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Diagnostic Criteria, Treatment and Long-Term Considerations for Individuals with Autism: Foundation for the Life Care Plan

Kristi B. Bagnell, MD, FAAP, CLCP

Abstract

The most recent prevalence study revealed that autism spectrum disorder (ASD) affects 1 in 59 children in the United States (Baio et al., 2018). Many have warned about the "autism epidemic" rapidly approaching adulthood that has already been estimated to have costs in the hundreds of millions of dollars annually. Persons diagnosed with ASD display varying degrees of impaired social, communicative and cognitive skills. There is frequently an overlap with intellectual disability in this group; however, autism has specific characteristics making its course and treatment distinctive. Diagnostic criteria for autism spectrum disorder were revised in the 2013 publication of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Specifiers are now included to enhance descriptive severity and sub-typing of this population with respect to the presence or absence of intellectual impairment, language impairment, catatonia, and known medical, genetic, or environmental factors. With these diagnostic features, approaches to treatment and long-term care for each person with autism can become more individualized. The development of a life care plan with projected needs for an individual with autism will enhance their quality of care and will serve as a basis for financial planning to ensure a safe, healthy and productive life.

Diagnostic Criteria, Treatment and Long-Term Considerations for the Individuals with Autism: Foundation for the Life Care Plan

The American Psychiatric Association (APA) has defined autism spectrum disorder as "a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication and restricted/repetitive behaviors" (APA, 2019, p.31). Although there is significant variability in the effects of ASD and in the severity of symptoms, there are also characteristic behavioral aspects which have been shown to improve with targeted treatments. In addition, persons diagnosed with ASD often have accompanying medical irregularities, such as gastrointestinal disorders, seizures, sleep disturbances, anxiety disorders and other comorbid mental health conditions. All medical and mental health concerns must be identified and addressed when developing a life care plan for an individual with autism.

History of Autism

Leo Kanner, M.D., first described autism in 1943. The Austrian-American psychiatrist reported of 11 children with an apparent inability to relate to other people as well as an over-sensitivity to change in the non-social environment. Their "powerful desire for aloneness" was in stark contrast to the profound social interest of a normal child. Dr. Kanner further observed language characteristics including echolalia, pronoun reversal, and concreteness among his study group. The children also exhibited unusual, repetitive or ritualistic movements now known as stereotypies (Kanner, 1943). Autism was originally thought to be a form of childhood psychosis. By the 1970s, evidence suggested that autism was a highly distinctive diagnosis, and by 1980, autism was officially recognized in the *DSM-III* (Volkmar & Klin, 2005).

For the *DSM-IV-TR* publication in 2000, the diagnosis of autism required deficits in the three domains of social relatedness, communication/play, and restricted interests and activities. The onset of symptoms must have occurred by 3 years of age (APA, 2000; Volkmar et al., 2014). The disturbance in social relatedness combined marked impairment in nonverbal communication, peer relationships, and social-emotional reciprocity. Disturbances in communication encompassed those who were verbal and non-verbal. Difficulties in sustaining or initiating conversation, or evidence of stereotyped or repetitive language were the hallmark features used when diagnosing verbal individuals. Additionally, the associated lack of developmentally appropriate make-believe or social play were required criteria. Other specifications included impairment in interests and activities with preoccupations and adherence to apparently nonfunctional routines or rituals, stereotypies and motor mannerisms, as well as persistent preoccupations with parts of objects.

The APA's *DSM-5* workgroup on neurodevelopmental disorders concluded that there was little evidence to support diagnostic differences among the various pervasive developmental disorders and autism. Prior categories were then absorbed into the new diagnosis of autism spectrum disorder for the *DMS-5* publication in 2013. The diagnostic domains were reduced from three to two, focusing on social communication and interaction deficits, and restricted, repetitive patterns of behaviors and interests. The strict requirement for onset before 3 years of age was changed to onset in the early developmental period, which may not become fully manifest until social demands have exceeded a

child's limited capacities. The "early developmental period" is approximated as age 8 and younger. It is also now recognized that symptoms may also be masked by learned strategies later in life (APA, 2013; Volkmar & Klin, 2014).

A severity scale for impairments in each of the two core domains is now included for ASD. This may allow for diagnostic reporting that could enhance descriptive subtyping of this population and provide significant value to the development of a life care plan. Additionally, there are specifiers for the presence or absence of intellectual impairment, language impairment, catatonia, and known medical, genetic, or environmental factors, all of which the life care plan may need to address. The new criteria also allow for a history of symptoms that may not be present at the current time, acknowledging that through intervention or during normal development, some children with autism may no longer demonstrate some symptoms later in life (APA, 2013; Volkmar & Klin, 2014). The changes in diagnostic criteria for ASD will likely have implications for the future study of autism prevalence and other aspects of autism assessment and treatment.

