DEVELOPMENTAL DISABILITIES AND CO-OCCURING MENTAL HEALTH DISORDERS



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Introduction

Autism Spectrum Disorder (ASD) is a life-long developmental disability which is typically diagnosed in childhood. ASD is categorized as a "spectrum" because it encompasses a group of developmental disorders with accompanying characteristics varying in severity. ASD is shown to cause restricted and repetitive patterns of behaviors (e.g., bizarre fixation with specific parts or sensory aspects of an object), impairments in social relatedness (e.g., failure to develop appropriate peer relationships), and impairments in verbal and nonverbal communication (e.g., delay or absence of spoken language) (American Psychiatric Association [APA], 2000). The autism spectrum includes Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (APA, 2000). It is important to note that in May 2013, significant changes to the criteria and categories of ASD will occur with the release of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). These changes are discussed in *Autism Spectrum Disorder Diagnoses in the Future* later in this section.

Because ASD is a developmental disability, youth diagnosed with ASD require a combination and sequence of interventions and supports that are individually planned and coordinated and are of lifelong or extended duration. Such a combination of services enables individuals with disabilities to be more active, productive, and independent.

Complicating matters further is the fact that youth with ASD may also have diagnosable mental health disorders. Co-occurring mental health disorders may cause significant clinical impairment and place additional burdens upon these children and their families. Unfortunately, it is frequently assumed that behaviors associated with co-occurring mental health disorders are related to the ASD diagnosis. Holding to this assumption can leave mental health issues untreated and exacerbate symptoms.

At its November 9, 2011 meeting, the Commission on Youth recommended that the *Collection's* section on ASD be revised to include discussion of co-occurring mental health disorders and to specify that ASD is a developmental disorder. Accordingly, this revised section includes additional information about ASD, as well as commonly co-occurring mental health disorders.

Prevalence

ASD, according to current estimates, is more prevalent in the pediatric population than spina bifida, diabetes, cancer, or Down syndrome (Filipek et al., 1999). The Centers for Disease Control (CDC) has been tracking ASD for over a decade through the Autism and Developmental Disabilities Monitoring (ADDM) Network. In 2008, the

CDC gathered data to determine the current prevalence rates of ASD. The information discussed in this paragraph is taken from the CDC (2012). The CDC determined that age 8 was a reasonable index age to monitor peak prevalence because previous work has shown that by this age most children with ASD have been identified for services. Using this peak age, the CDC reviewed evaluation records in the 14 sites participating in the ADDM Network. These 14 communities comprised over 8 percent of the U.S. population of 8-year olds in 2008. The CDC estimates 1 in 88 children (11.3 per 1,000) has been identified with ASD. This is a 23 percent increase since the 2009 report and a 78 percent increase since the CDC first reported prevalence rates in 2007. Findings from the 2012 report include the following statistics:

- The number of children identified with ASD varied widely across the 14 ADDM Network sites, from 1 in 47 (21.2 per 1,000) to 1 in 210 (4.8 per 1,000).
- ASD is almost 5 times more common among boys (1 in 54) than among girls (1 in 252).
- The largest increases over time were among Hispanic children (110 percent) and African American children (91 percent).
- There were increases over time among children without intellectual disability, although there were also increases in the estimated prevalence of ASDs at all levels of intellectual ability.
- More children are being diagnosed at earlier ages, a growing number of them by age three, although most children are not diagnosed until after they reach age four.

The CDC has noted that increasing awareness and improvements in the way children are identified, diagnosed, and served in their local communities has likely resulted in increased ASD prevalence. In addition, ASD prevalence was significantly higher in ADDM sites that had access to education sources, compared to sites relying on health sources for case identification (CDC, 2012). It is worth noting that the surveillance areas are not representative of the United States as a whole.

A current controversy is whether rising numbers indicate an upward trend in the actual incidence of the disorder or whether they reflect changes in diagnoses. Based on a detailed time trends analysis of 28 studies published since 1987 indicating prevalence rates of ASD, the conclusion was that most of the increase in incidence is accounted for by both improved identification and by changes in diagnostic criteria and concepts (Fombonne, 2005). However, recent studies suggest that most, but not all, of the increased prevalence observed in children is a result of improved identification and there is speculation that there may be a sizable population of children and adults with undiagnosed ASD (U.S. Department of Health and Human Services Interagency Autism Coordinating Committee [IACC], 2012).

Causes and Risk Factors

ASD affects youth in all racial, ethnic, and social groups. Although the causes of ASD are not yet known, it has been established that ASD is not caused by any psychological factors (National Information Center for Children and Youth with Disabilities [NICHCY], 2001). Much evidence points, however, to a genetic basis for the disorders (Volkmar, Westphal, Gupta & Wiesner, 2008).

