

Kentucky's Family Guide to Autism Spectrum Disorders



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Kentucky's Family Guide to Autism Spectrum Disorders

*This guide was developed and written
by parents of individuals with
autism spectrum disorders. The examples
provided are from their experiences.
The information included in this manual
is a result of their answer to the question:
When your child was first diagnosed,
what information did you need most?*

The Topics Addressed in this Guide include:

- Chapter 1** Autism Spectrum Disorders: What is ASD, Diagnosis, and Screening
- Chapter 2** Living with ASD: You Are Not Alone
- Chapter 3** Interventions: A Review of Therapies, Models, and Strategies
- Chapter 4** Accessing Educational Services: Navigating Through The School System in Kentucky
- Chapter 5** Social Service Programs: Kentucky Resources
- Chapter 6** Advocacy: Raising Awareness and Influencing Service Delivery
- Chapter 7** Future Planning: Growing into Adulthood
- Chapter 8** Introducing Your Child to ASD: How and When to Talk to Your Child About the Diagnosis

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2010 Kentucky Autism Training Center
All listed websites are current as of date of publication, April 2010

DISCLAIMER: The content of this manual does not necessarily reflect the position or policy of the Kentucky Autism Training Center, College of Education and Human Development, University of Louisville nor should the content of the manual be considered an endorsement for the use of any particular intervention.



This publication is possible because of the combined efforts of the following members of the Kentucky Family Guide for Autism Spectrum Disorders Work Group, who gave generously with their time and expertise:

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Kentucky Family Guide for Autism Spectrum Disorders Work Group would like to express a deep gratitude to members of the Ohio Center for Autism and Low Incidence (OCALI) Parent Resource Manual Task Force for serving as an inspiration and providing Kentucky with a frame work to develop this much needed resource for families.

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*We welcome your feedback about this Guide. Please visit our website to complete a brief survey.
<http://louisville.edu/education/kyautismtraining>*



Dr. Thomas Pinkstaff, a longtime Lexington pediatrician, passed away April 12, 2009. During his long career in pediatrics, Dr. Pinkstaff was an active member on a wide range of associations, committees and boards, including the Kentucky Autism Training Center, and served as president of the Kentucky Chapter of American Academy of Pediatrics. He was a tireless advocate, consultant, and educator regarding children's health issues, but was especially passionate about education and support for individuals with autism.

The KATC honors the compassion of Dr. Pinkstaff by dedicating the second edition of the Kentucky's Family Guide to Autism Spectrum Disorders to his memory.

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

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). 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 |
|--|--|---|--|
| DSM-IV | qualitative impairment in social interaction | qualitative impairment in communication | restricted repetitive and stereotyped patterns of behavior, interests, and activities |
| IDEA | 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 |
| KAR (Kentucky Administrative Regulations) | 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, 3rd 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 CCDD 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, 2nd 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.

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.

CHAPTER 2

Living with ASD: You Are Not Alone

This chapter provides parents of children with ASD practical strategies and suggestions for how to handle situations that may arise when living with a child or children with ASD. The chapter explores such topics as toileting, family outings, physician appointments, family issues, finances, and other family issues. .

Upon receiving a diagnosis of ASD, parents experience a host of strong emotions. Few forget the day when they realized that their child had a developmental disability and that their journey of parenting might be quite different from what they had imagined. In an article entitled *You Are Not Alone*, Patricia McGill Smith (see box below) tells of a parent describing it as if a “black sack” was being pulled down over her head, and she could not hear, see or think in normal ways.

Each person may react differently to the news, but there are some common reactions that are shared by many. Parents grieve the loss of the “typical” child that they expected to have. You may experience some or all of the following:

- **Shock or denial** You may think, “How can this be happening to me?” or you may want to make the disability go away.
- **Anger** You may be angry at yourself or others for “causing” ASD. You may be angry at God, at medical personnel, at your spouse, or even your child.
- **Guilt** You may think there was something you could have done that would have prevented the diagnosis, or that you in some way “caused” the diagnosis.
- **Rejection** Some parents even report having a “death wish” for their child.
- **Confusion** Experiencing confusion is very common for families trying to sort through all the information about ASD and make choices about treatment.
- **Fear** You may fear the worst or have memories of other children and/or adults with disabilities and wonder if your child will have a similar life.
- **Isolation** Because of the unique communication, social and behavioral issues presented by children with an ASD, you may feel very alone. Eating out, doing things as a family, finding time alone with your spouse or spending time with your friends becomes a challenge.
- **Envy** Seeing other parents with their typical children may make you feel envious and resentful.
- **Relief** Some parents report they are glad to know that their child’s behavior is not caused by poor parenting, and that there is an actual diagnosis for their child.

As extreme as some of these feelings may seem, they are normal. One of the ways you can take care of yourself is to realize that you, your spouse, or family members are not bad people for feeling angry or having other negative feelings — you are human. These are common feelings parents and families have reported as they go through the process of adjusting to a child’s diagnosis. You may find yourself feeling waves of grief throughout the lifespan at different times. Events like birthdays, school transitions, holidays, and other big events can trigger feelings of loss.

If you get stuck working through the stress and grief of having a child with an ASD, seek help and support.

Signs That Indicate That You May Need Help:

- Trouble sleeping or sleeping all the time
- Feeling tired all the time
- Loss of appetite
- Headaches, or other frequent pains
- Loss of interest in sex
- Thoughts of hurting yourself or others
- Feeling that you have to spend every waking moment learning about autism and how to help your child
- Losing all patience and desire to spend time with other members of your family.

See a health care provider and/or counselor for help.

Patricia McGill Smith's *You Are Not Alone* article can be found at the web link

<http://www.kidsource.com/NICHCY/parenting.disab.all.4.2.html>

You Can Do This!

Although at times it may seem almost impossible to handle the challenges that you are facing, you can do this! Remember, your child is not defined by his/her ASD. You will be able to parent your child successfully if you try to:

- Appreciate the uniqueness of your child. Don't compare him/her to others.
- Focus on your child's strengths. All children have things they do well.
- Show unconditional love. If you find yourself taking anger out on your child or someone else, get help.
- Get informed. Learn about your child's educational and other rights as well as programs that can help you and your family. Ask lots of questions!
- Don't be overprotective. Let your child do things for himself/herself as much as possible. Have fun!! Find things you both enjoy and do them often.

The *Autism Speaks 100 Day Tool Kit* is created specifically for newly diagnosed families, to make the best possible use of the 100 days following the diagnosis of autism. The kit contains information and advice collected from trusted and respected experts on autism as well as from parents of children with autism. There is a week by week plan for the next 100 days, as well organizational suggestions and forms that parents/caregivers can use to help with the paperwork and phone calls, as they begin to find services for their child.

http://www.autismspeaks.org/docs/family_services_docs/100_day_kit.pdf

Taking Care of Yourself and Your Family

The demands and challenges of raising a child with an ASD can be overwhelming. According to the Autism Society of America, research indicates that parents of children with ASD experience greater stress than parents of children with mental retardation and Down Syndrome. The best way to help your child is to deal with your own stress.

Having support can make a big difference, but you must take the initiative. You cannot always expect others to come to you.

Share your feelings with your spouse/ partner if you have one. Reaching out to each other helps both of you.

Enlist the help of friends and relatives. While they can help, be aware they may also be experiencing some of the same feelings of loss and confusion. Talk openly with them about your child and how they can help.

Involve your faith community. Some parents find comfort in their spirituality. See "Issues of Faith" later in this chapter.

See a counselor for individual or marital counseling if needed. Check with your doctor, mental health agency, or leader of your faith community for possible counselors. Ask if they have experience with special needs families.

Find other parents who understand the challenges of raising a child with ASD. The importance of parent-to-parent support cannot be overstated. Other parents of children with disabilities can identify with your feelings of loss and frustration, help you find programs and funding for therapies, laugh with you, and possibly even cry with you. Many enjoy the company of another parent because there is no judgment, but rather a true understanding of how hard parenting can be. Talking with another parent is a great place to find practical everyday help for issues that may be hard for you right now. You can find support informally by meeting for a cup of coffee, joining an online support group, or locating local organized support groups.

Parents report that they often learn as much from talking with other parents as they do from professionals and books. Parents before you have learned to negotiate education, funding and other service systems, and they can give you many helpful pointers on how to access services.

In Kentucky you can call
(502) 852-4631 to find out about
parent support groups near you

Online Support

In this age of technology, many people turn to their computers before going to the library or bookstore when researching information about ASD. The Internet can also be a place of refuge for parents who are hesitant to talk about their personal lives in the more public forum of a support group meeting. There are electronic (online) groups that are organized around the topic of ASD so that individuals can exchange information about topics of common interest. They can also serve an important support function for people who are strapped for time to attend meetings in person or are geographically isolated.

Electronic mailing groups or listservs are the safest to participate in. These Internet communities are commonly referred to as **listservs** (the copyrighted name for electronic mailing list or email list). They are also referred to as “**Internet groups**” or just plain “**lists.**” Both Yahoo and Google (two major Internet browsers) have “Groups” under their listings. Yahoo and Google both have thousands of these listservs grouped by categories. Particularly helpful are those online groups that are moderated, meaning that you must ask permission to join and someone reviews the postings to ensure that they are appropriate. There can be varying degrees of restrictions for membership, depending on how the groups were created.

Listservs will have archives of old postings. In order to search the archives of a group, or list, you must be a member. In other words, you cannot just open up a website and begin to participate. This extra level of security means that members can reduce the risk of “spamming.” Further, moderated groups have the ability to “unsubscribe” people who do not abide by the rules set up for the group.

While it is important to have an understanding network of family and friends to count on when the going gets rough, your existing circle of friends may not be able to understand your changing needs and their support may not be adequate. An electronic mailing group can be like having an autism help hotline available 24/7.

For example, on a recent electronic mailing group for parents of children with ASD, a parent reported that his child began having sleep problems again after months of sleeping through the night. The list member soon received responses from several parents who had similar experiences and who suggested strategies they used to deal with the problem. Parents may use the list to locate competent caregivers for their children.

“**Blogs**” (short for web logs) are also increasing in popularity. They are a kind of online journal created by an individual, but made public on the Internet so anyone interested can read about their experiences. Like the listservs, they can link people with common interests.

Chat rooms are roundtable discussions in real time where several people who are online at the same time can send messages to one another and discuss particular topics.

KATC LISTSERV

Learn more about upcoming events, trainings, workshops, support groups, disability related information and other useful information for families and professionals in the autism community in Kentucky. To join contact the KATC at katc@louisville.edu

<http://katcproviders.louisville.edu/>

This database is searchable by region, county, age and service. The demands of caring for an individual with autism are great, and families frequently experience high levels of stress. Often, the lack of appropriate services adds to the frustration of families. As a way to assist families in finding available services, the KATC has created a Kentucky Autism Services and Supports Directory to help parents and professionals share information.

Family Matters

Take Time for Yourself

Most parents of children with an ASD feel they do not have the time to do anything for themselves, but even a few minutes a day can help relieve stress. When we are stressed, our brains are working overtime and our judgment can be impaired. Sometimes we think we cannot stop out of guilt because we might not be helping our family enough. We continue to work harder and harder while getting more frustrated and possibly making mistakes.

Simple things like taking a short walk, listening to music, or cooking a favorite meal can help you to feel better. Take time to think about your unique abilities and interests that are separate from your role as a parent. It is okay to take a break from your child now and then. Taking a break is good both for you and for your child. In fairness to all family members, it is okay for your family to occasionally engage in activities without your child with ASD. Take an extended break if you are able. If it seems impossible to do, start small and gradually extend the time. You may have to learn to relax and let go. Here are some tips that may help.

