

## CHAPTER 1

### Autism Spectrum Disorders: What Is ASD, Diagnosis, and Screening

#### What is an Autism Spectrum Disorder?

The umbrella term *pervasive developmental disorders* (PDD) covers a group of five developmental disabilities that have a neurological basis; that is, they are caused by a brain disorder that affects how an individual thinks, communicates, and interacts with others. PDD includes the following categories of diagnosis:

- Autism
- Asperger Syndrome (AS)
- Pervasive developmental disorder-not otherwise specified (PDD-NOS)
- Rett Syndrome
- Childhood disintegrative disorder

All five of these disorders share these characteristics:

- They are pervasive; that is, they affect all aspects of an individual's life.
- They are developmental; that is, they occur early in life and affect a child's development.

The following table lists the main defining characteristics of the five categories of diagnoses under PDD:

#### Major Characteristics

Autism	<ul style="list-style-type: none"> <li>- significant impairment in communication and socialization</li> <li>- restricted interests</li> <li>- stereotypic behaviors (e.g., rocking, spinning, finger or hand flapping)</li> <li>- characteristics appear prior to age 3</li> <li>- four times more common in boys than in girls</li> </ul>
Asperger(AS)	<ul style="list-style-type: none"> <li>- less severe impairment in socialization and communication than autism</li> <li>- typically language development at normal age (or earlier)</li> <li>- typically normal self-help skills and normal (or above) intelligence</li> </ul>
PDD-NOS	<ul style="list-style-type: none"> <li>- marked impairment in communication and socialization</li> <li>- restricted interests</li> <li>- stereotypic behaviors</li> <li>- full criteria not met for autism and/or onset after age 3</li> </ul>
Rett Syndrome	<ul style="list-style-type: none"> <li>- initial development normal</li> <li>- onset 6-18 mo.; may not be noticeable until 1-4 yrs</li> <li>- progressive degeneration (begins 1-4 yrs)</li> <li>- severe loss of communication and cognitive ability, as well as motor skills</li> <li>- distinctive hand movements (wringing)</li> <li>- almost exclusively affecting females</li> </ul>
Childhood Disintegrative Disorder	<ul style="list-style-type: none"> <li>- initial development normal (2-4 yrs); onset can be gradual or sudden</li> <li>- progressive degeneration in all areas (e.g., motor, self-care, play)</li> <li>- severe loss of communication and cognitive ability</li> <li>- stereotypic behaviors</li> <li>- little improvement later (results in severe/profound mental retardation)</li> </ul>

Autism spectrum disorders (ASD) is a commonly used term that refers to three of the diagnoses under the PDD category: autism, Asperger Syndrome, and PDD-NOS. ASD will be used throughout this manual to refer to these three disorders, which represent a set of characteristics that appear in varying degrees. Individuals with ASD have challenges in areas of communication, behavior, and socialization, although the extent to which they are affected and the ways in which they are affected will differ from person to person.

Due to the communication delay in children with autism, they are often diagnosed before the age of 4. Because there is typically no delay in developing basic language skills, individuals with Asperger Syndrome may not receive the diagnosis until much later.

**Although the focus of this manual is on ASD, the information and strategies provided may apply to individuals with Rett Syndrome and Childhood Disintegrative Disorder. Rett Syndrome (which predominantly affects females) and Childhood Disintegrative Disorder are the rarest PDDs. They are characterized by regression, a loss of skills previously acquired, and significant cognitive and developmental problems.**

## History of the ASD Diagnoses

The ASD diagnoses have evolved over time as research has provided a better understanding of the unique aspects. Below is a timeline of this evolution.

1911	Swiss psychiatrist Eugen Bleuler (1911) first used "autism" to describe the social withdrawal of adults with schizophrenia.
1943	Dr. Leo Kanner (1943) first described autism as it is currently understood, basing his discovery on 11 children he observed between 1938 and 1943 who appeared to share a number of common characteristics that he suggested formed a "unique 'syndrome' not heretofore reported." The article characterized the children as possessing an "extreme autistic aloneness" from early in life.
1944	Hans Asperger (1944) published, in German, "Autistic Psychopathy in Childhood."
1940's - 1960's	The medical community felt that children who had autism were schizophrenic. In fact, "infantile autism" was listed as a form of schizophrenia in the International Statistical Classification of Diseases and Related Health Problems (WHO, 1980).
1960s - 1970's	Research studies began to delineate autism as a distinct disorder with a possible neurological basis that was associated with developmental conditions and mental retardation. This new research focus challenged the notion that autism was an early manifestation of schizophrenia.

1980	With this increased awareness and clarity in diagnostic symptomology, autism was officially recognized as a developmental disorder in the Diagnostic and Statistical Manual of Mental Disorders DSM-III (APA, 1980). Within this classification, infantile autism was included in a new class of disorder, the pervasive developmental disorders (PDD).
1987	Significant changes were made to the autism diagnosis with the revision of DSM-III to DSM-III-R (APA, 1987). Although PDD was retained as the broad class to which autism was assigned, the term "infantile" autism was dropped to reflect the recognition that the symptoms continue into childhood, which also emphasized the need to take more of a developmental approach to the diagnosis. Additionally, a new sub-threshold category of PDD-NOS was added.
1994	Research efforts continued to clarify diagnostic criteria and broaden the category. With DSM-IV (APA, 1994), clearer criteria for autism and PDD-NOS were presented to reduce the over identification nature of DSM-III-R criteria that resulted from a lack of clarity. Additionally, with this revision, Asperger syndrome was included as a distinct disorder for the first time. This inclusion again broadened the PDD category.

