

Cognitive Behavioral Intervention Package

Cognitive behavioral therapy has long been an evidence-based intervention for individuals diagnosed with anxiety disorders and depressive disorders (i.e., without ASD). There are manualized cognitive behavioral intervention programs that have been modified for youth and adolescents with ASD. These modifications can take different forms but usually involve making adjustments to materials (e.g., adding visual cues, role-play) or the structure of sessions. There are also cognitive behavioral intervention programs developed and individualized for specific purposes (e.g., to address anger management). Cognitive behavioral interventions often include several commonly used strategies that include:

- An educational component describing feelings/emotions, physical responses to emotions, and prevalence of individuals with similar challenges.
- A cognitive restructuring component in which the therapist assists the individual to modify cognitive distortions such as “all-or-nothing” thinking or “catastrophizing.”
- Development of scale to identify anxiety or distress. Some scales take the form of a thermometer, a ladder, or “volume control.”
- Homework assignments. Individuals are expected to work on skills in the home, school, and community setting. There may be a specific assignment that requires some type of recording of behavior or observations.
- Parent sessions. Cognitive behavioral interventions often take place for 45 minutes to one hour per week for a specified number of weeks (e.g., 16 weeks). During that time, there are often “parent sessions” in which the parents and therapist meet to discuss progress and strategies to support the individual with ASD.

Some of the manualized cognitive behavioral intervention packages modified in studies reviewed in the NSP2 included The Coping Cat Program and Exploring Feelings.

Comprehensive Behavioral Treatment for Young Children (CBTYC)

CBTYC programs involve intensive early behavioral interventions that target a range of essential skills that are associated with ASD (e.g., communication, social, and pre-academic/academic skills, etc.). These interventions are often described as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), or behavioral inclusive programs.

Applied Behavior Analysis (ABA)

In his mental health report for children, the U.S. Surgeon General recognized applied behavior analysis (ABA) as the intervention of choice for ASD (Rosenwasser & Axelrod, 2001). ABA, also called behavioral intervention or behavioral treatment, has consistently been recognized as one of the most well-researched and effective intervention techniques for children—especially young children—with ASD (Lovaas, 1987; Dawson & Osterling, 1997; Rogers, 1998; Smith, Groen, & Wynn, 2004). According to Green (1996), ABA can be used effectively to produce comprehensive and lasting improvements in many important skill areas for most children with ASD, regardless of their age. ABA, however, is most beneficial when intervention starts before three years of age (Dawson & Osterling; Lovaas & Smith, 2003) and the child undergoes intensive behavior therapy at least 15 hours a week (Dawson & Osterling).

Language Training (Production)

Language training (production) targets the ability of the individual with ASD to communicate verbally (i.e., functional use of spoken words). Language training (production) has recently been moved from the “What Seems to Work” to the “What Works” category. It makes use of various strategies to elicit verbal

communication from individuals with ASD and begins with appropriate assessment and identification of developmentally appropriate targets. Individualized programs often include strategies such as:

- Modeling verbalizations for the individual with ASD to imitate;
- Various prompting procedures including verbal, visual, and gestural prompts;
- Cue-Pause-Point;
- Using music as part of language training; and
- Reinforcement for display of targeted verbal response.

Modeling

The goal of modeling is to correctly demonstrate a target behavior to encourage imitation. Children can learn a great deal from observing the behavior of parents, siblings, peers, and teachers, but they often need to be taught which behaviors should be imitated. There are two types of modeling: live and video modeling. Live modeling occurs when a person demonstrates the target behavior in the presence of the child. Video modeling occurs when the target behavior is pre-recorded. Video modeling can be a great option for children and adolescents who have an affinity for television shows and movies, or who have an interest in seeing themselves on a monitor. Some children and adolescents may enjoy assisting in the production of the video.

Naturalistic Teaching Strategies (NTS)

NTS are a compilation of strategies that are used to teach children skills in their home, school, and community. The basic concepts include using materials in the environment and naturally occurring activities as opportunities to increase adaptive skills. These strategies are primarily child-directed.

Parent Training Package

The parent training package category is an addition to the interventions discussed in the Phase 1 report. Parent training package focuses on the elements of the interventions used in studies in which parents acted as therapists or received training to implement various strategies. This intervention acknowledges the critical role that parents and caregivers play in providing a therapeutic environment for their family members with ASD.

Peer Training Package

Difficulty interacting appropriately with peers is a commonly reported characteristic of ASD, and children with ASD often rely on adults for prompting and guidance. Peer training packages facilitate skill growth for children with ASD by training peers on how to initiate and respond during social interactions with the child with ASD. These programs have been used in school and community settings.