Epidemiological findings reveal that ASD is the most strongly genetic developmental disorder, with a heritability factor greater than 90 percent (Bailey et al., 1995). As stated previously, ASD is seen more commonly in boys than girls (ratio of 4:1) and biological siblings of an affected child run a higher risk of having the disorder (APA). Genetic studies are far from congruent, and no model has yet explained the gender disparity and variable phenotype across family datasets (Newschaffer & Curran, 2003). In the recent years, there has been a focus on searching for potential environmental causal factors, including immunizations, heavy metals, infectious agents, and pharmacological agents (Volkmar et al., 2008). For example, non-heritable risk factors, such as chemical exposure and childhood vaccinations, have been widely investigated in recent years as possible causes (Newschaffer & Curran). Pre-and perinatal maternal infections and birth complications associated with ASD have also been reported with some consistency (Newschaffer & Curran). In recent years, there has been increasing focus on a possible association between childhood immunizations and ASD (Newschaffer & Curran). However, there is no conclusive evidence indicating that these factors play any role in the etiology of ASD. This is described in more detail in the *Vaccines and Autism* discussion which follows.

To summarize, as observed by Kabot, Masi and Segal (2003), there is consensus that ASD can be classified as three different, but interdependent levels. These levels are:

- 1. a neurological disorder related to brain development;
- 2. a psychological disorder of cognitive and emotional; and
- 3. a relationship disorder impacting behavioral development, or in which there is a failure of normal socialization.

There is no reason to suppose that there is only one pathway or one specific risk factor; it would appear that several etiological pathways could lead to ASD.

Diagnostic Categories

Each category of ASD has specific diagnostic criteria outlined by the American Psychiatric Association (APA) in its *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (2000). However, there are no clearly established guidelines for measuring the severity of a child's symptoms. In many situations, it is difficult to isolate the characteristics of Autistic Disorder from PDD-NOS (Boyle, as cited by the National Information Center for Children and Youth with Disabilities [NICHCY], 2001). Accordingly, a child may be diagnosed by one practitioner as having Autistic Disorder and by another as having PDD-NOS. Therefore, it is important for practitioners to understand the diagnostic criteria for each category, since intervention will be based on diagnosis.

Table 1 outlines each of the categories of ASD and their distinctive diagnostic features.

Table 1

Categories of Autism Spectrum Disorder (ASD)

Disorder	Description
Autistic Disorder	The most common ASD, it is characterized by impairment in social interaction, communication, and imaginative play before the age of 3 years. Behaviors are stereotyped, repetitive, and limited in interest and range of activities.
Asperger's Disorder	Characterized by impairment in social interactions and the presence of restricted interests and activities. There is no significant general delay in language, although there are qualitative impairments and limited ability to have reciprocal social conversations. Differentiated from Autistic Disorder primarily by the relative preservation of linguistic and cognitive capacities in the first 3 years of life. Cognitive testing usually yields scores in the average to high-average range.
Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)	Also referred to as <i>Atypical Autism</i> . Diagnosis of PDD-NOS is made when a child does not meet sufficient criteria for a specific diagnosis but there are severe and pervasive impairments in specific behaviors, language, and social abilities.
Rett's Disorder	Defined as a "progressive disorder" characterized by periods of "normal" development followed by loss of previously acquired skills, as well as the purposeful use of hands. Replacement with repetitive hand movements begins between the ages of 1 to 4. So far, this disorder has been identified only in females.
Childhood Disintegrative Disorder	Characterized by "normal" or typical development for at least the first 2 years of age, followed by significant losses in previously acquired skills in the area of cognitive, social, language, and behavioral development.

Source: APA, 2000.

Autism Spectrum Disorder and Co-occurring Mental Health Disorders

While impairment due to the social and cognitive deficits characterizing ASD is well-demonstrated, less well-known is the impact of co-occurring mental health disorders. Accurate reliable diagnosis of co-occurring mental health disorders is critical, due to associated problematic behaviors. When a youth's symptoms can be attributed to the mental health disorder, more targeted intervention is possible (Leyfer et al., 2006).

Recent studies have shown that mental health disorders are common and frequently multiple in children and adolescents with ASD (Simonoff et al., 2008). Frequently, these children and adolescents are diagnosed with multiple mental health disorders. One study examined the adjusted odds of youth with ASD being diagnosed with a co-occurring mental health disorder (Rosenberg, Kaufman, Law & Law, 2011). This study found that the likelihood of a youth being diagnosed with a co-occurring psychiatric disorder rose significantly with each additional year of life and as autism severity increased. This study also revealed the likelihood of under-diagnosis of potentially treatable co-occurring disorders.

Another study investigated the rates and types of co-occurring disorders in a group of 84 children and adolescents with ASD (Moseley, Tonge, Brereton & Einfeld, 2011). This study found that 42 percent of those

youth with ASD had a co-occurring mental health disorder. The disorders included mood disorders, anxiety disorders, adjustment disorders, and behavior disorders. A significant finding from this study was that the rate of co-occurring disorders was between 2 to 4 times of that found among typically developing young people (Moseley, Tonge, Brereton & Einfeld).

A recently conducted study also sought to obtain a clearer picture of the prevalence of co-occurring mental health disorders in youth with ASD. The study was purposefully designed to use a population-representative sample of youth with ASD (Simonoff et al., 2008). The results from this effort revealed that 70 percent of youth with ASD represented by this study had at least one co-occurring mental health disorder (Simonoff et al.). In addition, the study found that having a co-occurring mental health disorder increased the risk of multiple diagnoses, with close to 60 percent of the study population having 2 or more disorders and one-third of the study population having 3 or more disorders in addition to ASD (Simonoff et al.). The prevalence of mental health disorders found to co-occur with ASD is outlined in Table 2.