## Possible Signs of an ASD

ASD impacts three main areas of functioning: communication, socialization, and behavior. However, behaviors and functioning can vary widely within and across individuals even if they have the same diagnosis.

*John is a 7-year-old boy who received a medical diagnosis of autism when he was 3 years old. He does not speak, but uses gestures to make his needs known. When he is not understood, he shows frustration by squealing, throwing himself on the floor and crying. In school, he receives full-day instruction in a classroom for children with autism. He can complete simple puzzles and match blocks by color when asked and supervised directly. John does not interact with his peers. He prefers playing alone and does not play with toys in the way they were intended.*

*Gracie is an 8-year-old girl who was identified by her school evaluation team under the category of autism. After her identification at school, her parents took her to a children's hospital for evaluation where she was diagnosed with Asperger Syndrome. Gracie is very verbal and attends a regular second-grade classroom. While she can read words at a sixth-grade level, her comprehension skills are at a first-grade level. Her teachers report that Gracie has difficulty interacting with her classmates. She loves to talk about spiders and bugs and has begun her own bug collection. She continually tries to dominate conversations with her peers around the topic of bugs. Gracie does not realize that her peers are not interested when they walk away while she is talking.*

While both of these students have an ASD, certainly, their characteristics in the areas of communication, behavior, and socialization vary greatly. The following is a list of some common behaviors or characteristics you might observe in your child:

**Communication**

- Difficulty in expressing needs (may use negative behavior instead of words)
- Laughs, cries, or shows distress for reasons not always apparent to others
- Delayed speech or no speech
- Has difficulty processing language (may not understand and/or may take longer to respond)
- Echolalic immediate or delayed repetition of the words of another person (family member, peers, TV character, singer, etc.)
- Not responsive to verbal cues – acts as if deaf although tests prove hearing is in normal range
- Does not use joint attention (showing or sharing something with another person); this is typically demonstrated by using eye gaze and gestures, particularly pointing, for social interaction.

**Socialization**

- May prefer to be alone; appears aloof
- Difficulty interacting with other children
- May not want physical contact – cuddling, touching, hugging
- Little or no eye contact
- Difficulty initiating conversation or play with others
- Acts or speaks in socially inappropriate manner (such as speaking too loudly or for too long)
- Difficulty interpreting facial expressions and body language
- Difficulty understanding and interpreting emotions (of self and others)

**Behavior**

- Difficulty transitioning from one activity or setting to another
- Tantrums or meltdowns
- Spins and/or lines up objects
- Inappropriate attachments to objects
- Frequently walks on tip toes (toe-walking)
- Stereotypic or self-stimulatory behaviors – repetitive movement of the body or other objects such as hand flapping, rocking, flicking fingers in front of face
- Restricted and persistent interests
- Insistence on sameness; resistance to change
- Self-injurious behaviors

**Other Areas**

- Uneven gross-/fine-motor skills
- Sensory processing issues; unusual responses to sensory input
- Apparent over-sensitivity or under-sensitivity to pain
- Noticeable physical over-activity or under-activity
- Eats limited food choices and/or textures
- Minimal awareness to physical danger

## Diagnosis and Screening for ASD

There is no blood test to determine if a child has an autism spectrum disorder. The diagnosis is referred to as a *descriptive diagnosis*, meaning the diagnosis is based on observation of the child's behavior. This section of the chapter covers early signs that parents might notice as well as screening and diagnostic instruments that professionals may use to make the diagnosis of autism spectrum disorder.

### Early Signs

The characteristic behaviors of ASD may or may not be obvious in infancy (12 to 18 months), but usually become more apparent during early childhood (18 months to 6 years). Children with high-functioning autism or Asperger Syndrome may not be identified until much later because they often show no delay in the development of fundamental language skills.

### “Red Flags” of Autism

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his own by 24 months
- May lose language or social skills after having acquired them

### “Red Flags” of Asperger Syndrome

- Clumsy
- Hyperactive
- Language processing speed (may be slow to understand and respond to requests or may not be able to say what she needs)
- Social skills (may make inappropriate comments, may talk to everyone about a topic of interest)
- Early reading and math skills (may read early but not comprehend what's read, or acquire math skills long before same-age peers)

Demonstrating more than one of these “red flags” does not necessarily mean your child has an ASD. However, it does indicate a need for further evaluation. Many of the behaviors associated with autism are shared by other disorders, such as cognitive disabilities (mental retardation), a behavioral disorder, or problems with hearing. Various medical tests may be ordered to rule out or identify other possible explanations for symptoms being exhibited. It is important to distinguish autism from other conditions, since an accurate diagnosis and early identification provide the basis for building an appropriate and effective educational and treatment program.

## DSM-IV Criteria for Diagnosis of Autism Spectrum Disorder

As previously noted, the current diagnostic criteria for the ASDs are outlined in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (Text Revision) (DSM-IV-TR; APA, 2000). Below is the specific criterion for each of the ASDs:

### Autistic Disorder (299.00 DSM-IV)

The central features of Autistic Disorder are the presence of markedly abnormal or impaired development in social interaction and communication, and a markedly restricted repertoire of activity and interest. The manifestations of this disorder vary greatly depending on the developmental level and chronological age of the individual. Autistic Disorder is sometimes referred to as Early Infantile Autism, Childhood Autism, or Kanner's Autism.