Learning Experience: An Alternative Program (LEAP)

LEAP is a peer-based educational program that embraces the educational and therapeutic value of peer-mediated interventions (Kohler et al., 2005). According to Campbell et al. (2008), LEAP provides classroom instruction, parent education (as needed), and the provision of speech and occupational therapy and other services within the classroom. The range of activities varies from quiet to active, from small group to larger group, and from child- versus teacher-directed. LEAP instruction is data-driven, individualized, and focused on generalizing learning skills through saturation of learning opportunities throughout the day. Family involvement is highly encouraged in this model and entails providing classroom support and instruction. In addition, families are asked to participate in curriculum development for the teaching of core behavioral principles that increase desirable behaviors and decrease maladaptive behaviors. Peers are also actively involved in the curriculum as intervention agents. According to Campbell et al., through the use of the LEAP

curriculum, children with ASD have shown decreases in ASD symptoms and long-term improvements in educational, cognitive, developmental, and social domains (Hoyson, Jamieson, & Strain, 1984; Strain & Hoyson, 2000).

Pivotal Response Training (PRT)

PRT focuses on targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues. Key to the delivery of PRT is parent involvement and implementation in the natural environment such as the home, community, and school setting. The development of PRT in part has resulted from findings from the DTT literature (Campbell et al., 2008). PRT is based on the theory that, if improvements in functioning can be achieved in the areas that are most disabling to children (i.e., pivotal areas), then effects should extend to other areas (Campbell et al.). Pivotal areas of intervention in PRT include teaching children to respond to multiple environmental cues and increasing motivation, capacity for self-management, and self-initiations. PRT has gained increasing evidence-based support in recent years (Campbell et al.; Sherer & Schreibman, 2005) and is now considered one of the more effective and proven interventions for children with ASD.

Schedules

Schedules can be used for children with ASD to increase their independence and allow them to plan for upcoming activities. A schedule simply identifies the activities that must be completed during a given time period and the order in which these activities should be completed. Children with ASD may better handle transitions when they can predict what will happen next. This can be accomplished through the use of schedules. Schedules can be used anywhere — at home, in classrooms, during doctors' visits, or on community outings. Schedules also can be used for any activity — including leisure time, social interaction, self-care, and housekeeping tasks. It is important for children and adolescents to possess prerequisite skills of picture identification (when using pictures) or reading (when using words/phrases) when considering use of schedules.

Scripting

Scripting occurs when a youth with ASD is provided guidance as to how to use language to initiate or respond in certain situations. These interventions involve developing an oral and/or written script about a specific skill or situation that serves as a model for the child. Scripts are usually practiced repeatedly before the skill is used in the actual situation. Scripting has recently been established as an effective treatment (What Works).

Self-Management

Self-management strategies have been widely used to promote independence with tasks in which adult supervision is not needed, accepted, or expected. The process can involve teaching youth with ASD to evaluate and record their performance while completing an activity. Self-management is also used to help these individuals monitor social behaviors and disruptive behaviors. These strategies involve teaching individuals to gain access to preferred items/activities for a job well done.

Social Skills Package

Social skills refer to a wide range of abilities, such as making eye contact appropriately, using gestures, reciprocating information, and initiating or ending an interaction. The challenges individuals with ASD face regarding social skills vary greatly. The general goal of any social skills package intervention is to provide individuals with the skills necessary to participate meaningfully in social environments.

Story-based Intervention

Story-based interventions identify a target behavior and involve a written description of the situations under which specific behaviors are expected to occur. Most stories aim to increase perspective taking skills and are written from an “I” or “some people” perspective. The most well-known story-based intervention is Social Stories.

What Seems to Work

As outlined in the National Standards Project, emerging interventions (What Seems to Work) are those interventions for which one or more studies suggest they may produce favorable outcomes but additional high quality studies are needed to consistently show these interventions are effective (National Autism Center, 2015). The National Standards Project identified 18 such treatments. Based on the available evidence, these treatments should be considered by a decision-making team if treatments classified as effective (What Works) are unsuccessful in producing positive outcomes.

As outlined by the National Standards Project, research findings have shown that the following practices have emerging support (What Seems to Work) for treating ASD.

Augmentative and Alternative Communication Devices

Augmentative and alternative communication is any form of communication that individuals use if they are unable or unwilling to use standard forms of communication such as speech (Research Autism, 2015). Augmentative communication systems are designed to complement and/or enhance standard means of communication. Examples include, but are not restricted to, pictures, photographs, symbols, communication books, and computers or other electronic devices (National Autism Center, 2009).

Developmental Relationship-based Treatment

These treatments involve a combination of procedures that are based on developmental theory and emphasize the importance of building social relationships. These treatments may be delivered in a variety of settings (e.g., home, classroom, community). All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals available, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (National Autism Center, 2009). These treatment programs may be referred to by other names such as floor time, DIR (differential, individual differences, relationship-based), or relationship development intervention (RDI). Floor time has become a popular intervention among parents, but it continues to lack scientific evidence (Lindgren & Doobay, 2011). Accordingly, floor time is listed in the Unproven Practice section.

Exercise

These interventions involve an increase in physical exertion as a means of reducing problems behaviors or increasing appropriate behavior (National Autism Center, 2009).

Exposure Package

These interventions require that the individual with ASD increasingly face anxiety-provoking situations. At the same time the use of maladaptive strategies used in the past is prevented (National Autism Center, 2009). Exposure treatment involves exposing youth to the non-dangerous situations that they fear, with a focus on having them learn that their anxiety will decrease over time.