- Set an alarm or timer to remind you to take breaks throughout the day.
- Schedule extended breaks (a few hours a week or whatever you can manage) on your calendar instead of waiting until you think you can fit it in. If it is not scheduled, it usually doesn't happen
- Spend time in prayer/meditation
- Take the time for daily exercising/walking/stretching
- Practice deep breathing/relaxation exercises
- Keep a journal
- Set realistic expectations, but have a "to-do" list to guide your activities
- Advocate for others; that is, help another parent take an action or say what they want or get what they need.

Make Time for You and Your Spouse

Parenting a typical child can place stress on a marriage. Parenting a child with special needs can be especially challenging. Couples need to have open discussions about their feelings, but they also need opportunities to stay connected and talk about things other than the children. Listening to and respecting your spouse's feelings can go a long way to remaining close. Recognize that your spouse may handle grief differently than you and allow your spouse to do it in his or her way. Remember that you are a "couple" in addition to being "parents". Try to find someone to care for the children and establish a "date night". Going to a movie or going out to dinner once in a while can help protect the romance in your relationship. If you are unable to find someone to take care of the children, make plans for a "date" at home-perhaps having a nice dinner after the kids have gone to bed. It is important that you stay connected with your spouse.

Single Parenting

Many parents face parenting without a spouse or significant other because of death, divorce, or separation. Divorce and death/loss are two of the most stressful events for any family.

After a divorce, the following may be beneficial:

- Incorporate a visitation schedule into your child's visual or written schedule

- Help your children to identify their emotions, even if it makes you or them uncomfortable. This is very important because negative behaviors may occur when children do not acknowledge their emotions
- Give your child time to adjust to the change in routine
- Use pictures/video of the different homes your child will be going to. This will help to explain the change in living arrangements
- Try to keep the rules and rewards the same in each household to help in managing difficult behavior
- If possible, keep the non-custodial parent involved in your child's development and education.

Single parenting may require you to ask for help more often than if you had a live-in spouse or partner. This can be hard, but it is an important part of keeping yourself healthy. Being a single parent, you may find yourself concerned with how you are going to handle all the expenses of raising a child with ASD alone. You may also question how you will be able to date or have a serious relationship with someone in the future, knowing that you have a child with ASD. These are legitimate concerns. Remember, these questions have gone through the minds of many other parents of children with an ASD. Other parents can be your best resource. Seek the support of those who have experienced similar circumstances.

Siblings

Siblings will be in the life of a person with ASD longer than anyone else. The sibling relationship can have a large impact on the future of both your typical children and your child with an ASD. In other words, the way a typical child reacts to having a sibling with an ASD will affect the relationship that they have in the future. Again, it is helpful to hear others' experiences. Many see having a brother or sister with special needs as something positive that teaches them to accept others as they are. Siblings can be the strongest protectors and loudest cheerleaders. In contrast, some siblings feel jealous, neglected, or rejected because of the time and energy they see being invested in the child with special needs. Typical siblings may worry about the future of their brother or sister and their future role in care giving. They may be concerned about how peers will react to their sibling with ASD and they may feel embarrassed. Some typical siblings become targets of aggressive behaviors. These can be difficult issues for parents.

What do siblings need?

Information/communication – Siblings need regular discussions about ASD that are suitable for their level of understanding. They need to be able to ask questions and share their concerns. A young child may be concerned about “catching” autism while older siblings may be more concerned about what is expected of them in future care giving. Try to make no subject “out of bounds” to discuss.

Support – Just like parents, siblings need support. They need a place to talk to other siblings about what it is like to have a brother or sister with ASD. Look for support

groups, Sibshops, or other programs for siblings in your area. There are also online support groups and listservs for siblings. (See the resources at end of the section.) If there is no formal group in your area, arrange some informal play dates with brothers and sisters of children with ASD that you know to give them the opportunity to interact with each other.

Respect and consideration for their uniqueness – Celebrate even “expected” milestones for siblings. Allow them to have choices about how involved they want to be with their sister or brother.

Safety – Siblings need to have a safe place for themselves and their belongings. Help them to learn to communicate with you and their brother or sister with ASD when they need space and time away. Be sure they know it is okay to ask for help.

Individual time and attention – Plan to spend regularly scheduled time alone with your typical children. They need to count on a specific time that is devoted just to them.

Acceptance of typical sibling behavior – Sibling conflict is normal in most households. Expect conflict and know this may help prepare the child with an ASD for real-life situations. Don't always expect the typical sibling to compromise or “know better.”

Opportunities to have a “normal” life – Give yourself permission to take a trip without the child with an ASD. Try to find respite resources so siblings can fully experience things they choose. Both siblings and the child with ASD need chores and responsibilities equal to their abilities. Don't assume that because your child has an ASD he/she does not have the ability to help around the house.

Strategies for dealing with their sibling, peers, and their own emotions – Siblings need to know how to deal with the unusual behaviors that are often exhibited by their sibling/s with ASD. They also need some guidance in how to deal with questions from peers and the general public. Siblings need to know that it is okay to feel embarrassed about their sibling or to worry about him/her. Sometimes the assistance of a professional counselor can help the typical child to cope.

Positive parents – Probably the greatest impact will be the attitude of the parent(s). Being positive will help you meet the challenge. How we choose to deal with our own emotions and attitudes will impact our experiences.

The following was written by a teenage girl with a brother with an ASD

c d

My brother has autism. His diagnosis has changed our family, from the constant presence of a therapist and dietary changes that encompass the whole family, to accommodating his sensory issues in all that we do. However, to dwell on these aspects implies that autism defines our family, when this is not the case. We simply do what must be done for him; all that this entails has become our norm. In the process of living with and loving

him, we have learned to cherish his true essence, rather than focusing on the superficial actions or differences of autism.

My brother has autism. Most of the time, I hardly think about it. But sometimes, when he and I are sitting together on the couch, I am overwhelmed with a painful and instinctive consciousness of an intangible barrier between us. I can sense the person inside my brother, shielded by autism. During these moments, I mourn for the relationship that has been denied us. Despite the pain, I am able to realize how blessed I am to know and love the sweet, gentle part of him that escapes the autism barrier.

As my brother and I enter our teenage years, our future lives, as adults, loom closer with each passing day, as is evidenced from his changing voice and newly acquired height. The unknown aspect of his future is frightening. Right now my parents are my brother's primary caregivers, but how will this role change in the future? I wonder if I will be capable of handling the responsibility of this position when the time comes. The future, in addition to posing challenges for me, contains incredibly difficult hurdles for him, including finding friends, activities, a job, and an independent life. While my family is doing everything we can to prepare him for his adult life, the uncertainty of what lies ahead for him is achingly real.

Above all, I wish that he will always be surrounded by love. If the world could see what we do when looking at him, instead of being blinded by his autism, my wish would be an instant reality. But this is not a perfect world. Therefore, my family and I will continue to fight for him, attempting to ensure a fulfilling and meaningful life for him.

Natalie Pope

b a

Grandparents and Other Family Members

Like parents, grandparents grieve the loss of the "typical" grandchild and are concerned for their own children in the process. They, too, will need information, open communication, and recognition that they are grieving. Many well-meaning family members offer advice on behavioral issues. However, parents can become frustrated and perceive a lack of support when grandparents do not agree with the parents on how to handle difficult situations with their child with ASD. Open communication and information can help enhance your support and allow family members the opportunity to learn about your child.

c d

“Why do you have to travel so often to see your grandchildren?” Was so often asked by my relatives and friends. At the time, I had one grandson in Atlanta and one granddaughter in

California. My response was, “You’ll never understand until you have a *grandchild* of your own.”

As time passed, my daughter gave birth to twin boys and moved to Kentucky with her family. A few months later, Eric, one of the twins was diagnosed with autism. As a result, Grandpa and I visited every two to three months offering as much help and support we possibly could during those short stays. This continued for a few years. One day Grandpa suggested we moved to Kentucky and be full-time grandparents. My first reaction was that my husband was not serious about the move. I was so wrong.

“*Why* or how could you give up 42 years in the same home, leaving your family and friends, and move to KY?” My response was a little different this time. “You could never understand unless you had a *grandchild with autism*.”

Our new journey began in October 2007 with our move to Louisville. Entering blindfolded and unaware of what autism really is, how can we possibly help?

I can only speak for myself. Looking at my three grandsons, I burst with love. With Eric there is an added feeling of heartache knowing he does not communicate much or have fun with his brothers like they do with each other. Mostly, I carry this feeling of guilt because I want to make everything okay. I want Eric to say, “Grandma, it’s okay.” and “Grandma I love you.”

Will the day ever come when he can leave his own little world to enter ours or allow us to enter his? Meantime, I will continue to love him, and let him know how special he is. I will do all I can to help Eric and his family.

Hopefully this will lessen the feeling of guilt. Why can’t I make him better? After all, I am Eric’s **GRAND**ma.

Jean Mannarelli

b a

Family/Social Gatherings

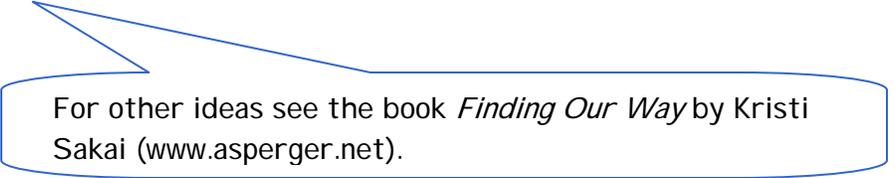
Holidays, family reunions, birthdays, visiting relatives, and other special celebrations can be especially stressful for a child with ASD. These activities may bring about unexpected events as well as excessive amounts of sensory stimulation. Such situations can contribute to anxiety and the child can soon feel overwhelmed.

Writing a letter before family visits can help make the event more enjoyable. Share the things that will help your child feel comfortable, activities that he/she enjoys, foods he/she likes, and how family members can expect your child to respond when situations may be too much for him/her. Bring special toys, videos, games, or other comfort items. Be sure to plan frequent breaks when traveling. Finding a place where your child can take a break from the crowd will help the visit be more enjoyable for everyone.

Holidays bring lots of change and increased social demands. Consider keeping the decorations simple and safe. Make sure your decorations will not choke or harm your child if he/she were to touch them or place them in his/her mouth. Send a list of preferred gifts to family members to help everyone feel more fulfilled. This way your child will receive a gift he/she prefers and the family member may get to witness him/her

enjoying the gift. Prepare your family for the possibility that your child may not want to participate in opening gifts or consider setting a limit on the number of gifts he/she is expected to open. At home, you may allow your child to open a gift a day so he/she is not overwhelmed on the actual holiday. Consider using a social narrative or social story to describe what will happen at holidays or birthdays or other special events.

If you plan to attend a family reunion or other large gathering, showing your child pictures of the unfamiliar people and places ahead of time may help ease anxiety. Preparing both your child and your family through open communication is always helpful.



For other ideas see the book *Finding Our Way* by Kristi Sakai (www.asperger.net).

Day-to-Day Issues in Living with ASD

This section is a broad overview with suggestions for navigating the many situations and decisions parents face as they negotiate their daily lives to support their child with an ASD. It covers friendships, finances, approaching therapy and education decisions, creating a workable daily home schedule, dealing with doctor appointments, and even discusses issues of faith.