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:

- 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
- Failure to develop peer relationships appropriate to developmental level
- 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)
- Lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:

- 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 gestures or mime)
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- Stereotyped and repetitive use of language or idiosyncratic language
- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - Encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus
  - Apparently inflexible adherence to specific, nonfunctional routines or rituals
  - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - Persistent preoccupation with parts of object

3. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- Social interaction
- Language as used in social communication
- Symbolic or imaginative play

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

### **Asperger's Disorder (299.80 DSM-IV)**

The essential features of Asperger's Disorder are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interest, and activity. The disturbance must clinically show significant impairment in social, occupational, and other important areas of functioning. In contrast to Autistic Disorder, there are no clinically significant delays in language. In addition there are no clinically significant delays in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior, and curiosity about the environment in childhood.

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - 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
  - Failure to develop peer relationships appropriate to developmental level
  - 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 to other people)
  - Lack of social or emotional reciprocity
2. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - Apparently inflexible adherence to specific, non-functional routines or rituals
  - Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  - Persistent preoccupation with parts of objects
3. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
4. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

5. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
6. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

### **Rett's Disorder (299.80 DSM-IV)**

The essential feature of Rett's Disorder is the development of multiple specific deficits following a period of normal functioning after birth. There is a loss of previously acquired purposeful hand skills before subsequent development of characteristic hand movement resembling hand wringing or hand washing. Interest in the social environment diminishes in the first few years after the onset of the disorder. There is also significant impairment in expressive and receptive language development with severe psychomotor retardation.

1. All of the following:

- Apparently normal prenatal and prenatal development
- Apparently normal psychomotor development through the first 5 months after birth
- Normal head circumference at birth

2. Onset of all of the following after the period of normal development:

- Deceleration of head growth between ages 5 and 48 months
- Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
- Loss of social engagement early in the course (although often social interaction develops later)
- Appearance of poorly coordinated gait or trunk movements
- Severely impaired expressive and receptive language development with severe psychomotor retardation

### **Childhood Disintegrative Disorder (299.10 DSM-IV)**

The central feature of Childhood Disintegrative Disorder is a marked regression in multiple areas of functioning following a period of at least two years of apparently normal development. After the first two years of life, the child has a clinically significant loss of previously acquired skills in at least two of the following areas: expressive or receptive language; social skills or adaptive behavior; bowel or bladder control; or play or motor skills. Individuals with this disorder exhibit the social and communicative deficits and behavioral features generally observed in Autistic Disorder, as there is qualitative impairment in social interaction, communication, and restrictive, repetitive and stereotyped patterns of behavior, interests, and activities.

1. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
2. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
  - Expressive or receptive language
  - Social skills or adaptive behavior
  - Bowel or bladder control
  - Play
  - Motor skills
3. Abnormalities of functioning in at least two of the following areas:
  - Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
  - Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
  - Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms
  - The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

### **PDD-NOS (299.80 DSM-IV)**

The essential features of PDD-NOS are severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills; and stereotyped behaviors, interests, and activities. The criteria for Autistic Disorder are not met because of late age onset; atypical, and/or sub-threshold symptomatology is present.

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"-- presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or sub-threshold symptomatology, or all of these.

SOURCE: Definition of Pervasive Developmental Disorders from the *Diagnostic and Statistical Manual of Mental Disorders* (2000) cited in Autism Society of America ([www.autism-society.org](http://www.autism-society.org)). Retrieved March 4, 2007

## Two Definitions of ASD

While medical and educational diagnoses of the ASDs identify the difficulties experienced by individuals with ASD in the areas of communication, socialization, and behavior, the medical and educational definitions of ASD serve different purposes.

The medical definition is required for a “diagnosis” of autism and must be made by a psychologist, psychiatrist, or a physician using criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR).

The educational definition was designed to identify children eligible for special education services under the Individuals with Disabilities Education Act (IDEA) in 1991. This identification is made by the school’s evaluation team and admissions and release committee (ARC), taking into consideration whether the child’s symptoms adversely affect his/her educational performance (see Chapter 4). A medical diagnosis is not required for an educational identification of ASD, nor does it automatically guarantee identification. Current eligibility criteria for special education services under autism are found in KAR 707 1:200, Section 4 and are as follows:

(1) The Admissions and Release Committee (ARC) shall determine that a child or youth has the disability of autism as defined in Kentucky Regulatory Statute (KRS) 157.200 and is eligible for specially designed instruction and related services if evaluation information collected across multiple settings verifies:

- deficits in developing and using verbal or nonverbal communication systems for receptive or expressive language;
- deficits in social interaction (participation) including social cues, emotion, expression, personal relationships, and reciprocal (contributing) interaction;
- repetitive ritualistic behavioral patterns including insistence on following routines and a persistent preoccupation and attachment to objects; and
- abnormal responses to environmental stimuli.

(2) The ARC shall document that the deficits are not primarily the result of one of the following: impaired hearing, physical disability, emotional-behavioral disability, specific learning disability, mental disability, visual disability, deafness and blindness, or traumatic brain injury.

(3) The ARC shall document its interpretation of evaluation information showing that the disability adversely affects educational performance and the child is eligible for specially designed instruction and related services.