Prevalence of Autism in the United States

The Center for Disease Control and Prevention (CDC) published a surveillance summary in 2018 revealing the most recent prevalence data for ASD (Baio et al., 2018). According to the Autism and Developmental Disabilities Monitoring Network, it is estimated that autism currently affects approximately 1 in 59 children in the United States. Males are diagnosed with ASD about four times more frequently than females. Non-Hispanic white children are affected at a higher rate than non-Hispanic black children, and both groups are identified with ASD more often when compared to Hispanic children. The prevalence study reported that 31% of children with autism are classified as having intellectual disability (IQ < 70), 25% were in the borderline range (IQ 71-85) and 44% have IQ scores in the average to above average range (IQ > 85). The median age of ASD diagnosis was 52 months, which did not significantly differ among genders, race or ethnicities. Based upon this report, the CDC released a Public Health Action noting an increase in the prevalence of ASD in the United States from the previous reporting period. The organization highlighted the increased need for behavioral, educational, residential, and occupational services. as well as the need for increased research regarding the genetic and nongenetic risk factors for ASD.

Screening and Diagnosis of Autism

The CDC's surveillance study further revealed that fewer than half of children diagnosed with ASD were identified prior to 4 years of age. Although developmental concerns were documented in the medical record of 85% of children with ASD by 3 years of age, only 42% of these children underwent a comprehensive evaluation. Healthcare providers for children are considered on the forefront in identifying patients with ASD. The American Academy of Pediatrics (AAP) recommends that developmental surveillance occurs at each health supervision visit, and that developmental screening be administered at 9, 18, and 24 months with an autism-specific screening at 18 and 24 months of age (Council on Children with Disabilities [COCWD], 2006). The surveillance should include taking a developmental history, observing the child, identifying their strengths and risk factors, eliciting parental concerns and then communicating the results to the parents and other providers as indicated. The screening is completed by the parent using a standardized screening tool (Table 1) at the specific ages advocated by the AAP, or whenever the parent or healthcare provider has a concern. When surveillance and screening are performed together, early identification of children with ASD and other developmental disabilities has been shown to be greatly improved (CDC, 2019). Unfortunately, a recent study revealed that only 37% of children age 9-35 months were granted developmental surveillance, and 30% received developmental screening as recommended by the AAP. Research efforts have clearly supported that early intervention services significantly improve outcomes in children with ASD and other developmental disorders (Hiral, Kogan, Kandasamy, Reuland & Bethall, 2018; Howlin, 2005). Therefore, endeavors toward better ASD screening in the healthcare setting are indicated.

Table 1
Examples of Standardized Developmental Screening Tools

Ages and Stages Questionnaire (ASQ-3)
Denver Developmental Screening Test II (DDST-II)
Early Screening Inventory – Revised (ESI-R)
Parents' Evaluation of Developmental Status (PEDS)
Examples – Autism-Specific Screening Tool
Autism Behavior Checklist (ABC)
Modified Checklist for Autism in Toddlers Revised with Follow Up (M-CHAT-R/F)
Screening Tool for Autism in Toddlers and Young Children (STAT)

When a screening indicates a concern for an ASD diagnosis, the child should be referred for an evaluation by a specialist, and early intervention services should commence in the interim. Healthcare providers who typically administer this type of assessment include developmental pediatricians, pediatric neurologists, child psychologists or psychiatrists. The comprehensive diagnostic evaluation will include an interview of the parents, observation of the child's behavior and development, and a careful review of past records and historical information. Other services may be completed, including hearing and vision screening, genetic testing and

referral, neurological testing and referral, and other medical testing based upon findings on physical examination, especially if dysmorphic features or congenital anomalies are present. The specialist then utilizes specific diagnostic tools (Table 2) for definitive ASD identification (CDC, 2019).

Table 2
Examples of Diagnostic Tools for Autism Spectrum Disorder

Autism Diagnosis Interview – Revised (ADI-R)
Autism Diagnostic Observation Schedule – Generic (ADOS-G)
Childhood Autism Rating Scale (CARS)
Gilliam Autism Rating Scale – Second Edition (GARS-2)

Diagnostic Criteria

In addition to the use of the diagnostic tools, healthcare specialists refer to the *DMS-5* for standardized criteria to meet the diagnosis of ASD. As previously stated, these criteria are categorized according to deficits in social communication and interactions across multiple situations (currently or by history) not accounted for by general developmental delays, as well as restricted interests and repetitive behaviors. The restricted or repetitive patterns must be manifested by certain characteristics, such as stereotyped or repetitive speech or motor movements, an inflexible adherence to routines, highly restricted and fixated interests that are abnormal in intensity, and/or an either hyper- or hypo-reactivity to sensory input. Each category must also specify a severity level (APA, 2013). With this identified severity level, the life care planner can begin to shape the dynamic document for the individual with autism reflecting future needs and the associated costs for their medical and rehabilitative projections.