Table 2

Prevalence of Co-occurring DSM-IV Disorders with ASD

Disorder	Prevalence (3 month prevalence rates)
Any Disorder	70.8
Any Main Disorder Attention Deficit Hyper Activity Disorder (ADHD) Oppositional Defiant Disorder/Conduct Disorder (ODD/CD) Emotional Disorders Anxiety Disorders Phobias Mood Disorders	62.8
Any Emotional Disorder Anxiety Disorders Phobias Mood Disorders	44.4
Any Anxiety or Phobic Disorder	41.9
Any Depressive Disorder	1.4
ODD/CD**	30.0
ADHD	28.2
Other Disorders*** Habit Disorders Tourette Syndrome Chronic Tics Trichotillomania	3.9

Source: Simonoff et al., 2008.

Another clinical study involving a sample of youth with ASD involved modifying an assessment instrument to reveal whether the youth also met the *DSM-IV* criteria for a co-occurring mental health disorder. The study sample demonstrated a high prevalence of certain mental health disorders, the most common being specific phobias, a type of anxiety disorder. An estimated 44 percent of children with ASD met the appropriate diagnostic criteria for specific phobias (Leyfer et al., 2006). The second most frequently diagnosed co-occurring mental health disorder was obsessive-compulsive disorder (OCD), which was diagnosed in 37 percent of the study sample (Leyfer et al.). The third most common diagnosis, attention deficit hyperactivity disorder (ADHD), was diagnosed in 31 percent of youth with ASD. This rate increased to nearly 55 percent when including subsyndromal symptoms, meaning those not quite meeting the diagnostic criteria for ADHD (Leyfer et al.). Nearly a quarter of the youth with ASD in this study met lifetime diagnostic criteria for major depressive disorder, with 10 percent meeting full *DSM-IV* criteria and 14 percent just falling short of meeting *DSM-IV* criteria.

^{*} All symptom combinations meeting diagnostic criteria were identified.

^{**} The study noted high rates of ODD but not CD, which is consistent with other study findings.

According to the *DSM-IV-TR*, ASD coexists with intellectual disability (mental retardation) in approximately 75 percent of those with the disorder (APA, 2000). An estimated half of those with Autistic Disorder, the most common ASD, do not have functional speech (Prizant, 1996). Hyperactivity, attention deficit, obsessive compulsive-type symptoms, self-injurious behavior, tics and affective symptoms are also frequently noted in youth with ASD (Volkmar et al., 1999).

According to the practice parameters published by Volkmar et al. (1999), recent research has also centered on brain abnormalities measured by an EEG (electroencephalogram). While some associations appear to be relatively frequent in youth with ASD, other comorbid conditions appear to be much less common. Studying extensive databases in Israel and Sweden, researchers discovered that ASD and schizophrenia shared a genetic link, representing a heightened risk within families. They found that people who have a schizophrenic sibling are 12 times more likely to have Autistic Disorder than those without a family history of schizophrenia. The same study showed the presence of bipolar disorder in a sibling had a similar pattern of association, but to a lesser degree (American Friends of Tel Aviv University, 2012).

Unfortunately, co-occurring mental health disorders in youth with ASD are difficult to diagnose. This is because communication with the child or adolescent may be impaired; almost half of youth diagnosed with ASD are functionally nonverbal (Leyfer et al., 2006). Moreover, youth with ASD may also have a cognitive difficulty, which makes it difficult for them to describe their mental state. Thus, it is challenging to ascertain whether the youth's difficulties originate from the core features of their ASD or from the attributes of a co-occurring mental health disorder (Leyfer et al.). Another particular challenge to diagnosing co-occurring mental health disorders in ASD is the specific exclusionary criteria contained in the *DSM-IV* (Center for Autism and Related Disabilities at the University of South Florida [CARD-USF], n.d.). A diagnosis of ASD precludes the formation of a formal diagnosis of a number of other mental health disorders, including attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and Social Anxiety Disorder. Thus, there are specific challenges to identifying co-occurring mental health disorders because the symptoms may be attributed to the ASD (Simonoff et al., 2008).

Successful early intervention for those diagnosed with ASD includes the identification of co-occurring mental health symptoms in the toddler years (Matson, 2010). Research in this area has shown that toddlers diagnosed with ASD have more symptoms related to tantrum/conduct behavior, inattention/impulsivity, avoidance behavior, anxiety/repetitive behavior, and eating/sleep problems when compared with their same-aged peers without an ASD diagnosis but who were also atypically developing. In older children diagnosed with ASD, findings have been similar.

Current research shows that potentially treatable co-occurring mental health disorders in youth with ASD have likely been under-diagnosed. This may be explained because no assessment instrument has the validity and reliability to deem it a "gold standard" for diagnosing present and lifetime mental health disorders in youth with ASD (Leyfer et al., 2006). Accordingly, it may be prudent to incorporate an assessment for a co-occurring mental health disorders upon diagnosis of an ASD (Simonoff et al., 2008).

