research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may be harmful or that interfere with learning. Applied Behavior Analysis (ABA) is the use of those techniques and principles to address socially important problems and to bring about meaningful behavior change.

Hundreds of published studies have shown that specific ABA techniques can help individuals with autism learn specific skills, such as how to communicate, develop relationships, play, care for themselves, learn in school, succeed at work, and participate fully and productively in family and community activities, regardless of their age. A number of peer-reviewed studies have examined the effects of combining multiple ABA techniques into comprehensive, individualized, intensive, early intervention programs for children with autism. “Comprehensive” refers to the fact that intervention addressed all kinds of skills: communication, social, self-care, play, motor, pre-academic, and so on. “Early” means that intervention began before the age of four for most children. “Intensive” means that ABA methods were used to arrange large numbers of learning opportunities for each child every day in both structured and unstructured situations, which amounted to 25-40 hours per week during which children actively learned and practiced skills. These studies showed that many (but not all) children with autism who received 1-3 years of this type of treatment had large improvements on tests of their cognitive, communication, and adaptive skills. Some who participated in early intensive ABA for at least 2 years acquired enough skills to participate in regular classrooms with little or no ongoing help. Currently, it is very difficult to predict in advance how far any individual child might go with this treatment and more research is needed.

Create a Carve Out

Autism Services Group, Inc. (ASG) is a privately held New Jersey corporation conceived by Criterion Health. It was founded in 2010 to administer autism spectrum disorder (ASD) and other developmental disability (DD) services and benefits on behalf of health plans, employers and other purchasers of ASD and DD services. The ASG’s initial geographic focus is in New Jersey. Service protocols being sold include an infrastructure to support marketing, sales, account management, a proprietary state-wide

autism provider, provider and member service, credentialing, as well as benefits care coordination, billing, claims processing, utilization management and quality improvement.

ASG generates revenues through contracts with insurance companies and employers. These contracts will provide for payment to ASG for a menu of services that individual companies elect to purchase. For example, some might choose to purchase the services of the provider network and claims management; in other cases, some might choose to purchase credentialing, case management and claims management. Rates are negotiated with individual companies. The Company functions as a third party administrator in which fees are passed to the Company by insurance companies and in turn the Company pays its network providers via a contracted rate schedule, with the Company keeping the difference between the two amounts. The Company is not anticipating bearing financial risks beyond the scope of the description above. For example, the Company does not anticipate entering into capitation arrangements with insurance companies at this time.

While neuroscience continues to focus on the etiology of ASD and psychotropic medications can help manage self-injurious, self-stimulating and agitated behaviors, behavioral interventions have accumulated an evidence base and resulting functional gains from such interventions and can now be measured. Clinicians and educators trained in applied behavior analysis (ABA) conduct Functional Behavior Analyses (FBAs) to articulate an individual's strengths and needs, which are then used to develop the individual's Individual Support Plan (ISP). This permits systematic development of critical self-help, social, communication, educational and/or vocational skills. The Company believes interventions need to take place across all spheres of daily life, including in schools, home and clinical settings.

The aim of most interventions is to bridge the gap, as early and rapidly as possible, between the persons' chronological age and their developmental age and enable mainstream adjustment to the extent achievable. To insure that appropriate services are delivered in a non-redundant fashion, and that steady progress is being made, care should be coordinated across all settings of care. Board Certified Behavior Analyst (BCBA) is the credential which is most often recognized as the standard of excellence for providers of ABA services. Ideally, all behavioral ASD services should be provided by either a BCBA or provided under the direct supervision of a BCBA.

The Company has organized panels of New Jersey autism service providers whose roles are to deliver high quality specialized and coordinated care to ASD and DD plan members in New Jersey. The Company's mission is to establish a new level of client-sensitive, coordinated, cost effective, evidence-based autism care; improved access to autism services; and increased efficiency in the stewardship of funding resources that flow from employers, insurers and government agencies.

ASG's primary goal is to function as a one-stop provider network administrative resource for purchasers and providers of care for the target population and to serve as a direct resource to families in need of such care. Essential services will include providing ABA services and helping parents coordinate resources available across employers, insurers and participating government agencies. A secondary goal is to create systems and methods for improved care coordination across systems and providers. If requested, the Company will strive to be capable of serving as a private labeled outsourced intermediary to administer autism insurance benefits.

Principal Products, Markets and Methods of Distribution.

Consistency and quality of care for consumers of autism services has never been standardized across school, home and clinic settings. For the most part, traditional providers of autism services have not directly interfaced with health insurance plans. Accordingly, autism service providers are generally not familiar with formal credentialing processes or the rigors of billing and claims submission as well as care coordination with traditional primary care medicine.

While 23 states currently have insurance mandates regarding the treatment of autism, the trend is moving toward a focus on coordinated care and the inclusion of the Applied Behavior Analysis (ABA) treatment

model. This model often includes pre-certification by insurance companies and a diagnosis by a licensed clinical psychologist or psychiatrist as well as close care coordination via a credentialed practitioner with expertise in autism treatment and ABA services. Many autism spectrum ABA providers are often speech and language therapists, social workers and generic counselors who may not have been previously credentialed as independent health care providers. Traditional autism providers do have a wealth of expertise in ABA and are highly dedicated to delivering quality care to the individuals they serve. ABA contributes by developing programs and modalities for each individual served instead of taking a “cookie cutter” approach.