The *DMS-5* criteria for ASD also require that symptoms be present in the early developmental period and cause clinically significant impairment in social, occupational and other essential areas of functioning. The disturbances cannot be shown to be better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur. To make the comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for the general developmental level (APA, 2013). Currently, there are no reliable biomarkers to identify ASD, therefore the diagnosis of autism is made when the requisite *DSM-5* symptoms are present and when other disorders have been adequately excluded.

There are significant complexities in distinguishing ASD with other disorders of communication and cognitive impairment within the differential diagnoses, such as developmental language disorders, reactive attachment disorder, obsessive-compulsive disorder, and childhood schizophrenia. This is further complicated by the frequent presence of comorbid conditions with ASD. Most of the comorbidity studies have revealed increased rates of anxiety and attention deficit disorders (Leyfer et al., 2006). Ultimately, predictors of outcome of those affected by ASD have been shown to include the presence of communicative speech by 5 years of age and overall cognitive ability measured by IQ. However, it is again important to note that significant evidence exists recognizing that the early detection of ASD and onset of services correlate with a better long-term prognosis for the individual, making early diagnosis critical (Howlin, 2005).

Causation

Studies suggest that genetic factors contribute to the majority of ASD cases. However, other risk factors for the development of ASD have also been identified. Children born to older parents have a higher risk for being diagnosed with ASD (Durkin et al., 2008). Research has also delineated that the chance of having a second child affected with ASD for parents of a child with autism is more than 18% (Autism Speaks, 2019). Among identical twins, if one has ASD, the other twin will have a 50-70% chance of developing the disorder. For non-identical twins, if one is affected by autism, the other twin is affected approximately 31% of the time. The suggestion is that ASD results from a combination of both genetic and environmental influences (Autism Speaks, 2019; Hormozdiari, Dennis & LaSalle, 2018).

Seizure activity has been observed in as many as 25% of persons diagnosed with ASD, suggesting the presence of neurobiological factors in autism (Volkmar & Nelson, 1991). There have been a number of identified areas in the brains of those affected by autism, suggesting that a widely distributed group of neural pathways are likely altered. Postmortem studies have demonstrated various anomalies, most notably within the limbic system and cerebellum (Bauman & Kemper, 2005). Investigations using functional magnetic resonance imaging (MRI) have revealed abnormalities in the areas responsible for social and affective judgements as well as the processing of facial and non-facial motives (Schultz, 2005). Structural MRI studies have shown an increase in overall size of the brain, while diffusion tensor images have exposed defective development of white matter tracts (Wolff et al., 2012). An elevation in levels of the neurotransmitter serotonin has been reliably demonstrated in individuals with autism; however, the significance of this neurochemical finding is unclear. There has also been the suggestion that a dysregulation of dopamine may explain the overactivity and stereotyped mannerisms seen in ASD as well as the positive response to neuroleptic medications in ameliorating these behaviors (Anderson & Hoshino, 2005). Although there are no current decisive diagnostic biomarkers for ASD, a recent study has pointed to evidence that dysregulation of branch chain amino acids may contribute to the behavioral

characteristics of some sub-types of ASD (Smith et al., 2018). The authors concluded that identification of such metabotypes could lead to the development of metabolic tests that support early diagnosis and targeted therapeutic interventions for some with ASD.

Genetic and Environmental Associations

There are several known single-gene syndromes associated with autism, most notably Fragile X syndrome. This x-linked inherited genetic disorder is characterized by intellectual disability and physical features including a long, narrow face, large ears, flexible fingers and large testicles. About one-third of those affected by Fragile X syndrome are on the autism spectrum, and Fragile X syndrome cases account for 1-3% of ASD (Hormonzdiari, Dennis & LaSalle 2018). Further studies have revealed that hundreds of genes contribute to ASD, and copy number variations (CNV) testing is the most common procedure performed for children diagnosed with ASD, and other neurodevelopmental disorders. Copy number variations testing identifies a deletion or duplication genetic contributor (Hormozdiari, Dennis & LaSalle 2018).

Epigenetics is the study of factors that affect gene activity and expression, that is to say what turns genes "off and on". The research of epigenetic testing of ASD lags significantly behind genetic mutation investigations. One promising area under current epigenetic study is methylation testing. There have been commonly demonstrated methylation alterations in distinct genetic disorders and environmental exposures. One identified example is the overlapping set of genes that were hypomethylated either by the *UBE3A* duplication in Dup15q syndrome or by exposure to the persistent organic pollutant PCB 95 (Hollander, 2018). Methylation biomarkers could provide another diagnostic ASD tool in the future to identify infants for early intervention.