Balancing Life on the Spectrum

It is easy to feel overwhelmed by all the decisions that you will be making while living with an ASD. It can be challenging to find time and ways to help everyone feel valued and get their needs met-not to mention having your own needs met-as discussed earlier. If everything in your family revolves around your child with an ASD, other family members can become resentful. Do you define your family as a special needs family or a family with a special needs child? Finding the proper balance in decision-making and making choices that fit your family will help ease the stress of day-to-day living.

You may be wondering...

- Should I/we have another child, knowing there is an increased risk for having another with an ASD?
- Should I/we have another child so there is a sibling to take care of our ASD child when we are gone?
- Should we move or sell possessions to get better services?
- How many assessments and therapies are necessary for my child?

Evaluate your decisions carefully and try to keep some balance in your everyday life. Consider how decisions will impact your whole family and not just the child with an ASD. Unfortunately, there are people who take advantage of families that are desperate to help their child. Carefully research the services and/or treatments that are being offered to you and your child with ASD. Select the services according to what best meets the

needs of your child and family. While searching for answers you will find opinions that may differ even among the “experts.” Take one day at a time and try to keep your routines as normal as possible. It will help provide some consistency when things are hectic.

Your Changing Circle of Friends

One of the most difficult and surprising aspects of learning that your child has a diagnosis of ASD is discovering that your circle of friends will change. Your friends and close family members can be a true source of support and encouragement. Unfortunately, when we need our friends and family the most, sometimes they are not as supportive as we had hoped. As a result, you may find yourself confiding in total strangers at a support group meeting or seeking comfort in the listening ear of a coworker when you used to share *everything* with your sister, or your best friend.

Individuals are just that – *individuals*. The people who have been closest to you may react to your child's diagnosis in a variety of ways, just as parents react in a variety of ways. Some may be in denial while others may express a genuine sadness. Keep in mind, though, that your closest friends and family members love and care about you *and* your child. Their concern is for your well-being as much as it is for your child's.

When an adult friend or relative has experienced a life-changing event, many people do not know how to react. Some friends are uncomfortable in the presence of people with mental retardation or developmental disabilities. Others withdraw in fear that they would say or do the wrong thing. This may be true if your child has challenging behavior or has yet to attain functional communication. In an effort to be supportive, people may say all the wrong things:

“My cousin's son didn't talk until he was 4, and now he's a sophomore in college.”

“Einstein was autistic, you know.”

“Well at least he can walk.”

“I saw a lady on TV whose son's autism was cured with (fill in the blank).”

“God gives you only what you can handle.”

Others may be blunt:

“That kid just needs a spanking now and then!”

“Get over it!”

You will no doubt hear statements that will hurt your feelings or cause anger. It is difficult enough to ignore a stranger, but we expect much more from those close to us. Parents are vulnerable, especially when new to the diagnosis. If you are having difficulty with feelings of depression or anger, consult a professional counselor who has experience in working with parents of children with chronic disorders. A chaplain at the nearest children's hospital may be able to provide appropriate resources or referrals.

Also consider that, although we have crossed into the 21st century, many adults today did not grow up with much exposure to people with cognitive disabilities. And certainly,

most did not attend school with children with disabilities. So the reactions of your friends and family members, especially the older ones, may simply be due to a lack of knowledge.

The best way to react to these situations is to share information about ASD, and to encourage friends and relatives to spend time with your child. Invite them to your support group meetings or ask them to accompany you on a doctor visit. Explain to them that you not only need their moral support, but you also could use a little respite from time to time. The better they know your child, the more willing they may be to help. Make a mental note every time someone offers to help, however generic the offer may be. If you are experiencing a particularly difficult week, ask someone to run errands for you, help with laundry, or pick up your children after school. If you are affiliated with a church or a social club, fellow members may be willing to assist in some way on a regular basis. Be comfortable in asking for help when there is a need. Many people are happy to help. You will be supported, and your child will be exposed to a variety of people and personalities in the process.

Your daily routines have probably changed since your child's diagnosis. Much time is now spent with therapists, teachers, medical specialists, and other providers who understand and accept your child. It may be easy to consider these new adults in your life as your new friends. You may look forward to the brief encounters with professionals who truly understand. Certainly, they may be friendly people, and they can be a tremendous source of support to you; however, your *real* friends should not be forgotten. Include them as much as possible in your new routines. Think outside the box when planning visits with your friends. While your life may have changed, your friends' lives probably have not, so try not to let autism be the topic of every conversation.

Parents, grandparents, and siblings largely report that support groups have been very helpful. However, others are uncomfortable with the candid expressions of feelings and vulnerability displayed at support group meetings. Attending casual gatherings or informal activities sponsored by autism groups may be an easier way for some parents to meet new friends. Some areas in Kentucky have successfully started support groups and other activities just for dads, grandparents, or siblings of autistic kids. These provide opportunities for the attendees to meet other people who share similar experiences.

Family Finances

Having a child with ASD can be a drain on a family's resources due to the cost of expensive evaluations, home programs, and therapies. One family member may have to give up his or her job because of the care-giving demands of raising a child with autism, increasing financial pressures as a result. Because of the challenging behaviors often present in children with ASD, many parents find the need to seek out jobs with flexible hours or work different shifts so one parent is at home all the time. Some parents have developed their own home-based businesses, and still others rely on some form of government assistance to manage.

Networking with other parents, getting involved with local support groups or chapters of ASA will keep you informed of the latest sources of funding and other supports that could help. It may be difficult for you to ask for help, but there may be untapped resources out there.

Things to consider related to finances and funding services:

- If insurance denies a claim, appeal it.
- Parents in the same insurance company can band together. One company planned to drop coverage for speech therapy, but after several parents called and wrote letters, the benefit was reinstated.
- Ask providers if they have fees based on income.
- Use college students to help. They are more affordable these students may be able to earn course credit.
- Use volunteers from your community if you are doing a home-based program.
- Ask that money be given for services to help your child instead of extravagant toys and gifts.
- Consider hosting your own fundraisers.
- Explore possible tax deductions with your tax advisor.
- Consider consulting a Certified Financial Planner to discuss a Special Needs Trust and other financial planning issues.

10 Things I Want My Friends to Know

- Ø My life has changed, but I still want you to be my friend. We may need to be creative in thinking of new ways to spend time together.
- Ø Listen. I want you to know about my child and about how his life is affected by ASD. I may have days when I just need to “vent.”
- Ø Keep what I say confidential. As my friend, you may occasionally be my sounding board. Please respect the privacy of my family by not repeating what I say.
- Ø Don't judge my child or me. Ask questions if you have concerns about the choices we have made for our child.
- Ø Respect my feelings. My feelings may run the gamut from desperation to hopefulness and will change largely based on what kind of day my child is having.
- Ø Encourage and support me. I need to hear positive feedback. Be my guest at a support group meeting, or offer to keep my child while I go.
- Ø I really am happy for the milestones that your children are reaching. Don't exclude me from your celebrations; however, please understand if I am not always able to attend.
- Ø Ask questions. I'll be happy that you are interested.
- Ø Communicate with me. Please let me know if you can or cannot help with my child. It is OK to tell me if you are uncomfortable. I need to know how you feel.
- Ø Be my advocate. Other friends or acquaintances may not understand or may be judgmental. You may be able to keep them abreast of my child's progress and our family's needs.

Daily Functioning at Home

In addition to dealing with friends and finances, parents often find that they must create a daily home schedule that supports the child with an ASD and the family as well. Families engage in daily routines within the household that are executed with little thought or planning, and certain activities continue to occur without question over and over again. They are a part of living, a part of being in the household. These include activities such as:

| | |
|-------------------|--------------------------------------|
| Bedtime | Going to the grocery store/errands |
| Bath time | Household chores |
| Meals | Getting ready for school |
| Play time | Having other children visit the home |
| Nap or quiet time | Toileting/self-care |

Although a variety of strategies could be suggested here for each activity to help a child with ASD cope more easily, it is important to focus on the underlying characteristics and environmental factors of each child and each home situation as you think about these routines. As you encourage your child with ASD to participate in these routines and gain adaptive skills, consider the following:

Understand that your child's age may not equal his developmental level

It is important to remember that children with ASD often vary in developmental levels across areas. For example, a child may be on level with typical peers in communication skills, but lower in social interactions. Even within one area, a child's skill level can vary. A child might be comfortable entering into a conversation, but unable to maintain the conversation. With daily living skills, a child may be able to set the table with utensils for dinner, but may become overwhelmed when asked to clear the table and put away leftover food and dishes.

Create realistic expectations

As expectations are being created for the child, make sure they are appropriate for his/her ability level. Utilize skills that the child has mastered to build confidence and encourage the use of new, emerging skills. Take time to teach a task in small increments so that if a problem arises, the problem step can be re-taught and supported. Look for ways to break down complex tasks into smaller pieces so the child will be successful. For example, if a child is 18 years old, but developmentally 7 years old, do not expect him/her to do a full load of laundry alone. Consider steps for each task, such as gathering the dirty clothes, sorting by color and whites, or putting away the clothes when the laundry is complete. As the child masters one step, add another to build the child's ability to complete the entire task.

Understand the difference between schedules versus routine

Maintaining a routine is different from keeping a schedule. For example, a bedtime routine may be flexible in the schedule because it is not always precisely at the same hour. However, the bedtime routine stays structured in that the child always gets to

have one book read, is tucked in by a parent, and goes to sleep with his teddy bear. This allows for flexibility within the schedule while maintaining a routine.

For more detailed information on intervention strategies for a specific routine, refer to *Everyday Solutions: A Practical Guide for Families of Children with Autism Spectrum Disorders* by Mindy Small and Lisa Kontente (www.asperger.net).

Hygiene

Hygiene can pose challenges for individuals with an ASD in multiple areas. Most hygiene tasks involve lots of sensory information that can be overwhelming. Self-care usually involves many steps as well as motor planning. Socially, many individuals with ASD miss the importance of good hygiene as well as unwritten rules that go with visiting public restrooms and other social situations that relate to care of their bodies. The seemingly obvious, such as bathing regularly or wearing clean clothes, may not be important to children with ASD since they may not understand their significance. This understanding, along with the skills related to hygiene, will need to be taught.

There are many unwritten social rules related to self-care. Early on, we may be worried about just teaching the tasks, but as children get older and more self-aware, it is important to teach them the social behaviors that many of us take for granted. The following are just a few examples of the “hidden curriculum” that must be directly taught to children with ASD.

Public vs. Private Behavior

- Teach proper urinal behavior for boys such as not lowering pants fully to the ground or looking at others' body parts while toileting.
- Make it clear that scratching or adjusting one's private parts or underwear is not to be done in public.
- Teach that it is not appropriate to pick one's nose in public.

For Teenagers

- Help them learn what is “in” and what is “out.”
- Help them understand how much first impressions count.
- Help them see how hygiene can affect relationships and even employment.

Although challenging, teaching children to take proper care of themselves is a huge step toward independence. Many of the tools used to help in other areas are equally helpful when it comes to personal hygiene. For example, visual/written schedules, social narratives, desensitization, and gradual exposure to a task can all be used to help individuals with ASD learn new tasks.

Consider the sensory issues that are involved with these tasks. Hands and heads are some of our most sensitive areas. Select among the following options for making this a less traumatic experience for your child with ASD:

- If your child is a sound sleeper, trim hair and/or nails at night.
- Find a hair stylist who will come to your house.
- Play relaxing music or find a distracting toy, video game, or a favorite television show to occupy the child while the haircut or nail trim is occurring.
- If going to a stylist, visit the shop several times before actually going for a haircut. Use pictures or video to illustrate what is going to happen.
- Pick a time when the shop is not so busy.
- Go frequently, even for just a small trim, rather than wait a long time between haircuts.
- Experiment to determine whether clippers or scissors are better. Some children like clippers because they can make the cutting go faster, but they can also sound louder.
- Consider combing hair more than once a day to get used to the sensation.
- For nail trimming, do a finger at a time with breaks in between until more tolerable.
- Put hygiene checks into your child's daily schedule. Remember: If it is not seen, many do not think about it. Simply reminding them to look in the mirror may be enough.