Functional Communication Training (FCT)

FCT is a behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication (Lindgren & Doobay, 2011). After the communicative functions of disruptive behaviors are determined through functional behavioral analysis, socially appropriate behaviors are taught as replacements for problem behaviors. FCT has been shown to significantly reduce problem behavior and to increase communication and social interaction. This intervention is very effective with young children with limited cognitive and language skills, but it can be used with individuals of all ages. When delivered through weekly training sessions with parents and their children, FCT can be a very effective and efficient intervention strategy for reducing problem behavior and increasing communication and social behavior (Lindgren & Doobay).

Imitation-based Intervention

These interventions rely on adults imitating the actions of a child (National Autism Center, 2009).

Initiation Training

These interventions involve directly teaching individuals with ASD to initiate interactions with their peers (National Autism Center, 2009).

Language Training (Production & Understanding)

These interventions have as their primary goals to increase both speech production and understanding of communicative acts. Examples include total communication training, position object training, position self-training, and language programming strategies (National Autism Center, 2009).

Massage Therapy

This intervention involves the provision of deep tissue stimulation (National Autism Center, 2009).

Multi-component Package

These interventions involve a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations. These treatments do not better fit one of the other treatment packages discussed in this section nor are they associated with specific treatment programs (National Autism Center, 2009).

Music Therapy

These interventions seek to teach individual skills or goals through music. A targeted skill (e.g., counting, learning colors, taking turns, etc.) is first presented through song or rhythmic cuing and music is eventually faded (National Autism Center, 2009).

Picture Exchange Communication System

This treatment involves the application of a specific augmentative and alternative communication system based on behavioral principles that are designed to teach functional communication to children with limited verbal and/or communication skills (National Autism Center, 2009).

Reductive Package

These interventions rely on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors. Examples include water mist, behavior chain interruption (without attempting to increase an appropriate behavior), protective equipment, and ammonia (National Autism Center, 2009).

Sign Instruction

These interventions involve the direct teaching of sign language as a means of communicating with other individuals in the environment (National Autism Center, 2009).

Social Communication Intervention

These psychosocial interventions involve targeting some combination of social communication impairments (such as pragmatic communication skills, or the inability to successfully read social situations). These treatments may also be referred to as social pragmatic interventions (National Autism Center, 2009).

Structured Teaching

This intervention involves a combination of procedures that rely heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods. These procedures assume that that modifications can make thinking, learning, and understanding easier for people with ASD if they are adapted to individual learning styles of autism and individual learning characteristics. All of the studies falling into this category met the strict criteria of (a) targeting the defining symptoms of ASD, (b) having treatment manuals, (c) providing treatment with a high degree of intensity, and (d) measuring the overall effectiveness of the program (e.g., conducting studies that measure subcomponents of the program). These treatment programs may also be referred to as TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children) (National Autism Center, 2009).

Technology-based Intervention

These interventions require the presentation of instructional materials using the medium of computers or related technologies. Examples include Alpha Program, Delta Messages, the Emotion Trainer Computer Program, or use of a pager, a robot, or a PDA (Personal Digital Assistant) or other hand-held mobile device. The theories behind technology-based treatments may vary but they are unique in their use of technology (National Autism Center, 2009).

Theory of Mind Training

This training is designed to teach individuals with ASD to recognize and identify mental states in oneself or in others and to be able to take the perspective of another person in order to predict their actions (National Autism Center, 2009).

Pharmacological Interventions

Although pharmacological interventions cannot cure ASD, they may be considered for challenges such as aggression, self-injurious behavior, repetitive behaviors, sleep disturbance, anxiety, hyperactivity, inattention, destructive behavior, or other maladaptive behaviors (Myers, Johnson & the Council on Children with Disabilities, 2007). Pharmacologic interventions may increase the ability of youth with ASD to benefit from educational and other interventions and to remain in a less restrictive environment through the management of severe and challenging behaviors (Volkmar et al., 2014). After treatable medical causes and environmental factors have been ruled out, medication may be considered when behavioral symptoms cause significant impairment in functioning. It is important to note that these drugs do not alter or improve core ASD characteristics.

Antipsychotics (e.g., risperidone), selective serotonin reuptake inhibitors (SSRIs), and stimulants have been tested in different clinical studies with some proven benefits (Lindgren & Doobay, 2011). Antipsychotics such as risperidone and aripiprazole have been approved by the Food and Drug Administration for the treatment of irritability, consisting primarily of physical aggression and severe

tantrum behavior, associated with ASD (Volkmar et al., 2014). As noted in the updated AACAP Practice Parameter, the combination of medication with parent training is moderately more efficacious than medication alone for decreasing serious behavioral disturbances, and modestly more efficacious for adaptive functioning (Volkmar et al.). However, evidence also supports significant adverse effects of these medications (McPheeters et al., 2011). More rigorous, controlled studies are called for to establish the evidence-base of intervention efficacy (Myers, Johnson, & the Council on Children with Disabilities, 2007). Youth with ASD may be nonverbal, so treatment response is often judged by caregiver report and observation of specific behaviors (Volkmar et al.).