In recent years, there has been a focus on the measles-mumps-rubella vaccine and the mercury-containing preservative, thimerosal, as possible causative agents in the development of autism. Although scientific evidence has not supported either of these premises, a possible role of the immune system in some cases of autism has not been excluded (Pardo, Vargas & Zimmerman, 2005). Multiple studies have shown abnormalities in the peripheral immune system of individuals with autism, including an increase in activated B cells, natural killer cells, proinflammatory cytokines as well as T-cell dysfunction and autoantibody production (Chaste & Leboyer, 2012). Additional research has uncovered neuroglial activation that may have resulted from disturbances in prenatal or postnatal central nervous system development (Chaste & Leboyer, 2012).

A meta-analysis of the association between perinatal and neonatal factors and autism risk was published (Gardener, Spielegman & Buka, 2011). This revealed that abnormal presentation, umbilical cord complications, fetal distress, birth injury or trauma, multiple births, maternal hemorrhage, summer birth, low birth weight, small for gestational age, congenital malformation, low 5-minute Apgar score, feeding difficulties, meconium aspiration, neonatal anemia, ABO or Rh incompatibility, and hyperbilirubinemia were all found to be associated risk factors for ASD. The report emphasized that the various brain abnormalities found in those affected by ASD suggest that this "etiologically relevant period" extends from in utero through early infancy.

Treatment Planning Considerations

Life care planning represents a process of analyzing the health care goods and service needs of individuals with disabling conditions from injuries or chronic diseases. By definition, life care plans are based upon standards of practice, comprehensive assessment, data analysis and research that provides an organized and concise plan for projected future medical and medically related goods and services and associated costs (International Academy of Life Care Planners, 2003). Using the life care planning methodology, a systematic approach is applied to trace all of the needs relating from the disability to the end of life expectancy. This process often requires the coordination and management of information from many sources. Medical, social, psychological, vocational, educational and rehabilitation details are taken into consideration. The impact of aging with disability and progression of disease are reflected. The life care plan provides for services that are needed to prevent or significantly reduce known complications over time. The current cost data are utilized, representing the usual customary costs for goods and services in the geographic domain where the majority of care is anticipated. The life care plan serves as a guide for those with disability or chronic disease, their family members, case managers and health care providers. It is not a prescription for care but serves as a blueprint for anticipated health care and other related needs based upon reasonable medical and rehabilitation probability and current concepts of patient care management. The information aids those charged with the fiduciary responsibility to provide for future care. The life care plan can also be used by financial administrators tasked with selecting appropriate investment strategies to preserve funding over the life of the patient. This article serves as the author's intent, and the first attempt, to outline all of the needs and services for persons on the autistic spectrum that are currently recognized as evidence-based and relevant to the development of their life care plan.

Medical Treatment Considerations

Epilepsy is more prevalent in those affected by ASD. The presence of intellectual disability with ASD further increases the risk of developing seizure disorder. It has been found that up to 60% of children with ASD display abnormal electroencephalogram (EEG) findings. The decision to initiate anti-epileptic medication is determined by a

neurologist based upon the patient's history, EEG findings and risk for future seizures. Sleep disorders are present in up to 80% of children with ASD (Ligsay, Bain, Veenstra-Vanderweele & Hagerman, 2018). There are some randomized controlled trials supporting the use of melatonin in sleep-onset insomnia; however, less information is available for other medications or for specific behavioral approaches for sleep irregularities. Therefore, treating providers must utilize other common treatments when attempting to improve sleep problems in children with ASD (Ligsay et al., 2018).

The evidence is clear that children with ASD have more gastrointestinal problems (Chaidez, Hanson & Hertz-Picciotto, 2014). Children with autism in fact are about eight times more likely to experience one or more chronic gastrointestinal disorders than other children. Constipation occurs more frequently in ASD and may be severe. Treatment with common laxative medications are indicated with referral to a gastroenterologist for refractory cases. The abdominal pain associated with constipation in a non-verbal child with autism may manifest by self-injurious behavior, thus a high index for suspicion is warranted by the treating provider (Buie et al., 2010). Gastroesophageal reflux disease (GERD) also occurs more frequently in ASD, particularly in those who have associated intellectual disability. A referral for gastroenterological consideration should take place if histamine receptor blocking medications or protein pump inhibiting agents are ineffective, as an upper endoscopy may be important to distinguish a structural cause for the GERD and esophageal erosions. Food allergies have been shown to be more common in children with ASD, granting them a higher risk of developing eosinophilic esophagitis. Nutritional monitoring is imperative, as some with ASD have significant food selectivity, causing deficiencies in essential vitamins and minerals. Individuals with ASD may also develop obesity. Nearly a third of 2 to 5-year-old children with autism are overweight, and 16% are obese. In contrast, 23% of 2 to 5-year-olds in the general population are overweight and 10 % are considered medically obese (Hill, Zuckerman & Fomonne, 2015). This can be in association with certain genetic syndromes, such as 16p11.2 deletions, or an increase in appetite or impaired metabolism due to treating medications like risperidone and aripiprazole. Attempts at an increase in exercise may be difficult for youths with ASD (Ligsay, 2018).