In concert with New Jersey’s autism insurance legislation, ASG has established panels of qualified individually licensed and certified practitioners. Through credentialing and oversight ASG builds a network of ABA programs that makes services available to individuals under age 21 who are diagnosed (DSM IV, 299. codes) as having autism, or a “related developmental disorder.”

The kind of provider service standards that ASG aspires to achieve at maturity in its provider network will meet URAC Health Plan standards and as such, will include among other things, outcomes management consisting of monitoring each individual’s functional gains at time appropriate intervals as well as formally organized performance improvement initiatives. There will also be periodic surveying of family and provider satisfaction. ASG will strive to deliver administrative services that will seek to optimize improvements in access to and the quality of care delivered and will result in improved plan member and provider satisfaction ratings in this politically and emotionally charged service area.

Our outcome model will be accountability for:

- Access; facilitating prompt, convenient appointments and choices in delivery practitioners and programs to plan members

- Acceptability of services to plan members and their families as well as accrediting bodies

- Impact of services as measured by evidence of functional gains and quality of life improvement, providing a true measure of cost-effectiveness

- Value to purchasers

APPENDIX A

CHRONOLOGY OF OUTCOMES OF INTENSE ADVOCACY

Date	Event
1999	The 2000 Children's Health Act established the National Center on Birth Defects and Developmental Disabilities at the CDC and authorized the establishment of Centers of Excellence at both CDC and the National Institutes of Health (NIH) to promote research and monitoring efforts related to causes, diagnosis, early detection, prevention, and treatment of autism.
May 3, 2001	Indiana enacted legislation
2005	California created the California Legislative Blue Ribbon Commission on Autism with the goal of addressing the needs of children and adults with autism spectrum disorders. Other states have utilized Home and Community Based Waivers to make Medicaid funds available to assist individuals with autism.
2006	Ohio created an Autism Scholarship Program, which provides scholarships for children with special education needs. The program makes it possible for these children to utilize private education providers and individual education plans without placing an enormous financial burden on the parents
2006	The Combating Autism Act was enacted, which provides almost $1 billion over five years for autism spectrum disorder and developmental disabilities research, screening, treatment and education. The Act established a federal advisory committee, the Interagency Autism Coordinating Committee (IACC) to develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research.
2007	The Expanding the Promise for Individuals with Autism Act was introduced in Congress, which provides approximately $83 million in fiscal year 2008 to improve access to comprehensive treatments, interventions, and services for individuals with autism spectrum disorders and their families.
June 7, 2007	South Carolina enacted legislation
June 15, 2007	Texas enacted legislation
March 21, 2008	Arizona enacted legislation
May 2, 2008	Florida enacted legislation
July 2, 2008	Louisiana enacted legislation
July 9, 2008	Pennsylvania enacted legislation

Date	Event
December 13, 2008	Illinois enacted legislation
January 2009	The Interagency Autism Coordinating Committee(IACC) released its first blueprint for autism research
April 2, 2009	New Mexico enacted legislation
May 5, 2009	Montana enacted legislation
May 29, 2009	Nevada enacted legislation
June 2, 2009	Colorado enacted legislation
June 9, 2009	Connecticut enacted legislation
August 13, 2009	New Jersey enacted legislation
October 19, 2009	Wisconsin enacted legislation
April 12, 2010	Maine enacted legislation
April 14, 2010	Kentucky enacted legislation
April 19, 2010	Kansas enacted legislation
April 29, 2010	Iowa enacted legislation
May 27, 2010	Vermont enacted legislation
June 10, 2010	Missouri enacted legislation
July 23, 2010	New Hampshire enacted legislation
August 3, 2010	Massachusetts enacted legislation
2010	The following states endorsed reform bills for autism insurance: Alaska, Delaware, Georgia, Maryland, Michigan, Minnesota, New York, North Carolina, Ohio, Rhode Island, Tennessee, Virginia, Washington, and Washington, DC These states have reform bills for autism insurance pending introduction or endorsement: Alabama, Arkansas, California, Hawaii, Idaho, Mississippi, Nebraska, South Dakota, and West Virginia. Leaving only North Dakota, Oklahoma, Oregon, Utah, and Wyoming as the states not currently pursuing reform bills for autism insurance.

APPENDIX B

Filing an Appeal under the Mental Health Parity and Addictions Equity Act: When Should You Appeal?

When should behavioral health providers or consumers appeal a denial of coverage for mental health and addictions services by an insurance plan? The National Council, with the Parity Implementation Coalition, has released a toolkit to help you understand your rights under the Wellstone-Domenici Parity law. The toolkit provides tips and helpful resources for filing an appeal when you suspect your plan has unfairly denied behavioral health benefits. Whether an insurance plan has denied coverage for a mental health treatment, required disproportionately high co-pays for addictions services, or imposed other limitations on behavioral health, the Parity Toolkit can help you learn whether your plan may be violating the parity law and how you can appeal its decisions. For more information and resources on parity, visit the National Council's parity webpage.

RESOURCES

Autism Votes – an Autism Speaks Initiative
at:http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm

National Council of State Legislators (NCSL): http://www.ncsl.org/default.aspx?tabid=14390

For general information about behavior analysis and ABA, see:

www.abainternational.org [The Association for Behavior Analysis International]
www.BACB.com [Behavior Analyst Certification Board]
www.behavior.org [Cambridge Center for Behavioral Studies]
rsaffran.tripod.com/consultants.html [List of service behavioral intervention providers]

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Robert Dyer, Ph.D.

Criterion Health, Inc

Redmond, WA

(425) 641-4891

www.criterionhealth.net