Hand and Body Washing

Preferences are important for motivation. Consider the following:

- Does your child prefer aromas or textures for soap? Consider foam vs. bar vs. liquid.
- Does your child prefer a certain water temperature?
- Does your child like soft or rough washcloths and towels?
- Does your child prefer a schedule or list of tasks to be performed while washing?
- Is hand-over-hand support provided to help the motor planning and memory?

Toileting

Becoming toilet trained is one of the most important skills that your child will need to learn, and it is not easy. It takes real commitment from parents and caregivers, but it can be achieved with a systematic approach. This text is only a brief outline of one method. Refer to the resources after this section for more information on toileting.

To begin the process, your child should be able to:

- Follow simple directions.
- Sit in a chair for 5 minutes.
- Stay dry for 1-1/2 hours

Skills Involved in Toileting

Initially, focus only on teaching your child to eliminate in the toilet. Later, teach the other skills needed to be completely toilet trained, including:

- Recognizing when he/she has to go
- Waiting to eliminate
- Entering the bathroom
- Pulling pants down
- Sitting on the toilet
- Eliminating in the toilet
- Using toilet paper correctly
- Pulling pants back up
- Flushing the toilet
- Washing hand
- Drying hands

In the beginning, going to the toilet should be a casual matter with little required on the child's part other than to sit. In a 20-minute period, give your child two 5-minute chances to eliminate with a 10-minute break in between.

Elimination Records

About two weeks before you are ready to start toilet training, start recording when your child urinates and has a bowel movement to establish her elimination pattern – the times of each day when she is most likely to wet and/or soil her pants.

| Time | Monday | | Tuesday | | Wednesday | | Thursday | | Friday | | Saturday | | Sunday | |
|-------|--------|--------|---------|--------|-----------|--------|----------|--------|--------|--------|----------|--------|--------|--------|
| | Pants | Toilet | Pants | Toilet | Pants | Toilet | Pants | Toilet | Pants | Toilet | Pants | Toilet | Pants | Toilet |
| 7:00 | | | | | | | | | | | | | | |
| 8:00 | | | | | | | | | | | | | | |
| 9:00 | | | | | | | | | | | | | | |
| 10:00 | | | | | | | | | | | | | | |
| 11:00 | | | | | | | | | | | | | | |
| 12:00 | | | | | | | | | | | | | | |
| 1:00 | | | | | | | | | | | | | | |
| 2:00 | | | | | | | | | | | | | | |
| 3:00 | | | | | | | | | | | | | | |
| 4:00 | | | | | | | | | | | | | | |
| 5:00 | | | | | | | | | | | | | | |
| 6:00 | | | | | | | | | | | | | | |
| 7:00 | | | | | | | | | | | | | | |

In the Pants column, you will record every hour:

- D=dry
- U=Urinated in pants
- BM=Bowel movement
- U/BM=Both

During these two weeks, there is no failure or success. You are only trying to see what your child's elimination pattern is so that you can set up a toileting schedule that makes sense for him/her.

Determining a Toileting Schedule

The bathroom routine should be:

- Bring your child to the bathroom on schedule or when he/she signals. Pull his/her pants down to below the knees, encouraging her to do the rest.
- Have him/her sit on the toilet for 5 minutes. Stay with him/her, praise him/her, and explain what is expected in a straightforward, non-demanding
- If he/she eliminates, praise her and give her a reward.
- If he/she does not eliminate, remove him/her from the toilet, and take him/her out of the bathroom for 10 minutes. Return to the bathroom for another 5-minute sitting.
- Carefully analyze the Elimination Record. At this point, decide whether you will focus on urine or bowel training. For this example, we focus on urine training.
- Circle all the U's on the forms and add them up.
- There will be a greater number of times for urination. Select four or eight times during the day when your child is most likely to eliminate. No two times should be closer than 1-1/2 hours.
- Arrange the toileting schedule so that your already established toileting times for bowel training become a part of it.
- Take the child to the toilet at all the schedule time.

Putting the Child on the Toilet

The bathroom routine should be:

- Bring your child to the bathroom on schedule or when he/she signals. Pull his/her pants down to below the knees, encouraging her to do the rest.
- Have him/her sit on the toilet for 5 minutes. Stay with him/her, praise him/her, and explain what is expected in a straightforward, non-demanding way.
- If he/she eliminates, praise and give a reward.
- If he/she does not eliminate, remove him/her from the toilet, take him/her out of the bathroom for 10 minutes. Return to the bathroom for another 5-minute sitting.

In the beginning, going to the toilet should be a casual matter with little required on the child's part other than to sit. In a 20-minute period, give your child two 5-minute chances to eliminate with a 10-minute break in between.

Using Visual Cues

You may create visual cues, consisting of photographs or pictures, to support the toilet-training process. A good aid to use during toilet training is a visual schedule to help the child through the toileting procedure. Here is an example:



In addition, a special visual prop can be helpful in setting the tone and in alerting your child to the activity. An example is to give the child a rubber duck when you want him/her to use the bathroom. Parents of nonverbal children may also consider incorporating sign language or a picture into the routine and teaching the child the sign or picture for toilet so the child will learn to indicate when he needs to use the restroom.

Intensive Training

Another method is called “intensive training” or “weekend training.” It consists of spending the entire day in the bathroom focused entirely on toilet training. This approach also uses the Elimination Record to record times when the child was placed on the toilet.

Using this method, the child is dressed in only a shirt and remains on the toilet until he eliminates. Once the child eliminates, he is given a 5- to 10-minute break, then placed on the toilet again. The child is given plenty of fluids and salty snacks to encourage elimination. Parents use favorite toys in the bathroom to occupy the child.

Sensory Issues

Parents face some consistent problems relating to sensory dysfunction when trying to toilet train a child with ASD. Many children on the spectrum are sensitive to such things as the feel of the water splashing from the toilet, the texture of the toilet paper, the sound of the flushing, the feel of the toilet seat, and the list goes on. It is not uncommon to see the following demonstrated by some children with ASD:

- Flushing or playing with water in the toilet
- Playing with toilet paper
- Smearing feces
- Being “addicted” to diapers
- Refusing to wash hands
- Refusing to eliminate in toilet
- Being afraid of flushing or frequent flushing for noise
- Refusing to sit on toilet

Set the Stage for Success

Be consistent: Keep the toileting routine as consistent as possible so that your child will come to expect it and be at ease with it.

Use a regular toilet from the beginning: If your child is too small, place a smaller seat on top of the regular toilet.

Avoid distracting toys and people: It is important for your child to learn that the bathroom is not a playroom; he is there for one reason only- to eliminate in the toilet.

Avoid distracting talk: Talk to your child about what he is supposed to be doing and what the toilet is for. Avoid talking about unrelated matters.

Puberty

Puberty can be an exciting time in a young adult's life. It's the time when the body makes many changes – both physical and emotional – to prepare for adulthood. It is a good opportunity to teach teenagers with ASD about their bodies and how they work.

When children become teenagers, their bodies start to dramatically change. They begin to grow pubic and underarm hair. They start to break out with acne. Girls begin to menstruate. Boys' voices change. For teenagers with ASD, these changes to their bodies may be frightening if they are not forewarned and prepared.

Parents need to decide the best way to talk with their teenagers with ASD about human sexuality based on their beliefs and traditions. Basic introductions should address the following topics:

1. Describe the basic physical changes that occur on the outside of the body during puberty.

2. Describe the basic physical changes that occur inside of the body during puberty.
3. Describe the basic emotional changes that occur during puberty.
4. Identify ways to manage or handle these changes.

Puberty

| Typical Changes | Changes in Girls | Changes in Boys |
|---|-----------------------|-----------------|
| Increased attention to physical appearance | Growing breasts | Erections |
| Interest in romantic love | Beginning periods | Wet dreams |
| Increased need for independence | Premenstrual syndrome | |
| Masturbation | | |
| Unpredictable changes in mood | | |
| Desire to be accepted and liked by peer group | | |
| Pubic and underarm hair | | |

Human Sexuality

Eva Markham, Ed.D.

When we think about sexuality, we tend to fast forward to romantic, consensual relationships between adults. Most of us, as parents, would prefer not to spend a lot of time thinking about our children and sexuality. Somewhere along the line, we may impart a few choice nuggets of information about physical growth and development. Most parents also attempt to communicate their personal values on topics such as premarital sex, same sex relationships, etc. Much of what is viewed as a part of the general area of sexuality is very socially derived. For this reason, it is imperative that caregivers and educators who care for young persons on the autism spectrum take a life-span approach to sexuality. This is of value for two reasons:

First, the young person can develop to the fullest of her or his abilities and have the skills necessary to engage successfully with another person in a romantic/ sexual relationship if that is her or his choice. Second, and sometimes more important,

teaching the complex nuances of sexuality may enable young persons with an autism spectrum disorder to avoid becoming the object of criticism or scorn for exhibiting behaviors that others find offensive or sexually inappropriate. Some common examples include the youngster with autism who fails to develop the sense of modesty typical peers usually get around puberty or the young woman with autism who is too direct in her expression of interest in a young man she has just met.

Individuals who are involved with youngsters having autism spectrum disorders may wish to peruse some of the links appended to this article and decide how best to approach the topic of sexuality/ sex education given her or his own values and comfort level. In all likelihood, it will be helpful to recognize that a much more structured approach to teaching in this area may be needed for the individual with autism. While those of us who are “typically developing” likely learned a lot about sexuality and related topics through observational learning and through our peer relationships, this mode of information will be less successful for persons on the autism spectrum. To view the component parts of sexuality education as ongoing and natural will be helpful. Thinking in terms of such broad areas as public versus private, acceptable versus unacceptable, safe and unsafe may make it easier to approach the myriad behaviors that comprise sexual behavior. Just as we have learned that certain teaching strategies are better for educating persons having autism, so can we use those same techniques to assure that the individual is prepared to be a safe, happy, and successful member of our culture, equipped with all the skills she or he will need to form lasting relationships if that is his or her choice. We can be assured that we have added to the quality of life of persons with autism spectrum disorders. Last, but not least, we can consider that we have enabled the individual to be safer, and less likely to be victimized or penalized.

Safety

All too often, we hear about stories such as these:

A boy in Florida slipped out of a house crowded with family members during a holiday celebration. He was found in the bottom of a pool, said Wendy Fournier, president of the National Autism Association.

Many children with autism, unfortunately, do not recognize safety issues when they arise. They also may have difficulty identifying an oncoming dangerous situation. With many of our children unable to clearly communicate to other individuals or understand what someone may be saying to them, they are capable of being in great danger more often than not.

Children with autism can be very curious individuals, to the point that wandering from home is more common than the general public realizes for these families. Many times, we hear of stories of children with autism wandering into the streets, pools, and woods. Many times, we hear of the sad ending when these children were not found until too late.

These incidents can happen any time of the day or night, whether a parent, babysitter or grandparent is watching the child. These incidents also happen at relatives homes and

when people are off guard. There could be many people at the home for a family gathering and the child slips away easily. Other times, the child darts out of the house and is gone in an instant.