Dental problems and decay more commonly affect those with ASD, feasibly due to the difficulty in allowing their teeth to be brushed and flossed. Therefore, routine dental examinations and cleanings should be scheduled every six months, ideally with a dentist who specializes in the treatment and behavioral techniques necessary for persons with autism. A dental issue should also be suspected as a source of discomfort for individuals with autism when signs of agitation and irritability are exhibited (Ligsay et al., 2018).

Behavioral Treatment Considerations

Behavioral abnormalities are commonly observed in individuals with ASD. These include attentional deficits and hyperactivity, aggression, self-injurious behaviors, obsessive-compulsive symptoms, stereotypies, and tics as well as affective symptoms such as lability, anxiety and depression (Leyfer et al., 2006). Numerous randomized controlled studies of medication use in children with ASD have been completed. Currently, only risperidone and aripiprazole have been approved by the Food and Drug Administration for the treatment of irritability, physical aggression, and severe tantrum behavior associated with ASD. The goal of pharmacological intervention in ASD is to improve the person's ability to benefit from behavioral treatments and educational activities while remaining in less restrictive environments (Volkmar et al., 2014).

Attention and hyperactivity disorders are frequently seen (30-61%) in conjunction with ASD and are listed as an additional diagnosis. The Research Units on Pediatric Psychopharmacology Autism Network (2005) found, in a large randomized controlled trial, that a subset of children with autism with elevated scores for hyperactivity had a 49% positive response rate to treatment with methylphenidate. An estimated 11-40 % of children and teens with ASD are also affected by anxiety disorders (Vasa et al., 2016). Schizophrenia has been observed in 4-35% of adults diagnosed with autism, in contrast to 1.1% of the general population (Chisholm, Lin, Abu-Akel & Wood, 2015). Recently, a 20-year study was published revealing that females with ASD were three times more likely to die from suicide as females without ASD (Kirby et al., 2019). Young individuals with autism had over twice the risk of suicide compared to their peers not affected by ASD.

Unfortunately, there is a lack of evidence for most forms of psychological intervention in ASD. One exception is the benefit of cognitive behavioral therapy for anxiety and anger management in higher functioning youths with ASD. Children with ASD are hospitalized in psychiatric units at much higher rates than children without ASD. There is some evidence for the efficacy of psychiatric hospital interventions, if the facility specializes in autism treatment (Volkmar et al., 2014).

There are many associated challenges with ASD. It is estimated that one-third of people with autism are non-verbal, although many are able to communicate with the help of visual supports and assisted-communication devices (Wodka, Mathy & Kalb, 2013). In one study, nearly 28% of 8-year-olds with ASD displayed self-injurious behaviors including head-banging, arm biting and skin scratching (Soke et al., 2016). Many children with autism have a unique fascination with water or other hazardous areas like active roadways or around trains. Nearly half of those affected with autism wander or bolt from safety, and drowning remains a leading cause for deaths of children age 14 and younger with ASD, and accounts for about 90% of deaths associated with

wandering or bolting. Parents should highly consider installing motion sensor alarms on doors and windows and/or acquiring a GPS locator for their child with autism to wear (Autism Speaks, 2019).

Applied behavioral analysis.

The practice of applied behavioral analysis (ABA) has evolved over the last several decades as an effective treatment for ASD. Using the principles of behavior to produce meaningful change, ABA has allowed individuals with ASD and other developmental disorders who previously were institutionalized and thought to be unable to learn, or live independent, productive lives within a community. Evidence-based research has shown that ABA procedures are helpful for increasing adaptive skills, social behavior, and self-help skills, as well as decreasing stereotypy and tantrums (MacDonald, Parry-Cruwys & Peterson, 2018). Many published studies note the importance of beginning treatment early, especially prior to 3 years of age, with the most significant gains when treatment is initiated before 24 months of age. Therefore, a "wait-and-see" approach is ill-advised when a clinician assesses a child for autism.

The core characteristics of ABA therapy include:

- An objective assessment and analysis of the client's condition by observing how the environment affects the client's behavior, as evidenced through appropriate data collection
- Importance given to understanding the context of the behavior and the behavior's value to the individual, the family, and the community
- Utilization of the principles and procedures of behavior analysis such that the client's health, independence, and quality of life are improved
- Consistent, ongoing, objective assessment and data analysis to inform clinical decision-making (Behavioral Analyst Certification Board [BACB], 2014)

The more commonly provided behavioral treatment procedures and models that incorporate ABA techniques are the Pivotal Response Treatment (PRT), the Early Start Denver Model (ESDM) and Verbal Behavior therapy. These treatment programs include varying degrees of "discrete trial instructions" (primarily provider-directed teaching in simplified and structured steps) and "naturalistic instruction" (providing choices to increase motivation to learn, primarily client-directed), and are also now focusing on establishing social relatedness (Autism Speaks, 2019). Other variations in treatment include the extent to which peers and parents are involved. If one ABA procedure or combination of ABA procedures does not provide the desired outcomes for the individual with autism, a different one is systematically implemented and then evaluated for its effectiveness (BACB, 2014).

