CoPA Definitions

Autism is an umbrella term for a wide spectrum of disorders referred to as **Pervasive Developmental Disorders (PDD)** or **Autism Spectrum Disorders (ASD)**. The terms PDD and ASD are used interchangeably. They are a group of neurobiological disorders that affect a child's ability to interact, communicate, relate, play, imagine, and learn. These disorders not only affect how the brain develops and works, but may also be related to immunological, gastrointestinal, and metabolic problems. Signs and symptoms are seen in early childhood. The term spectrum is important to understanding autism because of the wide range of intensity, symptoms and behaviors, types of disorders, and considerable individual variation. Children with ASD may have a striking lack of interest and ability to interact, limited ability to communicate, and show repetitive behaviors and distress over changes, as in the case of many with classic autism, or Autistic Disorder. On the other end of the spectrum are children with a high-functioning form of autism who may have unusual social, language, and play skills, as in Asperger Syndrome. The autism spectrum consists of the following disorders: Autistic Disorder or Classic Autism, Rett's Disorder or Rett Syndrome, Childhood Disintegrative Disorder, Asperger's Disorder or Asperger Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).

Since there is no biological way of confirming a **diagnosis of ASD** at this point in time, diagnosis should be based on the observation of the behavioral features using the DSM-IV-TR® framework. The Autism Diagnostic Observation Schedule (ADOS) is the instrument considered to be the current gold standard for observing features of ASD and should be used in making a diagnosis, along with information from parents. A diagnosis should include information about the child's developmental and medical history, current activities, and behaviors, and is often done by an inter- or multi-disciplinary team of professionals from several different specialties. Often, this will include at least one physician, such as a neurologist, psychiatrist, or developmental pediatrician; a psychologist specializing in child development; a speech-language pathologist; an occupational and/or physical therapist; a social worker; and special educator. Although a diagnosis of ASD is not necessary to get intervention, in some states the differences in the services provided to children with and without a diagnosis of ASD can be huge. Once a child has had a diagnostic evaluation and is determined eligible for services, additional assessments may be completed to better understand the child's strengths and needs in order to plan intervention goals and strategies

DSM-IV-TR® or Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, is a handbook used widely by medical professionals in diagnosing and categorizing mental and developmental disorders. It is published by the American Psychiatric Association and lists the criteria, or characteristics, of many disorders. The Fourth edition of the DSM was published in 1994 with text revisions that were completed in 2000. The DSM-IV-TR uses the term Pervasive Developmental Disorders (PDD), also referred to as Autism Spectrum Disorders (ASD) in other sources, as the umbrella term that includes 5 disorders: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and PDD-Not Otherwise Specified. According to the DSMIV-TR, an ASD diagnosis is given if a child has impairments (defined as problems that limit development or participation in everyday activities) in social interaction, impairments in communication, and restricted interests and/or repetitive behaviors. It is important to understand that while some children may show many or most of these features, other children will show only some of these features. The DSM is expected to be updated with a fifth edition to be published in 2011. (Adapted from American Psychiatric Association, 2000)

Diagnostic Criteria for 299.00 - Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
   1. qualitative impairment in social interaction, as manifested by at least two of the following:
      a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
      b. failure to develop peer relationships appropriate to developmental level
      c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
      d. lack of social or emotional reciprocity
   2. qualitative impairments in communication as manifested by at least one of the following:
      a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
c. stereotyped and repetitive use of language or idiosyncratic language
d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   b. apparently inflexible adherence to specific, nonfunctional routines or rituals
   c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
   d. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Echolalia is the repetition of words, phrases, intonation, or sounds of the speech of others. Children with ASD often display echolalia in the process of learning to talk. Immediate echolalia is the exact repetition of someone else's speech, immediately or soon after the child hears it. Delayed echolalia may occur several minutes, hours, days, or even weeks or years after the original speech was heard. Echolalia is sometimes referred to as "movie talk" because the child can remember and repeat chunks of speech like repeating a movie script. Echolalia was once thought to be non-functional, but is now understood to often serve a communicative or regulatory purpose for the child.

Emotional regulation is a child's ability to notice and respond to internal and external sensory input, and then adjust his emotions and behavior to the demands of his surroundings. Emotional regulation includes the body's involuntary reactions (heart rate, respiratory rate, etc.) to events or perceptions, as well as voluntary responses. Voluntary responses may be behaviors that the child does to soothe, or excite himself, such as spinning the wheel of a toy car, rubbing a smooth surface, rocking, or hand flapping. This may also include the use of communication to get help modulating emotion, such as reaching to request comfort when afraid. Many children with ASD have difficulties with emotional regulation and often have abnormal or inappropriate responses to the ordinary demands of their surroundings. They may also have problems adjusting to change, and transitioning from one activity to another, responding with strong negative emotions, tantrums, stereotyped, or even self-injurious behaviors.