The following are suggestions to help increase the safety of your child in his or her surroundings:

- Take a walk around your neighborhood streets and see how many fences, wooded backyards or pools exist. Get a sense of where in the neighborhood you might look your child wandered off
- Check your home's windows and doors and the types of locks on them.
- Circulate photos of your child to neighbors and let them know a child with autism lives close by. Make sure they have your name and phone number. Many children with autism do not know this information, especially their phone numbers.
- Visit the local police and fire stations with a photo of your child, if at all possible.
- You may want to investigate the use of tracking bracelets with GPS devices.

Besides the risks of a child that could escape from home, there are also dangers inside the home at various times of the year. During the holidays, you need to be very cautious with Christmas trees and decorations, especially if your child is a climber. During the summer months, you may be cooking outdoors on the grill and pool dangers may be evident. Screen doors may not be locked at all times.

If your child has ever escaped from your house, this is a warning sign and you need to take action. Everyone who works with your child needs to know this could happen under their supervision.

Consider the many behaviors an individual with autism may engage in that could be unsafe: climbing, throwing, breaking, jumping, peeling, cutting, pulling down, throwing plates and cups, sweeping items off surfaces, dumping drawers and bins, and climbing out of or breaking windows. Or consider what can happen when natural curiosity and household appliances converge: putting items in appliances, flushing things, touching burners, turning hot faucets, inserting items into electrical sockets, chewing on wires, and crawling in a washer or dryer. Finally, consider the potential dangers that can result from playing with matches, lighters or fire.

Often children with autism who display such behavioral concerns do not understand the ramifications of their actions. At best, these behaviors can be bothersome and at worst, can be devastatingly tragic. Therefore, it becomes incumbent upon the caregivers in the home to provide both a safe environment and ways to teach their children to be safe.

There are several environmental and safety modifications that can be made in the home, as well as steps that can be taken to prevent unsafe or inappropriate behaviors. Many strategies have been found to be helpful in preventing dangerous behaviors and ensuring a safer environment. The suggestions range from using locks for security, limiting access to the individual, to labeling every functional item and area in the home with photographs or symbols to assist in communication.

Sometimes parents balk (initially) at the idea of having to place locks on doors or cabinets, having to place alarms outside a child's bedroom, or having to label the house with photos or cards. They often say: "This is not a classroom." However, your home is indeed a natural learning environment, just like a classroom.

Establish priority areas for modification. Modify the most important areas first - such as the individual's bedroom, bathroom, leisure areas, kitchen, and back yard - since these are the primary areas of interaction for many children. When getting started, think about the room(s) in which your child spends the most time; for some children it would be a recreation/ family room, for other children it might be the bedroom or kitchen. In addition, consider the behaviors to be modified and the relationship of those behaviors to the environment. Behavior modification works to alter an individual's behavior through positive and negative reinforcement. Remember that behaviors always serve some purpose--and in order to alter a particular behavior it must first be understood. If the individual likes to put things in the toilet or run hot water in the bath, modifications should begin in the bathroom. If your child runs out of the house, modifications should begin with securing exterior doors with locks.

Elopement or Wandering

Have you ever found yourself worrying about your child wandering off and getting lost? All parents are concerned about their child's safety – whether the child has special needs or not. The concern of parents of children with ASD is often heightened due to the child's deficits in communication and socialization.

You can use direct instruction to teach your child that wandering away is not appropriate. You can use stories to explain that it is dangerous for your child to leave your house or yard. Still, some children and adolescents with ASD have an overwhelming desire and talent for leaving their homes and wandering unattended. This does not only happen at home. Children often wander away from a parent at a busy store or at the park. This is very dangerous because most children with ASD do not understand or obey the rules of the road or private property.

Neighbors can be very helpful in keeping an eye out for your child. Talk to them and explain what to do and how to approach your child if they should see him out alone. You can also inform neighborhood children and teenagers about what to do if they see your child out alone.

Make sure to contact your local police and fire department to alert them about your child and his/her tendency to wander. They should be able to "red flag" your telephone number and home if you ever call 911. This specific information may be embedded in the 911 database, so that the dispatcher will be able to tell the police and fire department about your child before they arrive.

If wandering is a typical problem for your child, you can install extra locks on all exterior doors high enough so your child cannot reach them, even when standing on a chair. Many parents have installed sliding bolt locks on the top frame of the door. There are also bed and door alarms available to signal when a child or adolescent is out of bed or

opens a door or window. You can even get an alarm that plays a recorded message when a door is open, like “Jack! Do not leave the house!” and then sounds a siren to alert the parent. Children or adolescents can also wear bracelets that trigger an alarm once they pass through a protected doorway.

A very helpful precaution is to have a medical identification tag for your child to wear that lists name, diagnosis and contact information. These can be ordered at a drug store or online from MedicAlert. These medical emblems can be worn on the wrist, around the neck, or laced into a shoelace.

To be prepared, parents can create an emergency handout about their child for the time when they do wander off.

Sample Autism Emergency Contact Handout

If your child is a habitual wanderer, keep a copy of this handout at home, at school, in the car and on their child in case of an emergency. The sheet should include the following information:

- Name of child
- Current photograph and physical description, including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers, and emergency contact persons
- Sensory, medical, or dietary issues and requirements
- Inclination for wandering and any atypical behaviors that may attract attention
- Favorite attractions and locations where child may be found
- Likes and dislikes as well as approach and de-escalation techniques
- Method of communication. If nonverbal – sign language, picture boards, written word
- ID jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted

Out in the Community

As parents of a child with an ASD, we are familiar with our son's or daughter's behavior, but others may not be accustomed to this disorder. Most of our children appear normal to others. It is only when they start to exhibit bizarre or out-of-control behavior that they

come to the attention of others. Outings in the community can be a great challenge for most parents.

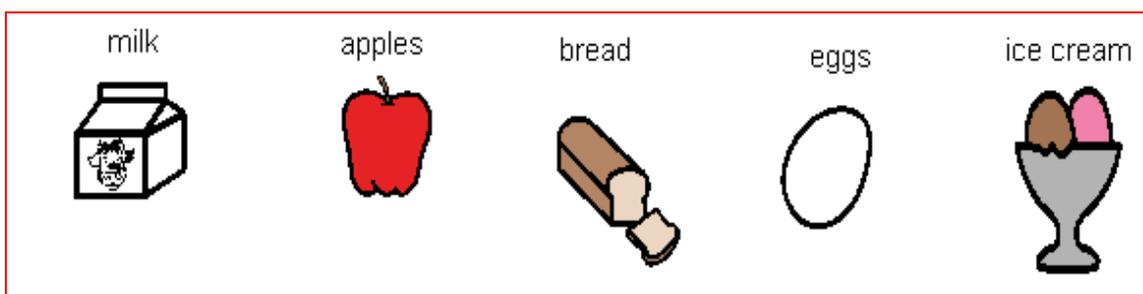
Tips for Successful Outings

- Keep outings short.
- Do what you say you will do in the order you say you will do it.
- Decide on the optimal number of stops.
- Do the most important things first.
- Prepare a visual schedule for your child.
- Offer a reward at the end of the outing for good behavior.

Shopping Trips

One of the biggest challenges a family faces is the weekly shopping trip. Sometimes it is considered more trouble than it is worth. However, shopping is a basic skill that needs to be learned by children with ASD. Shopping trips are a good opportunity to teach your child to become more independent.

- Create a visual shopping list using visual symbols of the list (see example below)
- Involve the child in the selection process. For example, if you are buying a dozen apples, have the child select them. Point out if one has a bruise so he can learn.
- Bring handheld toys or action figures to occupy the child.
- Allow the child to help push the cart once she is older and no longer fits in the cart.



Issues of Faith

For many families, attending religious services is an important part of family life. It is intended to be a time of worship and quiet reflection, but when a child with ASD attends, it can be anything but quiet.

Nevertheless, a family's place of worship can be a source of comfort and support. While some families are established within a faith community, others may be new to religious life having turned (or returned) to their faith as a source of strength upon the diagnosis of their child. Dedicated members of your faith community may be able to assist your family in various ways, from offering a listening ear to providing assistance in your home. A faith community may provide a comfortable setting for companionship and support.

Including a family member with ASD in religious services and activities may require some creative planning. Many religious bodies have programs for people with disabilities within their religious communities (see Resources at the end of this section). While not autism-specific, these programs may provide a blueprint for personalizing a program for your child.

It may be beneficial to request a meeting with the appropriate leader(s) in the faith community to discuss options for including your loved one in religious activities. Ask a teacher or service provider who may be of the same religious affiliation to accompany you and provide information about the kind of structure and support your child needs. This "team" can be a valuable resource.

Consider all the sensory stimulation during a service, including music, singing, stained glass windows, candles, flowers, and incense, which all together may be a lot for your child with an ASD to handle. Here are some ideas to help entertain your child:

- Personal stereo with headphones to block out extraneous sounds
- Coloring books and washable crayons/markers
- Picture books
- Stuffed animal or another comfort item

Some have questioned whether or not it is wise to teach religion to a person on the spectrum, the argument being that religion is too abstract to grasp. If your faith is an important part of your family tradition, do not be discouraged from seeking an appropriate environment for religious training and fellowship. If you are not looking for an in-depth religious program, it may still be wise to teach your child about the various religions and denominations to which he/she may be exposed. In his/her adult life, he/she may receive services from a faith-based organization and should be respectful of the caregivers' beliefs. Likewise, it may be necessary to teach your child strategies for politely declining unwanted invitations from religious organizations he/she (or you) does not wish to be affiliated with.

Restaurants

Eating out can be a fun family excursion as long as you keep some basic strategies in mind. Don't let autism keep you from the activities and places you and your family enjoy.

- Sit in a booth with the child with ASD on the inside to prevent bolting.
- Have plenty of napkins available.

- Remove all condiments and drinks from the child's reach.
- Have a snack or activity ready for the child when you sit down to occupy her until the food arrives.
- Take walks to the bathroom or arcade games to allow the child to explore the restaurant under your supervision.

Vacations

Family vacations – no matter how longed for – can pose difficult issues. The most important thing to remember is to maintain as much of a routine as possible for a child with ASD. For example, having your child wake at his normal time, followed by breakfast and then watching television as a way to start the day. It is also important to keep your child's sleep schedule the same.

Creating a travel book may be a good planning device for your child. It can include pictures of the kind of transportation you will be using, who you are going to visit, where you will sleep, and what you will do or see at your destination. Also, remember to pack some of his/her smaller toys that will occupy him/her and remind him/her of home.

Use your vacation destination as a way to experience new sensory activities, without overlooking your child's fragile nervous system. Textures, sounds, sights, colors, and music are just some examples of sensory experiences. Here are some ideas for guiding sensory experiences on vacation.

- Going to the beach and playing with sand.
- Walking through a forest and feeling the different leaves.
- Exploring a museum, identifying colors and shapes.

Make sure to take a lot of photographs of the places you visit to make a special memory scrapbook once you return home. Collect items from your trip like brochures, postcards, rocks, leaves, and other mementos to use in the scrapbook (remember to bring an empty coffee can or Ziploc bags to store the nature items).

Preventing Meltdowns in a Public Place

As any parent knows, when your child (typical or with an ASD) has a meltdown in public, it can be embarrassing and frustrating for yourself and other family members. Prepare ahead of time for going out in public. You can do this by creating a schedule of events, including pictures or drawings to illustrate what will occur and review it with the child before the trip. Sometimes you can even prepare a basic schedule on a napkin or a piece of paper to help your child understand what is going to happen. You can also bring an object that your child finds comfort in, or read a social story about the event ahead of time to prepare for the outing. These are just a few suggestions on how you can provide some predictability for your child before going into the community.