In 2014, the Behavior Analyst Certification Board (BACB) published guidelines for ABA treatment, recommending that the intensity of therapy should range from 10-25 hours per week for focused treatment and 30-40 hours of 1:1 direct treatment per week for comprehensive treatment, based upon multiple variables including treatment goals, client needs, severity of deficits and client response to treatment. Focused ABA treatment may include more than 25 hours per week for severe destructive behavior, for example, in a day treatment or inpatient program for severe self-injurious behavior. Comprehensive ABA treatment hours are increased or decreased based upon the individual's response to treatment and current needs. An increase in hours may occur to reach a treatment goal and decreases in hours of therapy will occur when a majority of treatment goals have been met (BACB, 2014). The organization strongly urged that their recommendations are based on research findings regarding the intensity required to produce good outcomes and that gaps in therapy may result in individuals falling further behind, resulting in increased costs and greater dependence on more intensive services during the lifetime. Applied behavioral analysis therapy has been shown to be effective across the life span (BACB, 2014).

Most ABA treatment programs utilize a tiered service-delivery model in which a Board- Certified Behavior Analyst (with a master's or doctoral degree, training course and passage of a certifying exam) designs and supervises the treatment delivered by Assistant Behavior Analysts (with a bachelor's degree, training course, and passage of certifying exam) and Registered Behavior Technicians (with a high-school diploma/equivalent, 40-hour training program and passage of a RBT Competency Assessment). Tiered service-delivery models have been shown to provide significant improvements in the cognitive, language, social, behavioral, and adaptive domains of ASD in a cost-effective manner, particularly in service of rural and underserved areas (BACB, 2014).

Other Diagnostic and Therapeutic Considerations

An occupational therapy evaluation will establish a person with autism's ability to learn, play, care for themselves and interact with their environment. Continuing therapy sessions will focus on the participation in typical day-to-day activities, such as independent dressing, eating, grooming, toileting and fine motor skills like writing and cutting. Therapy strategies can also help manage sensory issues common in ASD (Abbeduto, Hess, Wilbarger & McDuffie, 2018). Specialized occupational therapists are sometimes needed to address feeding and swallowing deficits in those affected with ASD.

Speech-language assessments, including the measurements of expressive and receptive abilities and language use, are helpful in the determination of diagnosis and treatment planning for those with autism. Ongoing speech therapy may address strengthening the muscles in the

mouth, making clearer speech sounds, matching emotions with correct facial expressions, understanding body language, responding to questions and modulating the tone of voice (Volkmar et al., 2014). Some individuals with ASD find that using an alternative augmentative communication (AAC) device or method is more effective than speaking. Examples of the AAC used include sign language, iPads, speech output devices such as the Dynavox, and the picture exchange communication system (PECS). A speech therapist with specialized training in the use of augmentative communication can help identify an appropriate AAC method and provide the necessary training for the person with autism.

A psychological assessment is indicated for the individual with autism to determine cognitive ability and adaptive skills needed for treatment planning. Standardized tests of intelligence may show considerable scatter, as some children with ASD have unusual areas of ability ("splinter skills" or "savant skills"). Higher functioning children often present with a single-minded area of pursuit that may interfere with other learning endeavors. Psychological testing helps to clarify areas of strengths and weaknesses, to better design an intervention program for the child with autism. Valid testing instruments for non-verbal persons may be required (Volkmar et al., 2014).

Children with ASD need a structured educational plan with explicit teaching. An effective program must include experienced, interdisciplinary providers who incorporate family involvement. One evidence-based example is the Treatment and Education of Autism and related Communication Handicapped Children program (TEACCH) developed by the University of North Carolina (Volkmar et al., 2014). The availability of such programs being offered in a public-school setting varies significantly by state and school district. Most schools struggle to administer a meaningful educational program for students with ASD, as the teaching must be provided by specifically-trained special education teachers, speech therapists and/or occupational therapists. It should always be noted that the public educational system under the Individuals with Disabilities Education Act (IDEA) only grants what is educationally relevant for a child with disabilities to learn in the current environment of the individualized education plan. Therefore, functional restoration and general habilitation of children with neurocognitive and neurobehavioral disorders like ASD are considered beyond the school's mandate or scope of service requirements. In the current educational environment, additional therapeutic services are likely to be required for many children with autism outside of the school for best outcomes. Numerous dedicated private schools and treatment centers for children and adolescents with ASD operate throughout the United States with proven success. Unfortunately, the costs for such educational opportunities are elusive for most parents.