To summarize the diagnostic criteria across DSM-IV-TR, IDEA and KAR, refer to the table below from the Kentucky Department of Education Technical Assistance Manual on Autism for Kentucky Schools (KDE, 1997):

Source	Social Interaction	Communication Functioning	Behavior Skills
<b>DSM-IV</b>	qualitative impairment in social interaction	qualitative impairment in communication	restricted repetitive and stereotyped patterns of behavior, interests, and activities
<b>IDEA</b>	a developmental disability that significantly affects social interaction	developmental disability that significantly affects verbal and nonverbal communication	engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual response to sensory experiences
<b>KAR (Kentucky Administrative Regulations)</b>	deficits in social interaction (participation) including social cues, emotion expression, personal relationships, and reciprocal interaction	deficits in developing and using verbal or nonverbal communication systems for receptive or expressive language	repetitive ritualistic behavioral patterns including insistence on following routines, persistent preoccupation and attachment to objects and abnormal response to environmental stimuli

According to the Individuals with Disabilities Education Act (IDEA), if a child has a disability, the child is entitled to a free and appropriate public education (FAPE). FAPE means an individualized educational program (IEP) that is designed to **meet the child's unique needs**. **FAPE includes special education and related services that are provided for the child's educational benefit**. In Kentucky, the medical diagnosis of autism is not required for a child to be identified under the category of autism by the school team and to receive special education services. For more information about educational identification and accessing special education services, see Chapter 4.

## Where to Turn for an Evaluation

If you're concerned about your child's development, talk to your child's pediatrician. He or she may be able to refer you for further evaluation. If your pediatrician does not share your concerns, consider seeking a second opinion from a professional who specializes in ASD.

If your child is in preschool or elementary school, talk to his teacher. If your child is not yet in school, you may still contact your local school district. The school district is responsible for identifying all children with disabilities.

If your child is under 3 years of age, you may also contact Kentucky's early intervention program called ***First Steps***. *First Steps* is a statewide early intervention system that provides early intervention services to children with developmental disabilities from birth to age 3 and their families. *First Steps* is Kentucky's response to the federal Infant-Toddler Program (ITP) established by Public Law 99-457 Part C. *First Steps* offers comprehensive services through coordination with a variety of community agencies and service disciplines. *First Steps* is administered by the *Department for Public Health in the Cabinet for Health and Family Services*.

### Why does *First Steps* provide services?

Children with developmental delays or conditions likely to cause delays benefit greatly from *First Steps* services during critical developmental years. Services and support also benefit families by reducing stress. In addition, early intervention services can decrease the need for costly special education programs later in life by remediating problems early in the child's development.

### Who does *First Steps* serve?

*First Steps* serves children from birth to age 3 and their families. Child eligibility for the program is determined two ways:

#### By developmental delay

A child may be eligible for services if an evaluation shows that a child is experiencing significant developmental delays in at least one of five skill areas: cognition, communication, physical, social and emotional or self-help.

#### By established risk condition

A child may be eligible if he or she receives a diagnosis of physical or mental condition with high probability of resulting developmental delay, such as Autism, Cerebral Palsy, and Down Syndrome.

### How are *First Steps* services provided?

*First Steps* is available in all Kentucky counties. Services are typically provided within the child's natural environment, which is often the home or daycare setting. Services

may also be provided at child development or other designated centers, or in a clinical setting, depending on the needs of the child and family.

Anyone can refer a child for *First Steps* services by calling **800-442-0087**. Referrals are directed to teams at the district Point of Entry offices that help children and families access needed services. Services are available to any child and family who meet developmental eligibility criteria, regardless of income. A family's participation in *First Steps* services is always optional.

An evaluation can also be obtained at a children's hospital or clinic with a developmental psychiatrist or psychologist, or other appropriate, licensed professional.

## The Evaluation Process

Specific practice parameters for the diagnostic evaluation of ASD have been published by the American Academy of Neurology (Filipek et al., 2000), the American Academy of Child and Adolescent Psychiatry (Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999), the American Pediatric Association (Johnson et al., 2007), and a consensus panel with representation from multiple professional societies (Filipek, 1999). These parameters describe two levels of diagnostic assessment. The first level is screening as part of routine developmental monitoring. The second level, for those who fail the screening, involves a multidisciplinary assessment by a variety of clinicians with experience working with individuals with an ASD.

An ASD is diagnosed by observation of the child's communication, behavior, and developmental levels. A brief observation in a single setting cannot present a true picture of the child's abilities and behaviors. Parental (and other caregivers' and/or teachers') input and the child's developmental history are important components in making an accurate diagnosis.

Ideally, an evaluation is completed by a team of professionals from various backgrounds, which may include a combination of any of the following:

**Developmental pediatrician**— Treats health problems of children with developmental delays or handicaps. (A pediatric neurologist may be used in place of, or in addition to, a developmental pediatrician.)

**Child psychiatrist**— A medical doctor who can prescribe medication and provide help in behavior, emotional adjustment, and social relationships.

**Clinical psychologist**— Specializes in understanding the nature and impact of developmental disabilities, including ASD. May perform psychological and assessment tests, as well as help with behavior modification and social skills training.

**Occupational therapist**— Focuses on practical, self-help skills that will aid in daily living, such as dressing and eating. May also work on sensory integration, coordination of movement, and fine-motor skills.

**Physical therapist**– Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination, and motor skills.

**Speech/language pathologist**– Involved in the improvement of communication skills, including speech and language.

**Social worker**– May provide counseling services or act as case manager helping to arrange services and treatments.

The evaluation process may include a variety of assessment tools, such as:

- § Childhood Autism Rating Scale (CARS)
- § The Modified Checklist for Autism in Toddlers (M-CHAT)
- § The Social Communication Questionnaire (SCQ)
- § The Autism Diagnostic Observation Schedule (ADOS)
- § The Autism Diagnostic Interview – Revised (ADI-R)
- § Gilliam Autism Rating Scale (GARS)
- § Psychoeducational Profile, 3<sup>rd</sup> Edition (PEP-III)
- § Parent Interviews for Autism (PIA)
- § Asperger Syndrome Diagnostic Interview (ASDI)
- § Asperger Syndrome Diagnostic Scale (ASDS)
- § Social Responsiveness Scale (SRS)
- § Gilliam Asperger's Disorder Scale (GADS)

What will happen during the Diagnostic Assessment Process?