Handling a Meltdown in a Public Place

Always remember that your child with an ASD does not want to have a meltdown, so be patient and compassionate. However, when a meltdown does occur, the child is usually in extreme distress and may lose control of her raging emotions. When a meltdown does occur, try to remember the following:

Only move the child if there is an immediate safety concern. Moving the child while he is having a full-blown meltdown can be dangerous for you and the child because he is unable to process what is happening.

Do not try to give your child whatever he was asking for before the meltdown to stop it. This advice is not to say you should not give in and let the child have his way. It is because during the meltdown he is unlikely to be able to respond to the object or even process the fact that he has it.

Step back and do not intervene unless your child asks you to. At this point, your job is not to try and calm him down; it is to wait. A child can rarely express his immediate needs during a meltdown.

If there are others close by, move them. Well-meaning people may try to help, but tell them very clearly to stay back because their presence will only escalate the situation. This is when the autism awareness cards may be helpful (see box below).

Make sure your own reactions don't escalate. Try to step back and disconnect enough so that you are not caught up in your child's intense emotions. Try to think rationally.

Try not to take it personally. It hurts when our children are angry and lash out at us, but try thinking of it as a symptom of something your child *has*, not who he *is*.

Take this opportunity to step back to observe your child carefully. Pay attention to his/her environment to determine if there are triggers – lighting, noise level, etc.

Do NOT restrain your child. However tempting, restraints may reinforce future meltdowns because some children find deep pressure relaxing. It is not only potentially dangerous for you and the child, in the long term, restraining is ineffective. THE ONLY EXCEPTION is when your child is hurting himself/herself or others, or is in danger.

When the Child Hits the Parent

There may come a time when your child hits you. First and foremost, do not take it personally. Your child is trying to communicate with you and may not be able to do so in a functional manner when in a state of distress. The following are important things to keep in mind:

- Your child may not remember he/she did it.
- Determine if he/she purposely hit you, or was flailing and randomly or accidentally hit you.
- Review what you might have done to inadvertently contribute to your child acting out toward you during a meltdown.

- Decide whether to bring up the hitting after the incident.
- Make sure your child knows that you forgive him/her when he/she makes a mistake, whether intentional or not.
- Call on your support group to get emotional support and to discharge some of the emotions you are feeling, if necessary.
- When you are of a clear and rested mind, you will need to ask some questions – is this an ongoing pattern and do I need to seek help from a behavior professional?
- If you want to make your own autism awareness cards, here is the copy you can put on each side of the card.

Example of an Autism Awareness Card

Side One

If you are puzzled by my child's behavior????? It is not boldness or lack of discipline!!!!!!! My child has autism ...

Side Two

Autism is a life-long neurological disorder that prevents the person from understanding what he sees, hears, or otherwise senses. People with autism often become confused and respond inappropriately in social situations. Autism strikes 1 out of every 150 people.

You can also make a card with the following messages:

Our son has autism, a severe language and behavioral disorder. He sometimes becomes confused, disoriented, or upset and may throw temper tantrums or scream. We are committed to teaching him how to function in the community and would appreciate your patience and understanding. If you would like to learn more about autism, please feel free to contact us or the American Autism Society (1-800-3Autism).

This young person has autism/Asperger Syndrome. It is a developmental disability that affects social and communication skills. People with autism tend to behave in an odd and unpredictable way as a result of their disability. Please help us by being understanding and showing tolerance.

Preparing Your Child for a Medical Appointment

Not unlike most children, children with ASD are not particularly fond of going to see the doctor. The experience can be traumatic because there are many sounds, sights, and smells that can seem frightening to them. It is extremely important that before going to a physician's appointment, your child is prepared and provided with an understanding of what will take place at the appointment.

Preparing for the Medical Environment

When initially setting up the appointment, whether for a routine pediatric visit, a dental appointment, or a visit to the hospital, mention your child's diagnosis to be sure it is added to the chart, if it is not already included. Ask that it is noted in a prominent spot so that all involved will be aware prior to meeting your child. This is meant to benefit your child. With proper information, even the initial interaction with the nurse or receptionist can set a positive tone for your child's visit.

Three to four days prior to your child's visit, call the office to touch base again. Ask what the routine and wait time will most likely be for your child's appointment. They should be able to tell you about transitions and specific steps (such as being weighed, measured for height) that will be included in the routine. Confirm that they are aware of your child's diagnosis. Explain your child's specific characteristics and express any stress triggers that might bother him/her. Suggest adaptations that could be made to ensure that the transition and actual appointment will proceed quickly and smoothly for everyone.

Suggestions may include the following:

- With medical professionals, reviewing the environment with the child in mind
- Limiting the number of people who will be involved in the child's care
- Designating a medical team member as the child's procedure coach
- Providing sensory items to help the child self-regulate
- Preparing the child for surgery or a physician's appointment according to the child's developmental level, not the child's chronological level
- Using visuals to help the child understand what will occur
- Providing simple, step-by-step information
- Developing coping techniques that are specific to your child, such as talking about the visit ahead of time and looking at pictures of the physician's office and equipment

If the visit to the hospital is an emergency and advance notice was not given, be sure to let the medical team know about your child's characteristics, needs, stress triggers, and sensory preferences as soon as possible. Putting these items in writing prior to arrival and bringing them with you will make it easier to convey your child's needs to the medical staff as well as give them a framework for how best to interact with your child in this emergency situation.

Preparing Your Child for the Medical Environment

Tell your child he/she will be making a visit to the doctor or dentist. Do not surprise her with this information upon arrival. All children are nervous about a medical visit, but giving them information in advance allows them to process, anticipate, and better absorb the reality of what will occur around them. It allows them to predict what will occur so they are not caught off guard by the flood of new sights and sounds around them – a major consideration for children with ASD.

Giving Information

Information should be given on your child's level, in the amount and manner in which your child can best understand it. If you are able to obtain pictures of the actual office, use them. Often major children's hospitals have online virtual tours with photos describing a visit to the hospital, or they allow you to visit the hospital for a tour prior to your actual visit. If these options are not available, consult children's books that depict a visit to the doctor, dentist, or hospital. It is important to familiarize your child with titles of people, equipment that might be used, the routine of the environment, and steps of the actual procedure, if at all possible.

Create a story specific to your child's visit. Include details such as:

- Steps in the routine
- Making transitions to different rooms
- Waiting in certain areas
- Wearing special pajamas during the visit
- People your child will meet
- Equipment your child will see
- Sights, smells, and sounds that your child will encounter

Add details that make your child's trip unique such as:

- Who will accompany him/her
- What he/she can bring along on the trip
- What he/she will do when the visit is over

Ask your child open-ended questions about what he/she is feeling and which steps seem hard or easy. Help your child make a plan to be successful, and remind him/her that it is okay to ask questions if something comes up he/she does not understand. Create a portable, step-by-step visual, such as a photo flipbook or a written schedule of each step. Make sure the schedule outlines the details you have discussed and the coping techniques chosen by your child to help with the visit. This predictability will give your child a sense of control as he/she ventures into an often unsettling encounter.

Medical Play

In addition to specific information about the encounter, allow your child to play through the medical experience. Refer back to the children's books and provide your child with a medical doctor's kit. Encourage your child to be both the doctor and the patient during various play series. Do not interrupt your child even if she engages in hostile or

aggressive play, unless it is endangering her own or others' safety. Sit back and observe what your child is expressing through words and actions. After the play sequence is finished and your child is in a state of attention, talk with her about what you observed and directly answer all the questions you can. Give honest information, using soft language so as to not frighten your child to provide accurate information.

Use a Transitional Item

Plan a transitional item that your child can bring to accompany him on his journey. This may be a favorite stuffed animal, a blanket, or some special treasure. This item allows your child to cling to something he/she is familiar with in the midst of an unfamiliar and invasive environment. Create a plan with your child as to who will hold the item during various steps in the procedure. The object may have to be out of your child's hands at times, and it is better if this is discussed prior to the moment when your child is being asked to release the item. If a plan is in place, your child can be reminded that the item will only be out of his/her hands for a few moments and returned during the next step.

During the Medical Encounter

In addition to all the advance preparation, your child will need you as a coach during the actual medical encounter. Encourage him/her to bring along the portable visual you created to support him through the visit. Be sure to leave space for flexibility, as the medical environment often entails emergencies or unforeseen delays.

As each step takes place, indicate to your child that it is over by crossing it off or turning the page of her special book or visual. Reiterate the decreasing number of steps remaining. Remind your child that he/she successfully completed previous steps and then guide him/her through the step that is next. For example, "Great job getting weighed. You have already finished three steps. You arrived at the doctor's office, waited in the waiting room, and got measured and weighed by the nurse. Now we are waiting for the doctor to come in."

You can also review previously chosen coping techniques or offer new choices on the spot. In the midst of the medical encounter, provide your child with limited choices. For example, "While we wait for the doctor to come in, do you want to play 'I Spy,' read your book, or talk about *Star Wars*?" Be sure to only offer choices that are available. Coping choices may change for different steps because of restrictions of body movement, room changes, or the effect of medication.

Leisure Activities

Leisure activities are something everyone enjoys and looks forward to. To the extent possible, children with ASD also need and should participate in leisure activities as individuals, in groups of peers, and with their families. By using your child's interests and strengths, encouraging skill building in small steps, and creating a fun and well-supported environment, leisure activities can be enjoyed by all.

Sample Community Activities to Consider for Your Child

| | |
|---------------------------|-----------------------------------|
| Playing on a sports team | Playing outdoors |
| Visiting the library | Visiting a museum |
| Scouts | Reading |
| Religious groups | Playing board games |
| Going to a birthday party | Watching a parade, event or sport |
| Camps | |

The following are some ways to adapt activities and build in support to create success for your child, given his/her special needs:

Provide a framework Prime your child in advance with information that will create a visual and prepare him/her for the overall experience. In your description, review items such as:

- **The overall environment**
 - Sounds
 - Sights
 - Smells
- **The people present**
 - Names
 - Descriptions
 - Role or function
 - Designated “safe person” such as a counselor, activity leader, etc.
- **The activity taking place**
 - Rules
 - Why he is participating
 - Working as a team
 - Being an individual
- **Boundaries and rules**
 - For the activity
 - Social “hidden curriculum” rules the child may not know

Provide opportunities If your child wants to participate in leisure activities, provide the opportunity to do so. You may need to ease him/her into a group function, so practice first at home playing one-on-one with your child. Eventually, invite three or four children over to play. Provide a structured activity for a predetermined, short length of time. As your child develops, transition him/her into a larger group, a bigger arena, or a lengthier interaction using increasingly more skills.

For example, if your child wants to play Little League, teach the basic skills one-on-one or invite peers to play baseball. Practice throwing, catching, and batting. After your child learns the subtle rules of team play and develops basic skills, invite the peers over again for a short game. Eventually, your child will be ready to transition into a full Little League team.

If your child wants to participate in non-sport leisure activities, practicing at home can also be beneficial. Create a scenario and role-play with your child prior to an actual encounter.

- Pull out shelves of books and a plastic card to pretend you are at the library. Review rules of being quiet and how to look for a book.
- For lunch, create a menu of choices. Present it to your child and ask him/her to make a selection. Review table manners, what to do while he/she waits, and choice making.