Complementary, Integrative and Future Treatments

Many biomedical therapies have been investigated for the treatment of ASD symptoms, but published evidence supports a limited number of them. To date, these treatments include melatonin, omega-3 fatty acids, injectable methylcobalamin (methyl B12), N-acetylcysteine, pancreatic digestive enzymes, probiotics, micronutrients, and immune therapies (IVIG) for some individuals with autism (Hendren, Widjaja & Lawton, 2018).

Those with access to music, art and animal therapies have reportedly demonstrated improvements in autism symptomatology. Music therapy supports speech development and language comprehension. Songs have been used to teach language and can increase an individual with autism's ability to put words together. Art therapy provides an effective nonverbal and symbolic way for an person with autism to express themselves and develop improved fine motor skills. Animal therapy for ASD might include working with dogs, horseback riding or swimming with dolphins. All of these animals have been thought to provide soothing sensory stimulation to this group, which offers the basis for future study to learn about behavior and communication. Therapeutic hippotherapy programs can improve coordination and motor development, create a sense of well-being and increased self-confidence for Individuals with Autisms. Dolphin therapy was described in the 1970's by psychologist David Nathanson, who believed that interactions with dolphins could improve a child with autism's attention and cognition. As conducted research is sparse for all these therapies, parents must judge these treatment options based upon anecdotal results (Autism Society, 2019b).

Repetitive transcranial magnetic stimulation has been shown to be a valid treatment for ASD in a small number of trials (CPT coding 90867-90869). The study findings thus far have included improvements in neuropsychological performance and a reduction in the core symptoms and associated features of autism. Larger, randomized controlled trials are warranted for this potential biomedical treatment for autism treatment (Enticott, 2018).

Clinical trials are currently underway investigating the use of stem cells in treating autism. Stem cell therapy from umbilical cord blood have been shown to help reduce inflammation and signal cells to help repair damaged areas of the brain (Siniscalco et al., 2018). Researchers from Duke University conducted a clinical trial using autologous umbilical cord blood infusions for 25 children with a confirmed diagnosis of ASD. There were significant improvements observed in social communication skills and autism symptoms by parent-reports, and clinician ratings showed overall improvements in autism symptom severity and degree. Standardized measures also revealed better expressive vocabulary and objective eye-tracking of the children's attention to social stimuli. The outcome data will serve as a basis for future study in this promising area of

research (Dawson et al., 2017).

Life Care Plan Costing Considerations

The American Medical Association's Current Procedural Terminology (CPT) codes are used by doctors and health care professionals as a uniform language for coding medical services and procedures. Because CPT codes are used for claims processing, they are helpful to the life care planner in determination of costs for medical, surgical, radiology, anesthesiology and laboratory procedures, as well as evaluation and management services. The CPT coding uniquely relevant in the medical and behavioral treatment of autism spectrum disorder are listed in Table 3. Codes established by the American Medical Association (2019) provide recognition that effectiveness of ABA therapy has been supported by research and is a medically necessary intervention. Autism insurance legislation is currently in place in 45 states requiring coverage for ABA services. As available services and service needs vary widely for each person with autism, contact with treating ABA providers and vendors will likely be required for the purpose of developing a life care plan.

Table 3

Autism-Related CPT Codes

Developmental Screening	**CPT 96110**
Developmental Testing	**CPT 96111**
Neurobehavioral Status Examination	**CPT 96116**
(May also be billed in conjunction with the appropriate E/M consultative and/or prolonged physician service codes and can be reported in multiple units for the same-day service.)	
Applied Behavioral Analysis (ABA)	**CPT 97151 – 97158**
(According to the Association for Behavior Analysis International (2018), new CPT coding for ABA therapy went into effect on January 1, 2019. Previous CPT codes and many of the HCPCS codes have been replaced using codes 97151 – 97158. Some of the technician codes remain in place (i.e. 0362T, 0373T) but the descriptors have changed)	
Repetitive Transcranial Magnetic Stimulation	**CPT 90867 –90869**

Long Term Care Planning Considerations

Transition from the more parent-supervised healthcare system in adolescence to the patient-centered adult care setting is challenging for persons on the autistic spectrum. The American Academy of Pediatrics published a clinical report in 2018 revealing that most youth and young adults with special health needs and families do not receive the support they need in the transition from pediatric to adult health care (White & Cooley, 2018). In addition, it has been estimated that 50,000 teens per year with autism will enter adulthood and age out of school-based autism services over the next decade. In fact, teens with autism have been estimated to receive transition services half as often as others with special healthcare needs. If the individual with autism has associated medical disorders, they are even less likely to receive transition support (Cheak-Zamora, Yang, Farmer & Clark, 2013).