You will very likely have to wait some time, from several weeks to several months, to obtain an appointment at an autism clinic or with a professional who performs autism assessments. Each diagnostic process will differ based on the practices of the professionals involved and the assessment(s) they are using.

When you make the appointment, be sure to ask the following:

- How long is the waiting period to obtain an assessment?
- What professionals will be involved?
- What assessments will be performed?
- What records will be required from you?
- What will you need to do to prepare for the appointment?
- How many adults will be in the room with your child during the appointment?
- What will happen with your child during the appointment?
- Will you accompany your child during the assessment process?
- How long will the assessment process take?
- How long will it be until you will hear the results of the assessment?
- How long will it be until you have a written report?

## After the Diagnosis: Working with Professionals

As soon as your child is diagnosed with autism, and possibly before, you will most likely begin working with a number of professionals. The following are some of the professionals you may encounter:

- Medical professionals— pediatrician, developmental-behavioral pediatrician, neurologist
- Mental health professionals – psychiatrist, psychologist, neuropsychologist, social worker, caseworker
- School personnel – special education teacher, general education teacher, school psychologist, counselor, special education director, school principal
- Therapists – behavioral therapist, speech therapist, occupational therapist, physical therapist, play therapist, music therapist
- Service coordinators – early childhood interventionist, MR/DD (mental retardation/developmental disabilities) service and support specialist

It can be intimidating to have to deal with so many different professionals. Professionals often speak in their discipline's "jargon," which helps them speak shorthand to each other. It can also serve to distance them from their patients/clients. This distance can sometimes seem like arrogance and insensitivity, and can seem particularly painful the first time a family is told their child has autism. Families remember this moment for the rest of their lives.

It is not that the professionals are uncaring; after all, they chose careers helping children. It is usually because they do not have the training (or the time) to help families process their feelings about the information they are receiving. It is unrealistic to think families will not have strong reactions to receiving a diagnosis of ASD for their child.

### Suggestions for working with Professionals:

First, allow yourself to have the feelings you experience. It is not necessarily a bad thing to show emotion in front of professionals. It will help them develop empathy and a better understanding of what you are going through.

- Communicate your level of stress by sharing actual examples of what you are going through. For example, let the IEP team know that your child is locking himself in the bathroom for three hours every night to avoid doing his homework or that your child is only sleeping three hours a night.
- Do not be intimidated by the expertise of professionals. They are the "expert" in their field, but remember that you are the expert on your child. You have information that is just as valuable and you deserve to be treated with respect.
- If possible, both parents should attend meetings. Even if you are a single parent, it is in your child's best interest for parents to work together. Each parent may request a separate parent teacher conference, but schools are only required to conduct one set of Multi-Factored Evaluation (MFE) or IEP meetings. Both parents should have

access to information about their child unless the court has prohibited one or the other parent from being involved.

- Everyone filters out some information, especially information that arouses intense feelings. Bring a friend or advocate to meetings to help you hear and remember what is being said.
- Make a list of questions when you think of them. Bring the list with you to appointments. Write down the answers as soon as you can or have a friend take notes.
- Ask professionals to explain what they have said in plain language until you understand it.
- If there is not time for them to explain everything to your satisfaction, ask to schedule another meeting.
- Find out how you can communicate with a professional if you have questions later on.
- Clarify early on what services you can expect from the professional. For example, find out if the particular doctor provides diagnosis or assessments for the disability you suspect. Some pediatricians cannot or will not diagnose ASD.
- Communicate often.
- Keep communication open. Discuss problems as soon as they arise. Be honest. Give the professional a chance to address any problems.
- Be prepared. Professionals have limited time. Appointments will go more smoothly if you have done your homework and are ready with questions.
- Keep appointments or call if you can't keep them.
- Put everything in writing. Keep notes of every appointment and phone call. (See Parent Record-Keeping Worksheet at the end of this chapter).
- View professionals as resources in their fields. Continue to ask questions until you understand their position. Sometimes the professional does not have the most current information. Parents of children with autism are often in a position of knowing more than the professional.
- Remember that everyone has biases. Ask and understand what they are. For example, a surgeon's solution to a medical problem is usually to cut. A medical doctor's solution may be to use medication. Ask for data to support their recommendations.
- Don't assume that professionals are only interested in what is best for your child. They may have competing interests. For example, a school system is only required to provide your child an "appropriate program," not necessarily the best program. They are trying to use their dollars most efficiently for many children. You want the best program for your child.
- Learn your rights.

- Be a good consumer. To advocate for a particular treatment method or service, do your homework and bring the research with you.
- Figure out what you really want for your child and state it as a goal. Instead of demanding a particular treatment or service, ask the professionals how they propose to help your child to achieve the goal. Then ask if what they propose is going to work and how they know that.
- Demand accountability. Professionals should have data and research to show what works.
- Ask for periodic reports so you can monitor your child's progress.
- Ask for a meeting to discuss options if a treatment or therapy is not working.
- Remember it is okay, and you have the right, to disagree with professionals and, ultimately, to decide what is right for your child and family.
- Be respectful, even if you disagree. Explain your point of view in a calm, courteous way.
- If a relationship with a professional breaks down and is beyond repair, or if you don't feel comfortable with the relationship, you have the right to leave.
- Beware if you are continually jumping from one professional to another. Ask yourself if you have some unresolved feelings you need to deal address.
- Nurture and cultivate relationships with professionals, especially those who are working directly with your child. Your child will need all the advocates he/she can get.
- Consider bringing brownies to a meeting. Chocolate makes everyone feel better.