Eye gaze is looking at the face of others to check and see what they are looking at and to signal interest in interacting. It is a nonverbal behavior used to convey or exchange information or express emotions without the use of words.

Hyperresponsiveness is abnormal sensitivity or **over reactivity to sensory input**. This is the state of feeling overwhelmed by what most people would consider common or ordinary stimuli of sound, sight, taste, touch, or smell. Many children with ASD are over reactive to ordinary sensory input and may exhibit sensory defensiveness which involves a strong negative response to their overload, such as screaming at the sound of a telephone. **Tactile defensiveness** is a specific sensory defensiveness that is a strong negative response to touch.

Hyporesponsiveness is abnormal insensitivity or **under reactivity to sensory input**, in which the brain fails to register incoming stimuli appropriately so the child does not respond to the sensory stimulation. A child who appears as if deaf, but whose hearing has tested as normal, is under reactive. A child who is under reactive to sensory input may have a high tolerance to pain, may be sensory-seeking, craving sensations, and may act aggressively, or clumsily.

Insistence on sameness refers to a rigid adherence to a routine or activity carried out in a specific way, which then becomes a ritual or nonfunctional routine. Children with ASD may insist on sameness and may react with distress or tantrums to even small changes or disruptions in routines. Sometimes such reactions are so big they are described as catastrophic. A child's response of insistence on sameness may reflect difficulty with change in

activities or routines or being able to predict what happens next, and therefore, may be a coping mechanism. Young children with ASD may also show some repetitive movements with objects, such as lining things up, collecting objects, or clutching similar small toys.

Children seek to share attention with others spontaneously during the first year of life. **Joint or shared attention** is first accomplished by the caregiver looking at what the infant is looking at. Infants learn early to seek joint attention spontaneously by shifting gaze between an object of interest and another person and back to the object (also called 3-point gaze), following the gaze or point of others, and using gestures to draw others' attention to objects (e.g. holding out and showing an object or pointing to an object), either by pointing to it or by eye gaze. This desire to share attention on objects builds to sharing enjoyment by looking at others while smiling when enjoying an activity, drawing others attention to things that are interesting, and checking to see if others notice an achievement (e.g., after building a tower of blocks, looking up and clapping and smiling to share the achievement). Ultimately, children learn to talk and use language to share enjoyment, interests, and achievements and later to share ideas and experiences. Impairment in joint attention is a core deficit of ASD.

Nonfunctional routines are specified, sequential, and apparently purposeless repeated actions or behaviors that a child engages in, such as always lining up toys in a certain order each time instead of playing with them. Children with ASD may follow routines that appear to be senseless, but may have significance to the child.

Obsessions are repetitive thoughts that are persistent and intrusive. In young children, preoccupations with specific kinds of objects or actions may be an early sign of obsessions.

The term **perseveration** refers to repeating or "getting stuck" carrying out a behavior (e.g., putting in and taking out a puzzle piece) when it is no longer appropriate.

Children with ASD who learn to talk usually have **repetitive use of language**. **Perseverative speech** refers to repeating the same phrase or word over and over or bringing up the same topic repeatedly with a sense of "getting stuck" when it is no longer appropriate.

Pointing is an important gesture of the index finger used to request an object (called **protoimperative pointing**) or to draw attention to an object to comment on it or share interest in it (called **protodeclarative pointing**). The ability to make pointing gestures typically develops by the age of 12 months.

A **preoccupation with a part of an object** is a persistent unusual interest or fixation in one aspect of something that is usually to the exclusion of interest in people, or in using the object in social interactions or in a functional way. Young children with an ASD may manipulate parts of an object, such as spinning the wheel of a toy car, flicking a handle, or opening and closing a door, rather than use the whole object functionally or in pretend play. Like preoccupations with restricted interests, preoccupations with parts of objects can interfere with a child's normal activity or social interaction, and can be related to anxiety.

The **regulatory and sensory systems** control a child's ability to take in or "register" and respond to internal sensory input (such as thoughts and feelings, heart rate, etc.), and external stimuli (sights, sounds, tastes, smells, touch, and balance), and then adjust his emotional and behavioral response to those stimuli and the demands of his surroundings. Many children with ASD have regulatory and sensory deficits, but other children do as well, so the presence of this kind of impairment is not part of the criteria for a diagnosis of an ASD. Regulatory and sensory deficits are associated features that are common in children with ASD, but not necessarily indicative of the disorder.