Identification and treatment of co-occurring mental health disorders in youth with ASD allows for better outcomes versus only addressing the youth's ASD symptoms (Leyfer et al., 2006). Please refer to the appropriate sections of the *Collection* for additional information on evidence-based and promising practices for the mental health disorders discussed in this section.

Early Warning Signs

The behaviors outlined in the following listing are early warning signs published by the American Academy of Pediatrics (AAP, 2006) to aid parents and professionals with early identification and, consequently, early intervention. These are:

- not turning when the parent says the child's name;
- not turning to look when the parent points says, "look at..." and not pointing to themselves to show parents an interesting object or event;
- · lack of back and forth babbling;
- · smiling late; and
- failure to make eye contact with people.

According to the AAP (2006), the following signs warrant immediate attention:

- no babbling or pointing or other gestures by 12 months;
- no single words by 16 months;
- no two-word phrases by 24 months; and
- regression or loss of language or social skills at any age.

Screening and Assessment

The American Academy of Neurology (Filipek et al., 2000), the American Academy of Child and Adolescent Psychiatry (AACAP) (Volkmar et al., 1999) and a consensus panel with representation from multiple professional societies (Filipek et al., 1999) have published specific practice parameters for the assessment and screening of ASD. These publications have made a significant contribution by laying out, for the first time, consensus guidelines for ASD assessment (Ozonoff, Goodlin-Jones & Solomon, 2005). According to these parameters, screening for ASD calls for two different levels of screening.

<u>Level I screening</u> is a developmental surveillance that should be performed on all children. It involves identifying children at-risk for any type of developmental disability and, if the Level I screening raises any cause for concern, the child should then be referred to the next level of screening. Table 3 presents the available evidence-based Level I screening instruments for identifying children at-risk for any type of developmental disability and, in particular, for ASD.

<u>Level II screening</u> of children already identified to be at risk for a developmental disorder involves both a diagnostic evaluation and more in-depth investigation. At this level, a distinction is made between autism and other developmental disabilities, and includes evaluation by autism specialists. The goal is to determine the best means of intervention, based on the child's profile of strengths and weaknesses (Siegel et al., 1998). Table 4 presents the available evidence-based Level II screeners/diagnostic tools for ASD.

Once a child has been recognized during the screening process as being at risk for ASD, a detailed assessment should be completed to establish a diagnosis. There are several considerations important to the assessment process.

- A developmental perspective must be maintained. Since ASD is characterized by an unevenness in development that varies over the lifespan (Ozonoff, Goodlin-Jones & Solomon, 2005), studying a child within a developmental framework provides a benchmark for understanding the severity or characteristics of delays and deviances.
- Evaluating a child with ASD should include obtaining information from multiple sources and contexts, as symptoms of ASD may be dependent on characteristics of the environment (Ozonoff, Goodlin-Jones & Solomon), measures of parent report, teacher report, and child observation across settings, cognitive and adaptive behavior assessments, and clinical judgments may all factor into a comprehensive assessment of ASD (Filipek et al., 1999).
- Assessments of ASD must be multidisciplinary whenever possible. They should incorporate findings from professionals in the fields of psychology, psychiatry, neurology, pediatrics, speech and language (Ozonoff, Goodlin-Jones & Solomon).

Table 3

Level I Screening Instruments

General Developmental Disability	ASD-Specific
Ages and Stages Questionnaire, 3 rd Edition	Checklist for Autism in Toddlers (CHAT;
(ASQ; Bricker & Squires, 1999)	Baron-Cohen, 1992)
Child Development Inventories (CDIs;	Modified Checklist for Autism in Toddlers (M-
Ireton, 1992)	CHAT; Robins et al., 2001)
Parents Evaluation of Developmental Status	Pervasive Developmental Disorder Screening
(PEDS; Glascoe, 1998)	Test II (PDDST-II; Siegel, 2004).
BRIGANCE® Screens II (Glascoe, 2005)	Australian Scale for Asperger's Syndrome
, , ,	(ASAS; Garnett & Attwood, 1997)

Source: Filipek et al., 2000.

Table 4

Level II Screening Instruments & Diagnostic Tools

Name of Measure	Type of Measure
Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994; Rutter, LeCouteur et al., 2003)	Comprehensive parent-interview with probes for symptoms of autism
Social Communication Questionnaire (SCQ - formerly, Autism Screening Questionnaire – Berument et al., 1999)	Parent-report based on ADI-R; briefer than ADI-R; yes/no format
Autism Spectrum Screening Questionnaire (Ehlers et al., 1999)	Checklist measure for completion by "lay informants"
Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; 2002)	Semi-structured interactive assessment; 4 different modules, according to language and developmental levels

Source: Rogers et al., 2005.

General Principles

Serving a child with ASD is determined by the child's individual needs. A combination of three principles can reduce challenges associated with ASD, lessen disruptive behavior, and provide the child with a degree of independence.

Early Intervention

According to a review published by Simpson, there are 37 intervention strategies identified for ASD (2005). Of these, 4 approaches are scientifically based, 13 are identified as promising, and the remaining 20 are unsupported by any research. While there is no consensus as to which interventions work best, mounting evidence from various diagnosis and intervention research suggests that early detection of ASD is key to improving developmental outcomes (Goin-Kochel & Myers, 2005; Dawson & Osterling, 1997). Early detection leads to early intervention, and for youth with ASD, participation in specialized intervention programs can optimize long-term outcomes (Volkmar et al., 2005). Some young children with ASD who receive early intervention have shown more significant improvements in cognitive, social, and language functioning than older children who undergo the same interventions (Rogers, 1998).