**Thank professionals in writing when they have helped you. Also write to their supervisors about how they have helped your child. You and your child will most likely be working with a host of professionals for his/her entire life.**

**You will get more help for your child if you can learn to build strong relationships with those who are in a position to help him/her. This will start with you believing that you are an equal partner in parent-professional collaborations and continue as you nurture those relationships.**

## **Dual Diagnosis or Comorbidity**

People with ASD can have two or more separate diagnoses, including mental health, medical conditions, or other developmental disabilities. This is referred to as *dual diagnosis*, *comorbidity*, or *co-existing conditions*.

**With Specific Developmental Disabilities:**

It can be difficult to identify and diagnose symptoms and traits of ASD as distinct from other developmental disabilities that can cause speech and communication delays, low muscle tone, sensitivities to/unawareness of light, sound, or different kinds of touch, or demonstration of repetitive movements. It is important to understand the difference between symptoms in children who only have other conditions and those who also have ASD, because it could impact the treatment and services a child receives.

It is well documented that ASD can co-exist with many other conditions. Each year more parents are getting accurate diagnoses of autism, ASD, PDD-NOS, etc., among their children who also have:

- Fragile X syndrome
- Epilepsy and seizure disorders
- Visual impairment/blindness
- Hearing impairment/deafness
- Down Syndrome
- Tuberous sclerosis
- Cerebral palsy
- Angelman's Syndrome
- Eating disorders
- William's Syndrome
- Prader-Willi Syndrome
- Fetal alcohol syndrome or effect

It is not the intent to describe each condition in detail here. However, if you suspect autistic behaviors or traits in your child who has another developmental disability, please pursue an evaluation from a qualified professional. Having an accurate diagnosis of ASD for a child with a co-existing disability can help make important decisions for treatment and education. (For example, behaviors may be misinterpreted without a proper diagnosis. Sometimes an adult may declare that a child is "choosing" to ignore verbal directions, when that child is, in fact, too overwhelmed by environmental noises as a result of her ASD. In such a case, using pictures or written words instead of verbal directions is recommended, but such interventions are often not considered for a child who has normal hearing and can say some words.)

Some disability support organizations, such as those for Fragile X, Down Syndrome, and sensory impairments (visually impaired, hearing impaired) offer specific resources and support for the dual diagnosis that includes ASD. These can include organizations like the Upside of Downs, the National Association of the Deaf, the National Federation for the Blind, and Disability Solutions.

**If anyone from whom you are seeking help says "There is no such thing as a dual diagnosis, you are just in denial about your child", seek another opinion!**

**With Other Diagnoses – Common Disorders That Can Occur with ASD:**

Just as a child with epilepsy can suffer from anxiety, depression, motor difficulties, speech delays, and any other condition, an individual with ASD can suffer from other symptoms or disorders. Though these conditions can and should be treated, their treatment does not address the distinctive symptoms of ASD, such as impairment in social interaction, restricted repetitive and stereotyped patterns of behavior or interests, and so on, and thus the primary diagnosis of ASD should not be ignored.

Examples of co-occurring/dual diagnoses include the following:

**(a) Mental Health**

- Bipolar disorder
- Generalized anxiety
- Obsessive compulsive disorder
- Oppositional-defiant disorder
- Depression
- Mood disorder

**(b) Neurological**

- Seizure disorder (estimated at up to 25% of individuals with ASD)
- Tourette 's Syndrome
- Sleep disorders
- Learning disabilities
- Attention deficit disorder (ADD or ADHD)
- Sensory integration disorder
- Executive functioning disorder

**(c) Physical**

- Cerebral palsy
- Muscular dystrophy
- Abnormal gait
- Poor coordination

**(d) Medical**

- Diabetes
- Asthma
- Heart conditions
- Vision loss
- Hearing loss
- Allergies
- Gastrointestinal conditions
- Hypoglycemia

In addition to the specific diagnoses above, unusual responses to sensory stimuli, sleep problems, and low muscle tone can occur in individuals with ASD.

While generalized anxiety or panic disorders are frequently co-occurring disorders in their own right, anxiety is also an inevitable outcome for individuals on the spectrum who try to fit into neurotypical society (Gutstein, 2004). Other symptoms of living with ASD may also look like a separate disorder, although they are an expression of ASD.

## Occurrence of Autism

Prevalence rates for ASDs currently range from 1 in 100 children (Centers for Disease Control and Prevention, 2009; Kogan, et al., 2009) to 1 in 166 children (Frombonne, 2003a, 2003b). This wide range is the result of differences in the findings of various research studies. Based on these estimates, approximately 24,000 children born in the United States every year will eventually receive a diagnosis of ASD. There are currently approximately 500,000 individuals, aged 0-21, with ASD in this country. ASD is more common than childhood cancer, Down Syndrome, and juvenile diabetes.

## Genetics Research and Autism

As mentioned, there is currently no known cause of ASD. During the past decade, scientists have made significant breakthroughs in understanding the genetics of autism. Researchers are now focusing on specific chromosomal regions that may contain autism-related genes. This has been accomplished by studying chromosomal abnormalities in individuals with autism and by screening each chromosome for evidence of genes associated with autism.

Current theory among autism genetics researchers supports the idea of “complex” inheritance. This means that multiple genetic factors are likely to be involved and may predispose an individual to develop autism. This theory also includes a role for environmental factors. That is, in addition to having a certain combination of autism-related genes, exposure to specific environmental factors may be necessary for autism to develop in some individuals. For instance, if one version of a gene makes a person susceptible to a particular chemical, exposure to that chemical could trigger autism to develop. By focusing on the study of genetic factors and determining their underlying mechanisms, researchers may be better able to pinpoint environmental factors that contribute to autism.