A recent study revealed that almost one in ten youth treated with antipsychotic medications were diagnosed with ASD and/or intellectual disability, and one in six youth with ASD received antipsychotics (Part et al., 2016). The study noted that both proportions increased in later years. This study also reiterated that the side effects of antipsychotics could be quite problematic, especially in children and adolescents. The researchers stated that clinicians should carefully assess the benefits and the risks prior to starting youth with ASD or intellectual disability on an antipsychotic, and that they should attempt to maximize non-pharmacologic interventions for comorbid disorders. Based on the study results and the known adverse effects of antipsychotics, the authors concluded that clinicians should consider using psychosocial interventions that are proven to be effective for behavioral dysregulation such as irritability and aggression before prescribing antipsychotics to adolescents with ASD or intellectual disability. The authors further stressed that, because outcomes of antipsychotic use in youth with ASD and/or intellectual disability require further study, it is imperative to regularly monitor both their efficacy and tolerability (Part et al.).

Unproven Practices

The following are complementary and alternative intervention approaches for which there is conflicting data on their effectiveness (National Autism Center, 2015).

- Animal-assisted therapy
- Auditory Integration Training
- Concept mapping
- DIR/Floor time
- Gluten-free and/or casein-free diet
- Facilitated communication
- Movement-based intervention
- Sensory integration
- Shock therapy
- Social-behavioral learning strategy (e.g., SODA)
- Social cognition/social thinking intervention program
- Holding therapy (Ennis-Cole, Durodoye, & Harris, 2013)

Table 6
Summary of Interventions for ASD

What Works	
Behavioral interventions	Includes antecedent interventions and consequent interventions.
Discrete trial teaching or training (DTT)	A type of behavioral intervention that uses operant learning techniques to change behavior. Also known as the ABC model (action request, behavior, consequence).
Cognitive behavioral intervention package	CBT modified for ASD youth
Comprehensive behavioral treatment for young children (CBTYC)	Also known as applied behavior analysis (ABA), early intensive behavioral intervention (EIBI), and behavioral inclusive programs.
Language training (production)	Targets the ability to communicate verbally
Modeling	Involves demonstrating a target behavior to encourage imitation
Naturalistic teaching strategies (NTS)	Child-directed strategies that use naturally occurring activities to increase adaptive skills
Parent training package	Involves training parents to act as therapists
Peer training package	Involves training peers on how to behavior during social interactions with a youth with ASD
Learning experience: An alternative program (LEAP)	A type of peer training program for peers, teachers, parents, and others
Pivotal response training (PRI)	Involves targeting pivotal behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues
Schedules	Used to increase independence in youth with ASD
Scripting	Providing scripted language to be used as a model in specific situations
Self-management	Strategies that involve teaching youth to track performance while completing an activity
Social skills package	Aims to provide youth with the skills (such as making eye contact appropriately) necessary to participate in social environments
Story-based intervention	Use stories to increase perspective taking skills

Table 6 (continued)
Summary of Interventions for ASD

What Seems to Work	
Augmentative and alternative communication devices	Communication systems designed to complement speech (pictures, symbols, etc.)
Developmental relationship-based treatment	Programs that emphasize the importance of building social relationships by using the principals of developmental theory
Exercise	Uses physical exertion to regulate behavior
Exposure package	Requires youth to face anxiety-provoking situations
Functional communication training (fct)	Behavioral method that replaces disruptive or inappropriate behavior with more appropriate and effective communication
Imitation-based intervention	Relies on adults imitating the actions of a child
Initiation training	Involves directly teaching individuals with ASD to initiate interactions with their peers
Language training (production and understanding)	Aims to increase both speech production and understanding of communicative acts.
Massage therapy	Involves the provision of deep tissue stimulation
Multi-component package	Involves a combination of multiple treatment procedures that are derived from different fields of interest or different theoretical orientations.
Music therapy	Aims to teach individual skills or goals through music
Picture exchange communication system	Involves the application of a specific augmentative and alternative communication system for youth with limited communication skills
Reductive package	Relies on strategies designed to reduce problem behaviors without increasing alternative appropriate behaviors
Sign instruction	Teaches sign language as a means of communicating
Social communication intervention	Targets some combination of social communication impairments
Structured teaching	Relies heavily on the physical organization of setting, predictable schedules, and individualized use of teaching methods
Technology-based intervention	Presents instructional materials using the medium of computers or related technologies
Theory of mind training	Aims to teach youth to recognize and identify the mental states of others

Table 6 (continued)
Summary of Interventions for ASD

Not Adequately Tested
<ul style="list-style-type: none"> • Animal-assisted therapy (e.g., hippotherapy: the use of horseback riding as a therapeutic or rehabilitative treatment) • Auditory integration training • Concept mapping • DIR/Floor time • Gluten-free and/or casein-free diet • Facilitated communication • Movement-based intervention • Sensory integration • Shock therapy • Social-behavioral learning strategy (e.g., SODA) • Social cognition/social thinking Intervention program • Holding therapy

Vaccines and Autism

Concern has been expressed during the past decade about vaccines and their role in the development of ASD. It was theorized that a link might exist between ASD and the use of thimerosal, a mercury-based preservative once used in the measles-mumps-rubella (MMR) vaccine (National Institute of Mental Health [NIMH], 2007). Although mercury is no longer used in childhood vaccines in the United States, some parents expressed concerns about vaccinations (NIMH). In May 2004, the Institute of Medicine (IOM) released a report that stated that thimerosal had no causal relationship with the development of ASD (NIMH).