Educational Implications

Early diagnosis and appropriate educational programs are important for youth with ASD (NICHCY, 1998). The Individuals with Disabilities in Education Act (IDEA) (Public Law 94-142, Public Law 99-457, and Public Law 102-119) requires that children with a disability receive a free and appropriate education. Children with ASD may have behavior and communication problems which interfere with learning and therefore will benefit from a structured plan which can be carried out both at home and school (Autism Society of America, 2002). Children with a disability from birth through the age 3 are also eligible pursuant to Part C of IDEA. This provision was expanded to ensure that all children with a disability receive appropriate early intervention services (Infant and Toddler Connection of Virginia, n.d.).

In Virginia, the Virginia Department of Behavioral Health and Developmental Services (DBHDS) is the lead agency which administers Part C of IDEA. Virginia's statewide early intervention system is called the Infant & Toddler Connection of Virginia. Infant/toddler services can be home-based, center-based, or a combination. The nature of the services is determined based on an assessment of the child and the family priorities. The services provided in response to this plan may include the identification of appropriate assistive technology, intervention for sensory impairments, family counseling, parent training, health services, language services, health intervention, occupational therapy, physical therapy, case management, and transportation to services (Biasini et al., 1999).

Once the child reaches the age of 3, special education programs established by IDEA are then available for the child and family (NICHCY, 2009). The services provided through IDEA to school-aged children are most often provided as home-based, center-based or in naturally occurring environments. An Individualized Education Program (IEP) is developed based on results of the team evaluation and parental input. This plan describes the objectives for improving the child's skills and may include family or parent-focused activities. These services must also be provided in the least restrictive setting possible, but must include a continuum of placements that includes

instruction in regular classes, special classes, special schools, home instruction and instruction in hospitals and institutions.

Family-centered Approach

Family involvement is a critical element of the child's educational program. A multi-disciplinary and family-focused approach, where the service providers and the parents work in a collaborative manner to develop appropriate interventions for the child, is considered the most effective method of service delivery for children with ASD and their families (Volkmar et al., 1999). A family-centered approach employs the expertise of the family regarding the strengths and needs of their child.

Evidence-based Practices

For this review, interventions for ASD are described as What Works and What Seems to Work.

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, especially for young children with an 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 3 years of age (Dawson & Osterling; Lovaas & Smith, 2003), and the child undergoes intensive behavior therapy at least 15 hours a week (Dawson & Osterling).

The goal of intervention, as described by Lovaas (1987), is to minimize the child's failures and maximize successes. ABA methods, which are based on scientific principles of behavior to build socially useful repertoires and reduce problematic ones (Cooper et al., 1989). This behavioral analytic view asserts that ASD is a syndrome of behavioral deficits and excesses with a neurological basis, but is also amenable to change in response to specific, carefully programmed, constructive interactions with the environment (Green).

ABA came into focus for children with ASD in 1966, when Lovaas and colleagues demonstrated that principles of learning could be used to teach speech to young children with ASD. In 1989, Lovaas & Smith observed that children with ASD do not readily learn in typical environments, but are often able to learn successfully when given appropriate instructions. Using empirically validated behavior modification procedures, like discrete trial instruction, ABA is an extremely structure-based intervention. The emphasis is on high-intensity reinforcement, using precise teaching techniques. Skills that are prerequisites to language – like attention, cooperation, and imitation – are emphasized. Strong emphasis is also placed on acquiring new behaviors, because the belief is that when children acquire a repertoire of constructive behaviors, there is a lesser likelihood of the occurrence of problem behaviors (Green).

Discrete Trial Teaching or Training (DTT)

DTT, which has its basis in ABA therapy, focuses on the principles of operant learning to intervene with children with ASD. In DTT, children learn appropriate responses to the presence of specific words and environmental stimuli. DTT may also be called the ABC model, whereby every trial or task given to the child to perform consists of an antecedent (directive or request to the child to perform an action), behavior (response from child), and consequence (reaction from therapist). Teaching trials are repeated many times, initially in rapid succession, until the child performs a response readily, without adult-delivered prompts (Green, 1996). A pause to separate trials from each other, called the inter-trial interval, is essential. Data is kept on multiple trials, and the child moves on to additional tasks as the old ones are mastered. The child's responses are recorded and evaluated according to specific, objective definitions and criteria. Timing and pacing of teaching sessions, practice opportunities and consequences delivery are designed precisely for each child's learning pace and style to help ensure success (Green). To maximize those successes, emerging skills are practiced and reinforced in many less-structured situations. For some high-functioning children with ASD, certain skills can be taught entirely in relatively unstructured environments from the outset (Green). However, to ensure that these "naturalistic" practices occur frequently, the practice opportunities have to be arranged carefully, and reinforcers given consistently. The overall emphasis is on teaching the child how to learn in a traditional environment and how to act on that environment in ways such that there are consistently positive outcomes for the child, their family, and others (Green; Lovaas, 1987; Lovaas & Smith, 1989).