Much of current research is based on the Human Genome Project, a 13-year scientific study to identify and analyze all the genes in human DNA. If you have questions about a possible genetic link regarding autism in your family, it is recommended that you consult a geneticist.

## Parent Record-Keeping Worksheet for Important Phone Calls and Meetings

This form allows you to take and keep clear, concise notes from important meetings, phone calls, and doctor's appointments. It is a good idea to file and keep these notes for future reference.

**Date:** \_\_\_\_\_ **Subject:** \_\_\_\_\_

**Phone Call: Received/Placed** \_\_\_\_\_ **Phone # Dialed:** \_\_\_\_\_

**Left Message:** Yes / No      **Other Message Dates:** \_\_\_\_\_

**Name of Contact Person:** \_\_\_\_\_

**Company/Agency:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Meeting:** \_\_\_\_\_

**Location:** \_\_\_\_\_

**Other Attendees:** \_\_\_\_\_

**Referred to:** \_\_\_\_\_ **Reason for Referral:** \_\_\_\_\_

**Telephone #:** \_\_\_\_\_ **Email:** \_\_\_\_\_

### Notes/Key Points of Conversation:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

### Results of Conversation/Next Steps:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

**Other Thoughts/Notes:**

## Letter to Request a Multi-Factored Evaluation

Date you write your letter **(Include month, day and year)**

Your Name

Your Full Address

Full Name of Person to whom you are writing **(the Principal or the Special Education Director)**

Person's Title **(Principal, Special Education Director)**

Name of School

Full Address of School

Dear **(Use their title [Dr.; Mr.; Mrs.; Ms.] and last name):**

I am the parent of **(Your child's name)**, who is in the \_\_\_\_ grade at **(Name of school)**. My child is not performing successfully in the general education classroom. **(Briefly state your concerns; examples: failing grades; problems with friends at school; it takes a very long time for your child to complete homework; child comes home very upset; etc.)**

Since my child is not performing successfully, I suspect he/she a disability. Under Child Find §300.125 in IDEA '97, I am requesting a complete multifactored evaluation.

Please consider my signature on this letter as my permission to test my child. It is my understanding that when a multi-factored evaluation is requested, the school district is required to provide parents with their procedural safeguards. Please forward them to me at the above address.

Thank you for your attention to my request. I may be reached at **(Your daytime phone number)**. I will expect to hear from you within 5 school days of receipt of this letter.

Sincerely yours,

**Your Full Name**

**Regional University Based Multi-Disciplinary Evaluation Services****Weisskopf Center for the Evaluation of Children (WCEC)**

(502) 852-5331

University of Louisville, 571 South Floyd Street, Suite 100, Louisville, KY 40202

The WCEC provides comprehensive multi-disciplinary evaluations that are based on referral concerns. Families are assisted in gaining a better understanding of the child's developmental needs. Available professionals include: Developmental Pediatricians, Genetic Counselors, Psychologists, Speech Pathologists, Occupational Therapists and Social Workers.

**University of Louisville Bingham Child Guidance Center**

(502) 852-6941

200 East Chestnut St, Louisville, KY 40202

Diagnostic evaluations of persons in whom "high functioning autism", Asperger's Disorder, or other social communication handicap is suspected but not proven. Uses the Autism Diagnostic Interview and Autism Diagnostic Observation Scales to solve "diagnostic dilemmas". Available professionals: Pediatric Psychiatrist and Pediatric Nurse Practitioner.

**Eastern Kentucky University Psychology Clinic  
(Developmental Disabilities Specialty Clinic)**

(859) 622-2356

Eastern Kentucky University, Department of Psychology, Richmond, KY 40475

The Developmental Disabilities Specialty Clinic provides parent, family, child, and group intervention services. Assessment services are available on a limited basis, including diagnostic consultation, behavioral consultation, psychological evaluation, and a limited number of multidisciplinary evaluations. Available professionals include: Psychologists, with consultation from Speech Pathologists, and Occupational Therapists.

**Kelly O'Leary Center for Pervasive Developmental Disorders**

(800) 344-2462

Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, Cincinnati, Ohio 45229-3039

The Kelly O'Leary Center at Cincinnati Children's Hospital Medical Center provides comprehensive, multidisciplinary, family centered services for children with Autism Spectrum Disorder (ASD) and their families. Available Professionals include: Developmental Pediatrician and Pediatric Nurse Practitioner.

**Riley Child Development Center (RCDC)**

(317) 274-8167

702 Barnhill Drive Rm. 5837, Indianapolis, IN 46202

The RCDC provides family centered interdisciplinary evaluations for children with autism spectrum disorders and other developmental disabilities. Evaluations are planned around questions from the family, primary physician, and school. Available disciplines typically include behavioral pediatrics, psychology, social work, speech therapy, occupational therapy, physical therapy, audiology, nutrition, pediatric dentistry, and nursing, and may include child psychiatry, child neurology, and genetics.

**Vanderbilt Center for Child Development & Research**

(615) 936-0264

Medical Center North 415, Vanderbilt University Medical Center, 200 Children's Way, Nashville, TN 37232-3573

Vanderbilt's CCDC provides clinical services, including diagnosis, assessment, and intervention planning for children with disabilities and their families. They also provide early intervention services, Pre-service training, and outreach training and they conduct research. All developmental disabilities are addressed, with an emphasis on children birth to 5 years of age. Available professionals include: developmental pediatricians, psychologists, and social workers, with access to occupational therapists, physical therapists, speech-language pathologists, and special educators.