Encourage your child's strengths and interests Ask your child in which activities he/she wants to participate. Getting consent from your child will increase his/her desire to participate. Find avenues to pursue the interests and activities that your child loves and in which he/she excels, and then adapt them for his/her level of participation and skill. Create leisure activities and social opportunities out of your child's interest. For example, if your child enjoys reading, start a small reading group, having the children read a story and complete activities that pertain to the theme. If your child enjoys playing a particular game, for example, chess, invite others over and create a chess tournament. If your child likes to play baseball, start a small, informal team in your neighborhood.

Talk with the leaders Prior to the event or start of a sport season, visit with the director, coach, or a parent of a peer to exchange information and create a plan of success for your child. Take time to explain your child's strengths and needs, providing information about sensory needs, need for visual supports, stress triggers, and how to anticipate and support a potential meltdown. Ask for information about the routine of the event, gathering as many details as possible. Also discuss adaptations that would be beneficial and determine how they will be incorporated.

Often when a child is starting or encountering a new leisure activity parents participate in a leadership role, such as being a coach or facilitating a troop. This allows you to add needed support and make accommodations for your child.

Bullying

Bullying is a pressing issue for many schools. While this damaging behavior affects both typical children and children with special needs, children with special needs are at more risk for being targets of a bully. Being bullied can cause kids to experience fear and anxiety and interfere with school work and self-esteem.

Types of Bullying

- Physical – hitting, kicking, pushing, etc.
- Verbal – name calling, teasing
- Emotional – excluding and ignoring others
- Sexual – touching, teasing, coercing
- Cyber bullying – sending threatening emails, text messages, harassing cell phone calls, etc.

Because children with ASD have trouble with language and social cues, they can become easy targets for bullies. Further, one of the main ways children protect themselves from being bullied is to predict the behavior of others and respond accordingly. Children with ASD have a very difficult time predicting what others may be thinking. For example, a group of students may talk a child with ASD into doing something he/she knows is wrong, but he/she may think they are trying to be friends-- and not realize what they are doing and comply after all. Students with ASD may also mimic what others do, including bullying others, without understanding the consequences. They may also try to retaliate.

The best bullying prevention programs involve the whole community and all staff at your school. Children not only need to learn ways to handle a bully, they also need to be able to address students who may watch, called bystanders. If your child is reporting increased headaches, stomachaches, or other physical problems or complaining about going to school more than usual, consider explaining what bullying is and ask if it is happening to him/her.

If your child is being teased, excluded, or harmed repeatedly by schoolmates, take action:

- Ask about school policies, training, and programs for bullying.
- Ask if there is supervision in hot spots like hallways, lunchrooms, bathrooms, and locker rooms. Bullying typically occurs under the radar of adults.
- Ask if there are classroom discussions about bullying.
- Look for teachers who are flexible and can help your child feel more alike than different.
- Consider using a social story and/or power cards to help your child know how to respond to bullies.
- If needed, you can address it on the IEP.

Useful Forms

The following forms may be helpful and can be printed out for your personal use:

- Developmental Milestones Form
- Family Health History
- Emergency Contact Information Form
- Parent Record-Keeping Worksheet
- Child/Student Profile
- Home-School Communication Form

You may want to keep all of your child's records and official documents in one place.

You may want to include:

- Birth Certificate
- Social Security Card
- Medical/Insurance Card
- Immunization Record
- Copies of Evaluations and Assessments
- Multi-Factored Evaluation (MFE)
- Copies of IFSPs/IEPs (current and previous)
- Other school records

Developmental Milestones

This is a form to record your child's development. It can help you keep track of developmental delays; therefore, it can serve as a reference when visiting the doctor or going through the evaluation process.

Date of Birth: _____ Date Completed: _____

Weight at Birth: _____ Length: _____

Complications/Notes: _____

Age when child was able to: (Represents typical age range)

1. _____ Hold head up (6 weeks)
2. _____ Smiles (2 months)
3. _____ Babbles (3-4 months)
4. _____ Roll over (4 months)
5. _____ Reaches for object (4-7 months)
6. _____ Sits without support (6-7 months)
7. _____ Crawls (6-7 months)
8. _____ Drink from cup (6-9 months)
9. _____ Stands alone (11-12 months)
10. _____ First word mama, dada (12 months)
11. _____ Walks alone (12-18 months)
12. _____ Uses two-word phrases (18 months-2 years)
13. _____ First tooth (6 months-1 year)
14. _____ Toilet trained (2-3-½ years)

Family Health History

This form allows you to track your family's health history and can serve as a reference when completing paperwork in the future.

| Condition | Yes | No | Family Member/Relative | Age Began |
|---|-----|----|------------------------|-----------|
| Autism Spectrum Disorders | | | | |
| Attention Deficit Hyperactivity Disorder (ADHD) | | | | |
| Obsessive Compulsive Disorder (OCD) | | | | |
| Anxiety Disorder | | | | |
| Bipolar Disorder | | | | |
| Schizophrenia | | | | |
| Depression | | | | |
| Other Psychiatric Disorders: | | | | |
| Other: | | | | |
| Other: | | | | |
| Other: | | | | |

Emergency Medical Form

This form is intended to provide basic medical information in case of emergency.

| | | | | | |
|--------------------------------------|--------|-----------------------|----------------------|---|--------|
| Name | | | Date of Birth | | |
| Blood Type | Age | Eye Color | Height | Weight | Gender |
| Allergies | | | | | |
| Address | | City | | State | Zip |
| Home Phone () | | Cell Phone () | | | |
| Current Medications | | | | | |
| Medication | Dosage | Schedule | Reason | Prescribing Physician or Over The Counter (OTC) | |
| Emergency Contact Information | | | | | |
| Emergency Contact Person | | Relation | | | |
| Home Address | | City | | State | Zip |
| Daytime Phone () | | Cell Phone () | | | |
| Evening Phone () | | Alternative Phone () | | | |
| Work Address | | City | | State | Zip |
| Primary Physician Information | | | | | |
| Name of Primary Physician | | | | | |
| Address | | City | | State | Zip |
| Phone () | | Emergency Phone () | | | |
| Other Physicians/Specialists | | | | | |
| 1. Physician/Specialist | | Reason | | | |
| Address | | City | | State | Zip |
| Phone () | | Emergency Phone () | | | |
| 2. Physician/Specialist | | Reason | | | |
| Address | | City | | State | Zip |
| Phone () | | Emergency Phone () | | | |
| Other Information | | | | | |
| Disabilities or Other Conditions | | | | | |
| Primary Language | | | | | |
| Primary Method of Communication | | | | | |
| Adaptive Equipment | | | | | |
| Special Notes or Considerations | | | | | |
| Insurance Information | | | | | |
| Insurance Company | | | Policy Number | | |
| Primary Subscriber Name | | | Group Number | | |

Emergency Response Information For Individuals with a Disability

This form may be filled out and provided to the local police or fire and rescue departments, either in preparation for possible emergencies or to be ready at their arrival at an emergency.

Name of Person with Disability

Home Address

Date of Birth

Home Phone

Cell Phone

Work Phone

Emergency Contact Name

Relationship to Person with Disability

Home Phone

Cell Phone

Work Phone

Name and telephone of person's specialist (doctor or teacher) if emergency contact cannot be reached

Is the individual able to communicate with speech?

Does the individual understand receptive language (what is being said to him/her)?
Yes / No If not, describe his/her method of communication

Would the individual be able to communicate his name, address, and telephone number in a high stress situation?

Does the individual engage in any unusual behaviors that might seem disrespectful or threatening (e.g., yelling, giggling, standing too close to people)? If so, please describe

In a high-anxiety situation, how would the individual most likely communicate?

Is the individual prone to respond in an unusual manner to sensory input (sounds, lights, smells, etc)? Yes / No

Circle what may result: seizure panic flight fight withdrawal other (please describe)

What might trigger what is circled above (e.g., dog bark, siren, touch)?

Does the individual have any specific fascinations (e.g., tree climbing, water)? If so, please describe

Is the individual threatened by any physical traits (e.g., whiskers, hats, uniforms)? If so, please describe

Does the individual have an accurate sense of danger?

Does the individual have any other medical conditions or is he/she taking medication? If so, please describe

Please describe anything else that would be helpful to emergency personnel (police, fire, EMT) who may have to respond to your household and interact with the

Adapted from Jackson County Sheriff Department, Jackson, MI.

Child/Student Profile

This form can be used to give some basic information about your child to a service provider, relative, babysitter, respite worker, or educational professional. It may be used as your child transitions from one provider or teacher to another. While its format can vary according to your needs and preferences, it is helpful to include:

- child's name
- child's disability
- family dynamics
- how the child learns best
- special interests
- strengths
- challenges
- things that upset
- signs the child is upset
- calming or soothing techniques
- motivators and preferences
- modifications, including curriculum, environmental, organization, and social support.

The following is one possible way of organizing this information and has been created for your use. The first page is a sample, completed form; the following page is blank for your use.

Adapted from Judy Marks, personal communication. Used with permission.

EXAMPLE of the Child/Student Profile

Name: Johnnie

Date of Birth: Feb 20, 2002

This Is Me: I have autism. This means I have trouble understanding you, and letting you know what I want and how I feel. Sometimes it seems like I don't want to play with you or other kids, but I really do, I just don't always know how! I am very active and love to move all the time. I find it hard to try new things or when my routine changes.

My Family: I live with my mommy. She has to work all day so I go to school. I have lots of friends that love me and help take care of me at our church. They are kind of like my family since my grandma and papa live far away.

I also go to a social group 2 days every week; there my friends and I learn to play better.

My Strengths:

- remembering the rules
- colors, numbers and letters
- saying Hi to everyone I meet

My Challenges:

- understanding what adults ask me or tell me to do
- telling you how I feel and what I want
- trying something new (food or activity)
- looking at you when I talk to you
- playing with other kids

I Learn Best When ...

- I know what you want from me
- I know what's coming next
- Visuals are used

My Special Interests:

- Blues Clues

My Motivators and Preferences: Singing, playing in water, Hide and Go Seek (anything that lets me move and run around), bubbles, tight hugs, French fries and ketchup, anything else I can dip in ketchup.

| | | |
|--|---|--|
| <p>Things That Upset Me:</p> <p>changes in routine stopping Blues Clues sitting still waiting</p> | <p>Signs I'm Upset:</p> <p>picking at my fingers laying my head down closing my eyes</p> | <p>How I Calm Down:</p> <p>a picture of when I get a break or can go back to Blues Clues</p> <p>go for a walk get a tight hug</p> |
|--|---|--|

Modifications for Me: Visual schedule, visual prompts, timers, lots of praise and reinforcement, breaks to run around during long sitting or waiting activities.

Name:

Date of Birth:

This Is Me:

My Family:

My Challenges:

**My Special
Interests:**

I Learn Best:

My Motivators and Preferences:

**Things That
Upset Me:**

**Signs I am
upset:**

**How I calm
down:**

Modifications for Me:

Home-School Communication Form

The following is one example of a form that can serve as a way to pass information from home to school and back to home. Also included is an issue of *Disability Solutions*, which offers several other excellent examples of such forms, as well as information on how to create your own.

Name: _____

Date: _____ **Monday Tuesday Wednesday Thursday Friday**

At home I ...

_____ Slept all night _____ Did not sleep well _____ Had a good morning
 _____ Ate all of my breakfast _____ Ate some of my breakfast
 _____ Did not eat breakfast _____ Was not feeling well

Other Comments:

Today at school I did ...

_____ Discrete Trial DTT _____ Story Time _____ Table Tasks
 _____ Independent Work _____ Art Activity _____ Reading
 _____ Sensory Play _____ Playground _____ Other

Comments: _____

I mastered _____

Today at school I ate ...