Pivotal Response Training (PRT)

PRT is a behavioral-based intervention that has gained increasing empirical support. According to Campbell et al., (2008), the development of PRT in part has resulted from findings from the DTT literature. PRT, developed by Koegel, Koegel & McNerney (2001) 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 an ASD.

Learning Experience: An Alternative Program (LEAP)

LEAP is an 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 setting. 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 which 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 on the autism spectrum have shown decreases in autistic symptoms and long-term improvements in educational, cognitive, developmental, and social domains (Hoyson et al., 1984; Strain & Hoyson, 2000).

Pharmacological Interventions

Although pharmacological interventions cannot "cure" ASD, pharmacologic interventions may be considered for maladaptive behaviors, such as aggression, self-injurious behavior, repetitive behaviors, sleep disturbance, anxiety, hyperactivity, inattention, destructive behavior, or other disruptive behaviors (Myers, Johnson & the Council on Children with Disabilities, 2007). After treatable medical causes and environmental factors have been ruled out, medication may be considered when behavioral symptoms cause significant impairment in functioning. Once the diagnosis of the co-occurring disorder is made, the child may be treated with medications typically used to treat these conditions. Modifications of diagnostic criteria may be necessary to account for clinical presentations of mental health disorders in children with developmental disabilities. Neuroleptics (e.g., risperidone), selective serotonin reuptake inhibitors (SSRIs; fluvoxamine & clomipramine), antidepressants (e.g., imipramine), and other mood stabilizers have been tested in different clinical studies with some proven benefits. More rigorous, controlled studies are called for to establish the evidence-base of intervention efficacy (Myers, Johnson & the Council on Children with Disabilities).

These are outlined as What Works in Table 5, which follows.

Promising Practices

Research findings have shown that the following practices appear to be effective for treating ASD. These are outlined as What Seems to Work in Table 5.

Educational and Communication Focused Interventions

The TEACCH (Treatment and Education of Autistic and Communication related handicapped Children) approach recognizes differences in the rate and nature of development among children (Ferrante, Panerai & Zingale, 2002). Teaching objectives are based on individual developmental patterns. The guiding principles of the TEACCH program are to provide strategies that support the person throughout the lifespan, facilitate autonomy at all levels of functioning, and accommodate individual needs (Ferrante, Panerai & Zingale).

Natural Language Methods

The following information is taken from Families for Early Autism Treatment, Inc. (n.d.). Significant gains for teaching language, such as speech intelligibility, have occurred in recent years. Speech and language pathologists often integrate communication training into the child's behavior program to provide a coordinated opportunity for structured and naturalistic language learning. The chief focus of skill development for children with ASD is communication, because it is the most pervasive area of developmental delay. Instruction in

communication skills is designed to provide a generative tool that will serve many immediate needs throughout the child's life.

Table 5

Summary of Interventions for ASD

What Works	Description
Applied Behavior Analysis (ABA)	Behavioral intervention aimed at improving cognitive, language, communication, and socialization skills at the level of specific behaviors; characterized by ongoing and objective measurement of behaviors, implementation of individualized curricula, selection and systematic use of reinforcers, use of functional analysis to identify factors that increase or inhibit behaviors, and an emphasis on generalization of learned skills.
Discrete Trial Teaching (DTT)	Behavioral intervention based on principles of operant learning; incorporates units of instruction used to teach and assess acquisition of basic skills; discrete trial incorporates same sequential components regardless of skills taught.
Pivotal Response Training (PRT)	Focus on the most disabling areas of a person's autism. "Pivotal" areas of intervention include teaching children to respond to multiple environmental cues, increasing motivation, increasing capacity for self-management, and increasing self-initiations.
Learning Experiences: An Alternative Program (LEAP)	Peer-mediated interventions in an educational setting with children with autism and typical peer; individualized, data driven, and focused on generalizing learning skills across context through saturation of learning opportunities throughout the day; family involvement is a big part of this intervention.
Pharmacological Interventions	May be considered for maladaptive behaviors and if the behavioral symptoms cause significant impairment in functioning.
What Seems to Work	Description
Educational and Communication Focused Interventions (TEACCH)	TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) provides strategies that support the individual throughout the lifespan, facilitates autonomy at all levels of functioning, and accommodates individual needs.
Natural Language Methods	Speech and language pathologists often integrate communication training with the child's behavior program to provide a coordinated opportunity for structured and naturalistic language learning. Instruction in communication is designed to provide a generative tool that will serve many immediate needs throughout the child's life.
Picture Exchange Communication System (PECS)	Helps children with ASD acquire functional communication skills. Children using PECS are taught to give a picture of a desired item to a communication partner in exchange for the item, thus linking communication with an outcome.
Other Behavioral Interventions	Joint attention behavior training may be especially beneficial in young, pre-verbal children. Joint attention behavior training shows promise for teaching children with autism behavioral skills. Social skills groups, social stories, visual cueing, social games, video modeling, scripts, peer-mediated techniques, and play and leisure curricula are also supported by the literature.
Occupational Therapy and Sensory Integration Therapy	Occupational therapy helps develop self-care skills, such as dressing, using utensils, personal hygiene and academic skills, and shows promise in promoting play skills and establishing routines to improve attention and organization.
(SI)	SI therapy often is used alone or as part of a broader program of occupational therapy for children with ASD. The goal of SI therapy is to correct deficits in neurological processing and integration of sensory information to allow the child to interact with the environment in a more adaptive way.