**Kentucky Children's Hospital Developmental-Behavioral Pediatric Clinic**

University of Kentucky (859) 323-6211

740 S. Limestone, 2<sup>nd</sup> Floor

Lexington, KY 40536

The Developmental-Behavioral Pediatric Clinic provides comprehensive diagnostic assessments and ongoing management of children and adolescents with developmental and behavioral concerns. Professionals involved include: Developmental Pediatrician, school psychologists, nursing staff.

## To Do List for Kentucky Families with Children Who Are Diagnosed with Autism Spectrum Disorder

Learn **all that you can** about the diagnosis of autism. There are many wonderful, parent-friendly resources to help you. The “Kentucky Family Guide to Autism Spectrum Disorders” can be found by visiting <https://louisville.edu/education/kyautismtraining/resources/family-guide>. The Kentucky Autism Training Center also houses an extensive resource library. These materials are available for loan free of charge to anyone in the state of Kentucky. Information about the library can be located by visiting <https://louisville.edu/education/kyautismtraining/resources>. The 100-Day Kit by Autism Speaks is a toolkit to assist families in getting the information they need in the first 100 days after an autism diagnosis. You can locate this by going to [www.autismspeaks.org/community/family\\_services/100\\_day\\_kit.php](http://www.autismspeaks.org/community/family_services/100_day_kit.php).

Consider **creating a notebook** to carry with you to all of your child's medical appointments and school meetings. It is easy to forget many of the fine points when a great deal of information is shared. Writing things down will help you to keep track of all of the important details.

Join the **Kentucky Autism Training Center's listserv** to learn about local, regional, state and national resources and trainings. Information at <https://louisville.edu/education/kyautismtraining/katc-listserv.html>

**If your child is under age 3 seek early intervention**, contact the **First Steps** Program. Referrals should be made to the Point of Entry (POE) for your local area. The POE list can be found at the First Steps website <http://chfs.ky.gov/dph/firststeps.htm> or by calling (800) 442-0087.

Under the Individuals with Disabilities Education Act (IDEA), all children with disabilities have the right to a free and appropriate public education. **If your child is age 3 or older, you can contact your local school to secure special education services entitled to your child.** Your regional Special Education cooperative can also assist in your child's programming. Your cooperative can be found by going to the website <http://www.education.ky.gov/KDE/HomePageRepository/Partners%2BPage/Kentucky%2BEducation%2BCooperatives.htm>

Check with your insurance company about the \$500 allotment for autism medical and behavioral health coverage. For information about this allotment, see the publication “Insurance Benefits for Children with Autism” at <http://insurance.ky.gov/kentucky/ALSearch/Information/fpubs.aspx>. If you have a problem accessing these benefits, contact the Kentucky Department of Insurance at (800) 595-6053 or by visiting <http://insurance.ky.gov>

Explore the possibilities associated with government-administered insurance programs. Information about eligibility guidelines for the Medicaid and KCHIP programs can be found at <http://chfs.ky.gov/dms/>. Eligibility information about Supplemental Security for children with disabilities can be found by visiting <http://www.ssa.gov/pubs/10026.html> or by calling your local Social Security office.

Learn about treatment and intervention options. For a brief overview of evidence-based interventions, consult chapter 3 of the Kentucky Family Guide to Autism Spectrum Disorders by visiting <https://louisville.edu/education/kyautismtraining/resources/family-guide>.

Find out what resources are available in your area. The Kentucky Autism Training Center's online Services and supports guide can be searched by local region. You can access the guide at <http://katcproviders.louisville.edu/>. In addition chapter 5 of the "Kentucky Family Guide to Autism Spectrum Disorders" discusses social service programs within the state. You can see this guide by going to <https://louisville.edu/education/kyautismtraining/resources/family-guide>

Learn about the Medicaid **waiver programs**.

- The Michelle P. Waiver (MPW) is a home and community-based waiver under the Kentucky Medicaid program developed as an alternative to institutional care for individuals with mental retardation or developmental disabilities. MPW allows individuals to remain in their homes with services and supports. Information can be found at <http://chfs.ky.gov/dms/mpw.htm>
- The Home and Community Based (HCB) Waiver program provides services and support to elderly people or children and adults with disabilities to help them to remain in or return to their homes. Information can be found at <http://chfs.ky.gov/dms/hcb.htm>
- Supports for Community Living (SCL) is a home and community-based waiver under the Kentucky Medicaid program developed as an alternative to institutional care for individuals with mental retardation or developmental disabilities. SCL allows individuals to remain in or return to the community in the least restrictive setting. For more information, visit <http://chfs.ky.gov/dms/scl.htm>
- Hart-Supported Living is a program that provides grants to persons with a disability. These grants provide a broad category of highly flexible, individualized services that provide necessary assistance for the individual to live in the community. Review teams who review each application make funding decisions. Applicants may apply for "one-time" or "ongoing" grants. Learn about this grant program by going to <http://chfs.ky.gov/dial>

Find other parents who understand the challenges of raising a child with autism. Consider joining a support group. A list of support groups is available from the Kentucky Autism Training Center at: <https://louisville.edu/education/kyautismtraining/resources/family-guide>. Check the websites of local groups to information about local services and resources.

Plan ahead for day care and summer needs such as aftercare programs or YMCA programs. Explore your local resources and make the contacts.

Kentucky Protection and Advocacy can help you understand your child's rights and advocate for your child's services. Visit <http://www.kypa.net/drupal/nodeconsult> or call (800) 372-2988.