In 2008, in response to persisting public concerns, the CDC commenced a study on thimerosal and ASD using data obtained from managed care organizations in the U.S. to determine whether exposure to thimerosal in infancy was related to ASD. The study's goal was to provide the best available scientific information about whether there is a causal association between exposure to thimerosal and the development of ASD. Study findings showed that prenatal and infant exposure to vaccines containing thimerosal did not increase risk for ASD (Price et al., 2010). Researchers also noted that these results applied to both boys and girls. The outcome noted by the CDC was that thimerosal-containing immunizations did not increase the risk of any of the ASD outcomes (Price et al.). The recommended vaccination course for all children continues to be two doses of MMR vaccine (CDC, 2007).

Under the National Childhood Vaccine Injury Act of 1986, Congress established the National Vaccine Injury Compensation Program (VICP) to provide compensation to people injured by vaccines (Institute of Medicine [IOM], 2011). The Health Resources and Services Administration (HRSA) asked the IOM to review a list of adverse events associated with eight of the 12 vaccines covered by VICP and to evaluate the scientific evidence about the event. The vaccines were those recommended by the CDC for routine administration in children and included the MMR vaccine (IOM). An analysis of more than 1,000 research articles concluded that few health problems were caused by, or clearly associated with, these vaccines (IOM). The report also asserted there was no link between immunizations and serious conditions that have raised concerns, including Type 1 diabetes and ASD (IOM). The data were inadequate to reach conclusions about other suggested adverse effects.

A 2013 CDC study added to the research asserting vaccines do not cause ASD. The study examined the number of antigens (substances in vaccines that cause the body's immune system to produce disease-fighting antibodies) from vaccines during the first two years of life. The results showed that the total amount of antigen from vaccines received was the same between children with ASD and those that did not have ASD (DeStefano, Price, & Weintraub, 2013).

A study published in 2015 also found that receipt of the MMR vaccine was not associated with increased risk of ASD, regardless of whether older siblings had ASD (Marshall et al., 2015). Study participants included children continuously enrolled in a health plan from birth to at least five years of age from 2001 to 2012 who also had an older sibling continuously enrolled for at least six months between 1997 and 2012. These findings indicate no harmful association between MMR vaccine receipt and ASD, even among children already at higher risk for ASD (Marshall et al.).

Activities in Virginia

In recent years, Virginia has responded to rising concerns about the Commonwealth's ability to provide high quality services to children diagnosed with ASD. In 2006, the Virginia Department of Behavioral Health and Developmental Services (VDBHDS), formerly the Department of Mental Health, Mental Retardation and Substance Abuse Services, convened a workgroup to assess how to best provide a coordinated response to educating and treating individuals with ASD. In 2007 the workgroup developed recommendations to address services and supports, including one to establish a central agency for ASD.

In 2007, the Joint Commission on Health Care (JCHC) convened the Workgroup Regarding the Commonwealth's Ability to Serve Children and Adults with Autistic Spectrum Disorder (ASD). The workgroup's objective was to recommend a primary agency for developing, coordinating, and overseeing autism services. This agency, as envisioned, would serve as the primary entity to oversee the provision of services for individuals diagnosed with ASD. The JCHC recommended having the Secretary of Health and Human Resources develop a plan to identify the state agency to be responsible for serving individuals with ASD and whether that agency should serve individuals with only ASD or with all developmental disabilities.

In 2008 the Virginia General Assembly passed House Joint Resolution 105, which directed the Joint Legislative Audit Review Commission (JLARC) to examine services available to Virginians with ASD. JLARC compared Virginia services to those provided in other states, assessed the availability of ASD training for public safety personnel, and identified best practices and ways to improve delivery of services to Virginians. Findings from this comprehensive review can be accessed on the JLARC website (Virginia Joint Legislative Audit and Review Commission, 2009).

One recommendation from the JLARC study was:

The Department of Behavioral Health and Developmental Services should create a detailed action plan reflecting the input of relevant stakeholders and the evaluation of options conducted by other State agencies, which specifies how the department will address the issues contained in this report and build a more effective system of care for Virginians with developmental disabilities, including autism spectrum disorders.

The status of the resulting plan can be accessed on the Department's website (Virginia Department of Behavioral Health and Developmental Services, 2013).

In 2011, legislation was passed requiring health insurance plans in businesses employing at least 50 people to offer coverage for ASD for 2 to 6 year olds (House Bill 2467/Senate Bill 1062). The Governor amended this legislation to license board certified behavior analysts (BCBAs). The legislation, however, did not authorize the Virginia Board of Medicine to promulgate regulations to govern the licensure. In

2012, legislation (House Bill 1106) was passed to require the Board of Medicine to license behavior and assistant behavior analysts. The bill also required the Board to convene a workgroup relating to the licensure and practice of applied behavior analysis and contained an emergency clause that requires the Board to promulgate emergency regulations within 280 days of enactment.