Source: Commission on Youth Graphic of references listed in text.

Picture Exchange Communication System

The following information is taken from Families for Early Autism Treatment, Inc. (n.d.). The Picture Exchange Communication System (PECS) is a communication-training program that helps children with ASD

acquire functional communication skills. Children using PECS are taught to give a picture of a desired item to a communication partner in exchange for the item, thus initiating a communicative act for an actual outcome.

Other Behavioral Interventions

Joint attention training uses a behavioral modification approach and may be especially beneficial in young, preverbal children. A recent study demonstrated that joint attention and symbolic play skills could be taught (Myers, Johnson & the Council on Children with Disabilities, 2007). Because joint attention behaviors precede social language development, joint attention behavior training shows promise in teaching behavioral skills (Myers, Johnson & the Council on Children with Disabilities). The successes of social skills groups, social stories, visual cueing, social games, video modeling, scripts, peer-mediated techniques, and play and leisure curricula are supported primarily by descriptive and anecdotal literature, but research-based literature is growing (Myers, Johnson & the Council on Children with Disabilities).

Occupational Therapy and Sensory Integration Therapy

While occupational therapy is helpful in developing self-care skills, such as dressing, using utensils, personal hygiene and academic skills, it also shows promise in promoting play skills and establishing routines which improve attention and organization in children with ASD (Myers, Johnson & the Council on Children with Disabilities, 2007). Sensory integration (SI) therapy may be helpful as part of an overall program that uses desired sensory experiences to reinforce a desired behavior and to assist with transitioning between activities (Myers, Johnson & the Council on Children with Disabilities). While research on the efficacy of occupational therapy in ASD is lacking, SI therapy is often used alone or as part of a broader program of occupational therapy for children with ASD. The goal of SI therapy is to correct deficits in neurological processing and integration of sensory information to allow the child to interact with the environment in a more adaptive way. Studies are being conducted to evaluate its effectiveness.

Unproven Practices

Table 6 lists complementary and alternative intervention approaches for which there is conflicting data on their effectiveness.

Table 6

Unproven Practices for ASD

Auditory integration training	Detoxication; chelation
Facilitated communication	Dietary manipulations, e.g., elimination of
Hyperbaric oxygen	gluten, casein
Secretin	Hippotherapy; dolphin therapy
Vitamin B6 and magnesium	Sensory integration therapy
Dimethylglycine (DMG)	Craniosacral therapy
Intravenous immunoglobulin (IVIG)	Behavioral optometry
AZT (zidovudine, Retrovir)	Steroids
Relationship Development Intervention (RDI)	Holding therapy
Antifungal medications	Music/art therapy

Source: Kallen, R., 2000.

Vaccines and Autism

Concern has been expressed in recent years about vaccines and their role in the development of ASD. It was theorized that a link might exist between Autistic Disorder 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 which 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 U.S. managed care organizations to determine whether exposure to thimerosal in infancy was related to ASD. The study 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, 2007b).

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 Department of Behavioral Health and Developmental Services (DBHDS), formerly the Department of Mental Health, Mental Retardation and Substance Abuse Services, convened a workgroup to review ways to provide a coordinated response to educating and treating individuals with ASD. The workgroup continued its work in 2007 and 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, including determining if that the agency should serve individuals with only ASD or with all developmental disabilities.

The 2008 General Assembly passed House Joint Resolution 105, directing the Joint Legislative Audit Review Commission (JLARC) to examine services available to Virginians with ASD. JLARC compared services provided to individuals with ASD in Virginia to those provided in other states, assessed availability of ASD training for public safety personnel, and identified best practices and ways to improve delivery of services to Virginians with ASD. 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 resulting plan can be accessed on the Department's website (Virginia Department of Behavioral Health and Developmental Services, 2010).

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 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 which 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.

Autism Spectrum Disorder Diagnoses in the Future

In early 2010, the American Psychiatric Association released draft revisions to its fifth revision of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*) and invited comments from both professionals and the public. The *DSM-5* will be published in May 2013 (APA, 2009). The *DSM-5* is expected to affect how ASDs are diagnosed. Among the proposed revisions are:

- changing the name of the diagnostic category to Autism Spectrum Disorders;
- including Asperger's Disorder, Childhood Disintegrative Disorder, and PDDNOS under the diagnosis of Autism Spectrum Disorders, rather than defining them separately, as is now the case;
- removing Rett's Disorder from the DSM and from the autism spectrum (APA, 2010, as cited by NICHCY, 2010); and
- merging several social/communication criteria (APA, 2010).