Services for adults with autism must be tailored, ideally during the transition years after formal secondary education. In 2014, the National Standards for Systems of Care for Children and Youth with Special Health Care Needs was published as a framework for states to implement as part of Title V action plans and strategies (Association of Maternal & Child Health Programs and National Academy for State Health Policy, 2017). The Standards provide for multiple services for children with disabilities, including eligibility and enrollment in health coverage, access to care, medical home management, community-based services and supports including respite care and home-based services, and ultimate transition to adulthood. As states begin to successfully implement these Standards, life care planners will be able to utilize the individual with autism's service plan to adequately project future medical and rehabilitative needs, and guide those who have fiduciary responsibility for their future care.

It has been reported that more than half of young adults on the autism spectrum are unemployed in the two years after high school, and nearly half of 25-year-olds with autism have never held a paying job (Shattuck et al., 2012). These statistics reveal lower rates of employment compared to young adults in other disability categories. A 2015 study showed that only 60% of individuals with autism who attended state-funded vocational programs were able to attain jobs, and 80% worked part-time at incomes putting them well below the poverty level (Chen & Sukyeong, 2015). Employment activities strengthen independence and have clearly demonstrated an increase in daily activity skills and a reduction in autism symptoms for this group (Taylor, Smith & Mailick, 2014).

Many have warned of an "autism epidemic" that is rapidly approaching adulthood. Families with members with autism are facing an ill-prepared and underfunded adult service system charged with meeting their needs. It is estimated that a majority of individuals with ASD will require some type of residential service or support. This might be for a limited time for some, but for others it may be appropriate for a life time. Unfortunately, residential services are in extremely short supply for adults with autism. There are exceptional adult day programs and employment-related programs available in every state; however, they tend to be difficult to find and lack availability (Gerhardt & Lainer, 2010). Vendor surveys for all of these services will present a challenge for a life care planner.

In 2015, a study estimated that the annual cost of caring for Americans with autism was $268 billion. Without more effective interventions and support across the lives of individuals with autism, the cost will rise to a predicted $461 billion by 2025 (Leigh & Du, 2015). A joint study of the costs of autism in the United States and the United Kingdom in 2014 found that ASD is the fourth most expensive condition in both countries, behind trauma, cancer and

cardiovascular disease (Buescher, Cidav, Knapp & Mandell, 2014). The largest costs identified for children were special education services and parental productivity loss. The highest costs in adulthood were related to residential care or supportive living accommodations and individual productivity loss. The medical costs for adults were substantially higher than for children.

The Combating Autism Act was signed into law in 2006 to provide a coordinated federal response to the dramatically rising numbers of individuals diagnosed with ASD. The law was reauthorized in 2014 as the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act. The bipartisan bill was passed unanimously in the House and Senate, focusing on transition services for students with disabilities. The law is due for reauthorization by September of 2019. Recommendations for improvements to the law by it's sponsors include addressing the pressing needs of individuals with ASD across the lifespan, including better health care, education, employment, and home and community-based services and supports. It is encouraged that more individuals on the autism spectrum participate on the Interagency Autism Coordinating Committee (Autism Society, 2019a).

Conclusion

Due to the heterogeneity of the effects and comorbidities for individuals on the autism spectrum, life care planning is and will be challenging. The results of the diagnostic testing for ASD will be useful in the development of the life care plan, as specifiers identify the severity of symptoms and comorbid conditions. Life care planners must be aware of all of the individual with autism's medical and mental health disorders to adequately project future diagnostic, treatment, and long-term care needs. Applied behavioral analysis therapy has emerged as an effective behavioral intervention for ASD and should be instituted as soon as possible for best outcomes. Applied behavioral analysis techniques have also been shown to be useful throughout the lifespan. Occupational therapy and speech therapy are often adjuvants to therapeutic treatment. Augmentative communication devices are helpful for many non-verbal individuals with autism. Other related approaches, such as music therapy, art therapy and animal therapy, as well as complementary biomedical treatments should also be considered on an individual basis. Many other current investigations are showing promise in the treatment of ASD, including repetitive transcranial magnetic stimulation and stem cell therapy. Future genetic and immunological research efforts surrounding diagnostic biomarkers, methylation alterations and immune dysfunction hope to reveal targeted therapeutic interventions for individuals with autism. Perhaps the most difficult projection for those on the autism spectrum will be for their long-term care, including provisions for education, employment, residential care and other community-based activities. A life care plan for the person with autism spectrum disorder will undoubtedly enhance their quality of care and serve as a basis for financial planning to ensure a safe, healthy and productive life.

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Author's note: Please direct all communication about this manuscript to:

Dr. Krisi Bagnell
Rehabilitation Professional Consultants
Consulting Physician, Certified Life Care Planner
16023 Via Shavano
San Antonio, TX. 78249
(210) 615-7772
Email: kristibagnellmd@gmail.com