Additional legislation was passed by the 2012 General Assembly with the goal of improving delivery of school-based services to youth with ASD (House Bill 325). This legislation required school divisions to ensure that aides assigned to work with a teacher who has primary oversight of students with ASD receive training in student behavior management within 60 days of assignment to such responsibility. School boards may also provide such training to other employees, including transportation employees. The Virginia Board of Education must provide training standards that school divisions may use to fulfill the training requirement. An enactment clause was added requiring the Virginia Board of Education, in consultation with Virginia Commonwealth University, to develop online training that school divisions may use to fulfill the requirements of this legislation. Such training must be made available to local school divisions free of charge.

In 2014, the General Assembly enacted legislation (House Bill 926) that established the Advisory Board on Behavior Analysis to advise the Virginia Board of Medicine on issues related to licensure of behavior analysts and assistant behavior analysts. In addition, the legislation provided for several exceptions to the licensure requirements. In 2015, the General Assembly enacted legislation (House Bill 1940) requiring health insurers, health care subscription plans, and health maintenance organizations to provide coverage for the diagnosis and treatment of ASD in individuals from ages two years through 10 years. The legislation does not apply to policies, contracts, or plans issued in the individual market or the small group market, which effective January 1, 2016, includes employers with no more than 100 employees.

In 2011, the Virginia General Assembly created the Virginia Autism Advisory Council (Senate Bill 1269). The Virginia Autism Council is the legislative body charged with promoting coordination of services and resources among agencies involved in the delivery of services to Virginians with autism spectrum disorders (ASDs) and increasing public awareness of such services and resources. The Council is to submit an annual report with progress updates and recommendations to the Governor and the General Assembly. The Council had a sunset provision, meaning that the statutory language creating the Council would expire July 1, 2016; however, legislation was enacted during the 2016 General Assembly Session (Senate Bill 225) that extended the sunset provision for the Council to July 1, 2018. The Council adopted a work plan in 2014 that tasked the Council with formulating potential strategies for lowering Virginia's current Medicaid waiver waiting lists and evaluating the adequacy of the Commonwealth's current employment support programs and efforts for students with ASD. The Council adopted a recommendation to continue assessing the issue of uniform application of dyslexic and ASD support across the Commonwealth. The Council invited parents of children with ASD and dyslexia from various regions in the Commonwealth to testify before the Council regarding their satisfaction and experiences with the services being provided in their area. The Council included in its work plan the issue of proper diagnosis (Virginia Autism Advisory Council, 2015).

In Virginia, individuals with ASD may be eligible to receive services from Virginia's Home and Community-based Medicaid Waivers program. Medicaid waivers provide funding for services that allow individuals with developmental disabilities, including those with ASD, to live in their homes/communities rather than reside and receive services in an institution.

In 2013, Virginia's Medicaid agency, the Department of Medical Assistance Services, and Virginia's Department of Behavioral Health and Developmental Services (Virginia's agency with operational authority for Virginia's waivers) undertook a study of three of Virginia's six existing Medicaid waivers (Virginia Department of Medical Assistance Services [VDMAS] & Virginia Department of Behavioral Health and Developmental Services [VDBHDS], 2015). The study reviewed Virginia's Intellectual

Disability (ID) Waiver, the Individual and Family Developmental Disability (DD) Supports Waiver, and the Day Support (DS) Waiver. Currently, Virginia's ID, DD, and DS Waivers distinguish eligibility separately between those with intellectual disability and those with a developmental disability. However, developmental disability is an umbrella term that includes individuals with intellectual disability. Accordingly, these three waivers are in the process of being revised to better serve individuals with a diagnosis of intellectual disability or a developmental disability. Under the current system, an individual with a diagnosis of ASD, but no specific diagnosis noting an intellectual disability, would only be eligible to receive services under the DD Waiver. In the new plan, the three waivers will be open to all eligible individuals, creating a unified system for individuals to access waiver services (VDMAS & VDBHDS).

The following are the waivers proposed to replace the existing ID/DD waivers:

- The current Day Support Waiver will become the “Building Independence” Waiver and provide supports for adults able to live independently in the community, with other support and or housing subsidies as needed.
- The current Developmental Disabilities Waiver will become the “Family and Individual Supports” Waiver and provide supports for individuals living with their families, friends, or in their own homes, including supports for those with some medical or behavioral needs. It will be available to children and adults.
- The current Intellectual Disability Waiver will become the “Community Living” Waiver and provide up to and including 24/7 services and supports for individuals with exceptional medical and/or behavioral support needs through licensed services. This waiver will include residential supports and a full array of medical, behavioral, and nonmedical supports. It will be available to adults and some children (e.g., those who require out-of-home residential supports) (VDMAS & VDBHDS, 2015).

The new waivers are to be implemented in two phases. The redesigned waivers include new services. They will have a nondiagnosis specific eligibility. Eligibility will be assessed based on a newly revised instrument (the VIDES) and level of need will be determined through use of the nationally validated Supports Intensity Scale (SIS). SIS scores will be used to determine provider reimbursement according to tiers for certain services. In addition, the Commonwealth will transition to a single statewide waiting list based on priority of need. Currently the DD Waiver waiting list is chronological and the ID waiver waiting list is based on local prioritization.