An epidemiological study of 5,000 school-aged children was conducted in Finland to compare the proposed criteria for ASD with existing criteria. Study findings revealed that the *DSM-5* draft criteria may make it more difficult to identify youth with ASD, particularly those with Asperger's Disorder and certain high-functioning youth with ASD (Matilla et al., 2011, as cited by Jabr, 2012). A systemic analysis using computer-generated models was also conducted based on symptom reports from nearly 7,000 youth diagnosed with ASD. This analysis revealed that a model with 2 groups of symptoms, similar to that proposed for inclusion in the *DSM-5*, captured how the symptoms clustered in the children better than the *DSM-IV* criteria (Frazier et al., 2011, as cited by Jabr, 2012). A third assessment using statistical analyses to evaluate the *DSM-5* criteria concluded that the 2-group *DSM-5* model is overall more accurate than the 3-group *DSM-IV* criteria, but still restrictive (Mandy, Charman & Skuse, 2011, as cited by Jabr, 2012). The *DSM-5* Task Force is scheduled to finalize revisions to the *DSM* in 2012 and publicize the final version in May 2013 (Jabr, 2012).

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 intervention is the most important element which can influence the outcomes for a child with ASD. Proper assessment is crucial in the diagnosis and service planning for youth with ASD. With appropriate and personalized interventions, effective communication can be achieved and the symptoms of ASD ameliorated.

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Virginia Resources

Autism Outreach, Inc.

http://www.autismoutreach.org

Autism Society of America

Central Virginia Chapter P.O. Box 29364 – Richmond, VA 23242-0364 http://www.asacv.org

Tidewater Virginia Chapter Independence Center 6300 E. Virginia Beach Boulevard, Norfolk VA 23502 http://tidewaterasa.org/Home.php

Commonwealth Autism Service

2201 West Broad Street, Suite 107 – Richmond, VA 23220 http://www.autismva.org

Infant & Toddler Connection of Virginia

Virginia Department of Behavioral Health and Developmental Services (DBHDS) 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

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

Virginia Autism Council

http://www.autismtrainingva.org

Virginia Autism Project

http://www.virginiaautismproject.com

Virginia Autism Resource Center

http://www.varc.org

Richmond Office: 4100 Price Club Boulevard – Midlothian, VA 23112 Winchester Office: P.O. Box 2500 – Winchester, VA 22604

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

1314 West Main Street – Richmond, VA 23284 http://www.vcuautismcenter.org/projects/diagnosis.cfm

Virginia Department for Aging and Rehabilitative Services

8004 Franklin Farms Drive – Henrico, VA 23229-5019 http://www.vadrs.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/ODS-default.htm

Virginia Department of Education

Office of Special Education and Student Services P.O. Box 2120 – Richmond, VA 23218-2120 http://www.doe.virginia.gov/special_ed/index.shtml

Virginia Department of Health

Child & Adolescent Health, Division of Child & Adolescent Health 109 Governor Street, 8th Floor – Richmond, VA 23219 http://www.vdh.state.va.us

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 Joint Legislative Audit and Review Commission

House Document 8, Assessment of services for Virginians with autism spectrum disorders Available: http://jlarc.virginia.gov/reports/Rpt388.pdf

Virginia Tech Autism Clinic

3110 Prices Fork Road – Blacksburg, VA 24061 autism@vt.edu http://www.psyc.vt.edu/outreach/autism

Organizations/Weblinks

American Academy of Pediatrics

http://www.aap.org

Asperger Syndrome Education Network (ASPEN)

http://aspennj.org

Association of University Centers on Disabilities

http://www.aucd.org/template/index.cfm

Autism and PDD Support Network

http://www.autism-pdd.net

Autism Research Institute (ARI)

4182 Adams Avenue – San Diego, CA 92116 http://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

Centers for Disease Control and Prevention

Autism Information Center http://www.cdc.gov/ncbddd/autism/index.html

Interagency Autism Coordinating Committee

http://iacc.hhs.gov/index.shtml

National Autism Center

http://www.nationalautismcenter.org

National Alliance for Autism Research

99 Wall Street, Research Park – Princeton, NJ 08540 http://www.autismspeaks.org/site-wide/national-alliance-autism-research

National Dissemination Center for Children with Disabilities (NICHCY)

P.O. Box 1492 – Washington, DC 20013-1492 http://nichcy.org

National Institute on Deafness and Other Communication Disorders

31 Center Drive, MSC 2320 – Bethesda, MD 20892-2320 http://www.nidcd.nih.gov/Pages/default.aspx

National Institute of Child Health and Human Development

http://www.nichd.nih.gov/Pages/index.aspx

National Institute of Medicine of the National Academies (IOM)

http://www.iom.edu

National Institute of Mental Health (NIMH)

6001 Executive Blvd., Rm. 8184, MSC 9663 – Bethesda, MD 20892-9663 http://www.nimh.nih.gov/index.shtml

National Network for Immunization Information (NNii)

http://www.immunizationinfo.org

Online Asperger Syndrome Information and Support (OASIS)

http://www.aspergersyndrome.org

The National Professional Development Center on Autism Spectrum Disorders

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

Individuals with Disabilities Education Act (IDEA) 2004 Regulations IDEA, 2004 News, Information and Resources

http://idea.ed.gov

IDEA 2004 Fact Sheet

http://www2.ed.gov/admins/lead/speced/ideafactsheet.html

U.S. Department of Health and Human Services

The Interagency Autism Coordinating Committee (IACC) http://iacc.hhs.gov/index.shtml

Wrights Law

http://www.wrightslaw.com