Repetitive behaviors and restricted interests are common in children with ASD. Children with ASD may appear to have odd or unusual behaviors such as a very strong interest in a particular kind of object (e.g., lint, people's hair) or parts of objects, or certain activities. They may have repetitive and unusual movements with their body or with objects, or repetitive thoughts about specific, unusual topics.

Repetitive motor mannerisms are stereotyped or repetitive movements or posturing of the body. They include mannerisms of the hands (such as hand flapping, finger twisting or flicking, rubbing, or wringing hands), body (such as rocking, swaying, or pacing), and odd posturing (such as posturing of the fingers, hands, or arms).

These mannerisms may appear not to have any meaning, or function, although they may have significance for the child, such as providing sensory stimulation (also referred to as self-stimulating behavior), communicating to avoid demands, or requesting a desired object or attention, or soothing when wary or anxious. These repetitive mannerisms are common in children with ASD.

Children with ASD who learn to talk usually have **repetitive use of language**. Repetitive language is seen in the use of **echolalia**, which is the repetition of words, phrases, intonation, or sounds of the speech of others. Children with ASD often display echolalia in the process of learning to talk. Immediate echolalia is the exact repetition of someone else's speech, immediately or soon after the child hears it. Delayed echolalia may occur several minutes, hours, days, or even weeks or years after the original speech was heard. Echolalia is sometimes referred to as "**movie talk**" because the child can remember and repeat chunks of speech like repeating a movie script. Echolalia was once thought to be non-functional, but is now understood to have a communicative or regulatory function for the child. Repetitive use of language can also be seen in stereotyped phrases that are used repetitively. **Stereotyped or stereotypy** refers to an abnormal or excessive repetition of an action or phrase over time. The term **perseveration** is a related term and refers to an adaptive behavior that is repeated beyond when it is needed and reflects getting stuck. Thus, the term **perseverative speech** is also used to refer to repetitive phrases. Children with ASD may have idiosyncratic use of language, which refers to language with private meanings or meaning that only makes sense to those familiar with the situation where the phrase came from.

Restricted patterns of interest refer to a limited range of interests that are intense in focus. This may also be referred to as **stereotyped or circumscribed patterns of interests** because of the rigidity and narrowness of these interests. This may be particularly apparent in very verbally fluent children with autism or Asperger Syndrome who often become obsessed with a single topic for months or even years. Restricted interests, obsessions, and compulsions can interfere with a child's normal activity or social interaction, and can be related to anxiety. In young children with ASD, similar restricted patterns may be evident in repetitive movements with objects. Rather than playing with toys in simple pretend play, or using objects in appropriate ways, children with ASD line up or stack toys or objects in the same way over and over again, persistently knocking down and rolling objects, or wobbling or spinning objects, and/or may show an intense focus and interest in how these actions or objects look.

Self-stimulating behaviors or "**stimming**" are **stereotyped or repetitive movements** or posturing of the body. They include mannerisms of the hands (such as hand flapping, finger twisting or flicking, rubbing, or wringing hands), body (such as rocking, swaying, or pacing), and odd posturing (such as posturing of the fingers, hands, or arms). Sometimes they involve objects such as tossing string in the air or twisting pieces of lint. These mannerisms may appear not to have any meaning or function, although they may have significance for the child, such as providing sensory stimulation (also referred to as self-stimulating behavior), communicating to avoid demands, or request a desired object or attention, or soothing when wary or anxious. These repetitive mannerisms are common in children with ASD.

Sensory experiences include touch, movement, body position, vision, smell, taste, sound and the pull of gravity. The process of the brain organizing and interpreting this information is called **sensory integration**.

Social reciprocity is the back-and-forth flow of social interaction. The term reciprocity refers to how the behavior of one person influences and is influenced by the behavior of another person and vice versa. Social reciprocity is the dance of social interaction and involves partners working together on a common goal of successful interaction. Adjustments are made by both partners until success is achieved. The skills involved in social reciprocity in very young children begin with showing interest in interacting with others and exchanging smiles. This builds to being able to share conventional meanings with words, and later topics, in conversation. Impairment in social reciprocity may be seen in not taking an active role in social games, preferring solitary activities, or using a person's hand as a tool or a person as if they are mechanical objects. This may lead to not noticing another person's distress or lack of interest in the focus or topic of conversation.