Another Virginia Medicaid Waiver also serves individuals with ASD. The Elderly or Disabled with Consumer Direction (EDCD) Waiver provides services that help individuals live in their own home or community instead of a nursing home. It is available to individuals 65 years of age and older, and to individuals of any age who have a disability. Individuals who depend on another person for supports and have medical or nursing needs may be eligible for the EDCD Waiver (Virginia Department for the Aging and Rehabilitative Services, 2008).

Cultural Considerations

Cultural differences for youth diagnosed with ASD exist in norms for social interaction, nonverbal communication, and relationships. Cultural and socioeconomic factors may also have an impact upon the individual's age at diagnosis (APA, 2013b). As discussed in the preceding section on prevalence, the most recent data on ASD prevalence was gathered in 2012 through the active surveillance system, Autism and Developmental Disabilities Monitoring Network (ADMM). The surveillance found that Caucasian children were more likely to be identified with ASD than African American or Hispanic children, and that African American children were more likely to be identified with ASD than Hispanic children. In order to receive early intervention, an accurate diagnosis is essential, which means the signs of developmental delay must be recognized and explored as soon as possible. Minority families may view developmental

delays as temporary and even normal (Ennis-Cole, Durodoye, & Harris, 2013). As a result, they may not identify subtle but meaningful warning signs for ASD (lack of pointing, lack of imitation, lack of eye contact, and lack of socially appropriated behavior) (Ennis-Cole, Durodoye, & Harris).

Traditional cultural perspectives may also influence treatment recommendations. Parent with information about interventions and practices that have strong research support are in a better position to select interventions that may be helpful for their children.

Overview for Families

The information discussed in this section is derived from the American Academy of Child and Adolescent Psychiatry Facts for Families Guide to Autism (2013).

Most infants and young children are very social creatures who want contact with others and need that contact to thrive and grow. They smile, cuddle, laugh, and respond eagerly to games like peek-a-boo or hide-and-seek. Occasionally, however, a child does not interact in this expected manner. Instead, the child seems to exist in his or her own world, a place characterized by repetitive routines, odd and peculiar behaviors, problems in communication, and a total lack of social awareness or interest in others. These are characteristics of a developmental disorder called Autism Spectrum Disorder (ASD).

ASD is usually identified by the time a child is 30 months old. It is often discovered when parents become concerned that their child may be deaf, is not yet talking, resists cuddling, and/or avoids interaction with others. Some of the early signs and symptoms that suggest a young child may need further evaluation for ASD include:

- No smiling by six months of age
- No back-and-forth sharing of sounds, smiles, or facial expressions by nine months
- No babbling, pointing, reaching, or waving by 12 months
- No single words by 16 months
- No two word phrases by 24 months
- Regression in development
- Any loss of speech, babbling, or social skills

A preschool age child with ASD is generally withdrawn, aloof, and fails to respond to other people. Many of these children will not even make eye contact. They may also engage in odd or ritualistic behaviors like rocking, hand flapping, or an obsessive need to maintain order. Many children with ASD do not speak at all. Those who do may speak in rhyme, have echolalia (repeating another person's words like an echo), refer to themselves as a "he" or "she," or use peculiar language.

The severity of ASD varies widely, from mild to severe. Some children are very bright and do well in school, although they have problems with school adjustment. They may be able to live independently when they grow up. Other children have significantly more challenges. Intellectual disability may or may not be a concurrent diagnosis.

The cause of ASD remains unknown. Children with ASD need a comprehensive evaluation and specialized behavioral and educational programs. Typically, a multi-disciplinary team diagnoses ASD. Such a team may include a developmental pediatrician, a neurologist, a neuropsychologist, and perhaps at times a psychiatrist. These providers can help families design and implement an appropriate treatment plan, which usually includes educational components.

Although there is no cure for ASD, appropriate specialized treatment provided early in life can have a positive impact on children's development and help them to achieve the best possible outcomes.

Conclusion

Each child and adolescent with ASD is unique, with differing strengths and needs. New evidence and information on ASD is being published almost daily. Early identification and intervention are key elements influencing long term outcomes for children and youth with an ASD diagnosis. Multi-disciplinary evaluations and child- and family-centered service planning are critical to assisting the child in improving communication and social skills, achieving educational and employment goals, and becoming as independent as possible.

Resources and Organizations

American Academy of Pediatrics

<http://www.aap.org>

Autism Focused Intervention Resources and Modules (AFIRM)

An extension of the National Professional Development Center (NPDC)

<http://afirm.fpg.unc.edu/selecting-ebp>

Asperger Syndrome Education Network (ASPEN)

<http://www.aspennj.org>

Association of University Centers on Disabilities

<http://www.aucd.org>

Autism and PDD Support Network

<http://www.autism-pdd.net>

Autism Research Institute (ARI)

4182 Adams Avenue

San Diego, CA 92116

<https://www.autism.com/index.asp>

Autism Society of America

7910 Woodmont Avenue, Suite 300

Bethesda, MD 20814-3067

<http://www.autism-society.org/>

Autism Speaks

2 Park Avenue, 11th Floor

New York, NY 10016

<http://www.autismspeaks.org>

Autism Spectrum Connection

<http://www.aspergersyndrome.org/>

Centers for Disease Control and Prevention

Autism Spectrum Disorder (ASD)

<http://www.cdc.gov/ncbddd/autism/index.html>

Center for Parent Information and Resources

<http://www.parentcenterhub.org/>

Individuals with Disabilities Education Act (IDEA)

<https://sites.ed.gov/idea/>

Interagency Autism Coordinating Committee

<https://iacc.hhs.gov/>

National Autism Center

<http://www.nationalautismcenter.org>

National Alliance for Autism Research

99 Wall Street, Research Park

Princeton, NJ 08540

National Institute of Child Health and Human Development

<https://www.nichd.nih.gov/Pages/index.aspx>

National Institute of Mental Health (NIMH)

6001 Executive Blvd., Rm. 8184, MSC 9663

Bethesda, MD 20892-9663

<https://www.nimh.nih.gov/index.shtml>

National Institute on Deafness and Other Communication Disorders

31 Center Drive, MSC 2320

Bethesda, MD 20892-2320

<http://www.nidcd.nih.gov>

National Network for Immunization Information

<https://www.immunizationinfo.net/>

National Professional Development Center

<http://autismpdc.fpg.unc.edu/>

U.S. Autism & Asperger Association

<http://www.usautism.org>

U.S. Department of Education

U.S. Office of Special Education and
Rehabilitative Services

400 Maryland Ave., S.W.

Washington, DC 20202-7100

**U.S. Department of Health and Human
Services**

The Interagency Autism Coordinating
Committee (IACC)

<https://iacc.hhs.gov/>

Wrights Law

<http://www.wrightslaw.com/>

Virginia Resources and Organizations

Autism Outreach, Inc.

<http://autismoutreach.org/>

Autism Society of America

Central Virginia Chapter

P.O. Box 29364

Richmond, VA 23242-0364

<http://ascv.org>

Commonwealth Autism

4108 E. Parham Road

Henrico, VA 23228

<http://www.autismva.org/>

Infant & Toddler Connection of Virginia

1220 Bank Street, 9th Floor

P.O. Box 1797

Richmond, VA 23219-1797

<http://www.infantva.org/>

**Parent Educational Advocacy Training
Center (PEATC)**

6320 Augusta Drive, Suite 1200

Springfield, VA 22150

<http://www.peatc.org/>

Partnership for People with Disabilities

<https://partnership.vcu.edu/>

The Radford University Autism Center

Department of Communication Sciences &
Disorders

P.O. Box 6961

Radford, VA 24142

[http://www.radford.edu/content/wchs/home/
cosd.html/autism.html](http://www.radford.edu/content/wchs/home/cosd.html/autism.html)

Virginia Autism Advisory Council

<http://www.autismtrainingva.org/>

Virginia Autism Project

<http://www.virginiaautismproject.com/>

Virginia Autism Resource Center

Richmond Office: 4100 Price Club Blvd.

Midlothian, VA 23112

Winchester Office: P.O. Box 2500

Winchester, VA 22604

<http://www.varc.org/>

Virginia Board for People with Disabilities

<https://www.vaboard.org/>

**Virginia Commonwealth University Autism
Center for Excellence (VCU-ACE)**

1314 West Main Street

Richmond, VA 23284

[http://www.vcuautismcenter.org/projects/dia
gnosis.cfm](http://www.vcuautismcenter.org/projects/diagnosis.cfm)

**Virginia Department for Aging and
Rehabilitative Services**

8004 Franklin Farms Drive

Henrico, VA 23229-5019

<https://vadars.org/>

**Virginia Department of Behavioral Health
and Developmental Services**

Office of Developmental Services

P.O. Box 1797

Richmond, VA 23219

[http://www.dbhds.virginia.gov/development
al-services](http://www.dbhds.virginia.gov/developmental-services)

Virginia Department of Education

Office of Special Education and Student Services

P.O. Box 2120

Richmond, VA 23218-2120

http://www.doe.virginia.gov/about/spec_ed_and_stu_svs/index.shtml

Publications:

Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/index.shtml

Autism Spectrum Disorders and the Transition to Adulthood

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_transition.pdf

Guidelines for Educating Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_guidelines.pdf

Models of Best Practice in the Education of Students with Autism Spectrum Disorders

http://www.doe.virginia.gov/special_ed/disabilities/autism/technical_asst_documents/autism_models_of_best_practice.pdf

Virginia Department of Health

Child & Adolescent Health, Division of Child & Adolescent Health

109 Governor Street, 8th Floor

Richmond, VA 23219

<http://www.vdh.virginia.gov>

Virginia Department of Medical Assistance Service

600 East Broad Street

Richmond, VA 23219

<http://www.dmas.virginia.gov/>

Virginia Institute of Autism

1414 Westwood Road

Charlottesville, VA 22903-5149

<http://www.viaschool.org>

Virginia Tech Autism Clinic

3110 Prices Fork Road

Blacksburg, VA 24061

<http://www.psyc.vt.edu/outreach/autism>

Virginia's Training/Technical Assistance Centers (TTAC)

<http://ttaonline.org/>

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