_____ Snack _____ Most of my lunch I had some _____
 _____ All my lunch _____ Very little lunch

Comments: _____

Bathroom routine: _____ I had no accidents today I had _____ accidents today.

Needed supplies:

Adapted from: *Home-School Communication Form from the Autism M.O.D.E.L. Community School, Great Lakes Center for Autism, 1615 Holland Rd, IRN-134122, Maumee, OH 43537, (419) 897-4400. Used with permission.*

CHAPTER 3

Interventions: A Review of Therapies, Models, and Strategies

Someone you love has been diagnosed with autism – what treatments are available for autism? What can you do to help them to reach their full potential? How can you help them to cope in the world?

Autism has no common cause and no known cure. Be wary if someone claims to be able to “cure” autism, especially if the only information available is from the person promoting the “cure.” This chapter will describe a variety of treatment options for autism, guidelines for choosing treatments, things to consider when choosing treatments, and how to determine if a treatment really helped.

Because there is no common cause, because autism is a spectrum disorder – that is, symptoms range from mild to severe – and because each individual with autism is “uniquely autistic,” there is no “one-size-fits-all” treatment. This puts the burden of determining what treatments will work best for a particular individual directly on the family and the professionals working with the family. Treatments and therapies can vary widely in cost and focus.

Choosing Interventions

Choosing appropriate intervention(s) for your child can be confusing; the amount of information available in print and on the Internet is overwhelming. The following are some important questions to help parents and caregivers make decisions regarding the best interventions for their child:

- Does the program/therapy and anticipated outcomes address your specific concern?
- Does the method meet the unique strengths/challenges/goals for my child?
- Are there any harmful side effects associated with this treatment? What are the potential risks? Is there any risk involved in discontinuing the intervention?
- Are there any activities, foods, and so on that will be restricted during treatment?
- What positive effects of treatment would I hope to see?
- What are the short-term and long-term effects?
- Can the treatment be integrated into my child's current program?
- How will the goals/outcomes be evaluated? How will I know if the child is making progress toward desired outcomes? What method will be used to evaluate the child's progress?
- What is the cost of treatment? Will my insurance company pay for the treatment?
- How much time does the treatment take? Can I realistically devote the time required to the treatment?

- Has this treatment been validated scientifically? Have I collected information about this from a variety of sources?
- Was I able to interview other parents and professionals about the treatment? If so, did I list pros, cons, and other areas of interest?
- Do proponents of the treatment claim that this procedure can help nearly everyone? If so, this should be seen as a “red flag” to slow down and be more careful in consideration of this technique, considering the wide range of abilities represented on the autism spectrum.
- What do the professional involved with my child think about the treatment’s appropriateness?
- Are there alternatives that are less restrictive or better supported by evidence?

Determining Effectiveness

Stephen M. Edelson, Ph.D., Center for the Study of Autism, Salem, OR (2007), offers these important tips for parents and caregivers to help determine if a particular treatment is effective:

- **Implement one treatment at a time** Change one thing at a time, allowing plenty of time to see the effects of a treatment. (Edelson suggests at least two months)
- **Keep your own data** Keep a daily record prior to the intervention as well as during the intervention. Your personal record can help you determine if any changes are taking place.
- **Seek objective information** Consider, if possible, not telling other adults your child may come in contact with about the new treatment to prevent biased feedback.
- **Collect data from those involved in treatment implementation** Ask teachers or clinicians to keep written data. After a period of time, compare others’ data with your own.
- **Note unexpected or unanticipated changes** Make note of surprising or unexpected changes your child may exhibit.
- **Educate yourself about the treatment** Be sure you learn as much about the treatment as possible before beginning. Look for both positive and negative information. Be aware of possible side effects.

As mentioned, no one treatment will have the same impact on all individuals with ASD. For this reason, it is important to make informed choices and use written data to monitor effectiveness.

Research on Autism Interventions

Individuals with autism spectrum disorders require individually designed interventions that meet their needs. In fact, no one intervention has been universally identified as being effective for all children with ASD. It is important, however, that parents and school professionals work together as a team to select empirically valid techniques (National Research Council, 2001; Olley, 1999).

You should conduct a careful research and review of the information available on the intervention you are considering. Many books and research journals can aid you in your search. As you read about various autism therapies, keep in mind the research that has been conducted on whatever therapy you intend to implement.

To say that a methodology is grounded in scientifically-based research means there is reliable, independent evidence that a given program or practice is effective for some individuals on the autism spectrum. To obtain reliable evidence about a reading strategy or instructional practice, for example, an experimental study may be done. Many studies involve using an experimental group that uses the intervention and a control group that does not to see if the method is effective in teaching children to read. Other studies on autism interventions use a single subject design. Ultimately, family members and professionals together must determine whether a particular strategy or method is effective or if a scientifically based method is suitable for an individual student.

Research is derived from theory and practice. While not all methodologies are currently founded in empirically based research (studies that follow specific scientific rules), many are backed by anecdotal reports (observations of individual cases by parents, caregivers, and professionals) of effectiveness. Care must be taken to evaluate each methodology on its merits and appropriateness for the particular needs of the individual with ASD.

Definition of Evidence-based Practices

The National Professional Development Center on ASD has developed the following definition of evidence-based practices. To be considered an evidence-based practice for individuals with ASD, a practice must be supported by research studies published in peer-reviewed scientific journals that use:

- **Randomized or quasi-experimental design studies** Two high quality experimental or quasi-experimental group design studies,
- **Single-subject design studies** Three different investigators or research groups must have conducted five high quality single subject design studies, or
- **Combination of evidence** One high quality randomized or quasi-experimental group design study and three high quality single subject design studies conducted by at least three different investigators or research groups, across the group and single subject design studies.

High quality randomized or quasi-experimental design studies do not have critical design flaws that create confounds to the studies, and design features allow readers/consumers to rule out competing hypotheses for study findings. High quality in single subject design studies is reflected by a) the absence of critical design flaws that create confounds and b) the demonstration of experimental control at least three times in each study. This definition and criteria are based on:

Horner, R., Carr, E., Halle, J., McGee, G., Odom, S., & Wolery, M. (2005). The use of single subject research to identify evidence-based practice in special education. *Exceptional Children*, 71, 165-180.

Nathan, P. & Gorman, J. M. (2002). *A guide to treatments that work*. NY: Oxford University Press.

Odom, S. L., Brantlinger, E., Gersten, R., Horner, R. D., Thompson, B., Harris, K. (2004). *Quality indicators for research in special education and guidelines for evidence-based practices: Executive summary*. Arlington, VA: Council for Exceptional Children Division for Research.

Rogers, S.J., & Vismara, L.A. (2008). Evidence based comprehensive treatments for early autism. *Journal of Child Clinical Psychology*, 37(1), 8-38.

Evidence-Based Practices

The National Professional Development Center on ASD has identified the following interventions as meeting the criteria for evidence-based practices. The National Professional Development Center on Autism Spectrum Disorders is a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders. The Center operates through three sites that include the FPG Child Development Institute at the University of North Carolina at Chapel Hill, the M.I.N.D. Institute at University of California at Davis Medical School, and the Waisman Center at the University of Wisconsin at Madison. Each year, three states are selected through a competitive application process for a two-year partnership with the Professional Development Center. Kentucky was chosen as one of these three states in 2008. The Center works in coordination with each state's Department of Education, Part C agency, and University Center for Excellence in Developmental Disabilities to provide professional development to teachers and practitioners who serve individuals from birth through twenty-two years with autism spectrum disorders.

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

Prompting is a behaviorally-based teaching strategy in which learners are assisted in some way to complete a task or activity. There are different kinds or levels of prompting that vary in the amount and type of assistance that are provided. Physical prompts, for

example, may be provided by touching learners (usually on the hand) and physically guiding them. Verbal prompts may be provided by giving learners extra verbal instructions. For example, when a learner is directed to "Throw the tissue in the trash," he or she might be verbally prompted by an adult for each step of the task, e.g., "Stand up, pick up the tissue, walk to the trash can, and put the tissue in the trash can." Not all prompts are verbal. For instance, gesture prompts (e.g., pointing) provide nonverbal cues to learners regarding what they are to do next.

Time Delay is a process for either fading prompt use or for preventing learners from becoming prompt dependent. When implementing time delay, the teacher waits for a pre-determined period of time (typically between 5-10 seconds) after the instruction is given before the answer is prompted. For example, with a learner who is dependent on verbal prompts to identify planets, a time delay procedure might be added with the instructor waiting several seconds after the instruction before they prompt the child to point.

Reinforcement is a core behavioral principle and includes anything that a person does or says that increases the likelihood of a behavior happening again. In other words, when people are reinforced, they are more likely to repeat the same behavior. For example, if a learner performs a skill (let's say tying his/her shoe) and someone says "Great job, you are so grown up!" and the learner continues to work on tying the shoe, we can assume that the verbal praise was reinforcing.

Task Analysis and Chaining is a teaching technique that consists of breaking a task down into small steps (i.e., task analysis) and then teaching each step until the learner can do the complete task. This technique is especially useful with skills that are physical or routine (e.g., self-care, work tasks). Chaining can be taught as either forward (i.e., start to finish) or backward (i.e., beginning at the last step of the task and then teaching the steps in reverse order). The decision to use forward or backward chaining depends on the type of task and characteristics of learners.

Shaping involves the reinforcement of successive approximations of a desired behavior to assist learners in reaching a more appropriate level of skill attainment. Shaping is a strategy used naturally by parents of typically developing children. For example, when children first begin to use utensils to eat, parents praise them for utensil use, even when much of the food ends up on the child, the parent, or their surroundings. Over time, parents praise the child only for actually getting the food to his or her mouth. Shaping is often used for promoting speech development. When children begin to speak, adults reinforce vocalizations and word approximations and then encourage children to say the word correctly. For example, a child may say, "Nana." The adult caregiver acknowledges and replies, "Nana. That's right, say, 'Banana.'" Shaping is especially useful with learners who give up easily or who have a long way to go from initial skill use to actual skill proficiency.

Computer-Assisted Instruction (CAI) includes the use of computers to teach. Research in this area has shown an evidence-base for the use of CAI in teaching language/communication, reading (including spelling and vocabulary), and math.

Differential Reinforcement of Other/Alternative Behaviors (DRO, DRA, DRI)

Reinforcement is provided for desired behaviors while inappropriate behaviors are ignored. Reinforcement can be provided when the learner is not engaging in the targeted inappropriate behavior (DRO), when the learner is engaging in a specific desired behavior other than the inappropriate behavior (DRA), or when the learner is engaging in a behavior that is physically impossible to do while exhibiting the inappropriate behavior (DRI).

Discrete Trial Teaching (DTT) is a one-to-one instructional approach that teaches skills in a planned, controlled, and systematic manner. DTT is used when a learner needs to learn a skill best taught in small repeated steps. Each trial or teaching opportunity has a definite beginning and end, thus the descriptor discrete trial. Within DTT the use of antecedents and consequences are carefully planned and implemented. Positive praise, sometimes with tangible rewards, is applied to reinforce desired skills or behaviors. Data collection is an important part of DTT and supports decision-making by providing the teacher with information about the learner's beginning skill level, progress and problems, skill acquisition and maintenance, and generalization of learned skills or behaviors.

Extinction is a strategy based on applied behavior analysis and is used to reduce or eliminate unwanted behavior. Extinction involves abruptly withdrawing or terminating the positive reinforcer that maintains an inappropriate target behavior. This abrupt withdrawal results in the stopping or extinction of behavior. The target behavior is likely to increase in frequency and intensity before it is extinguished as the learner seeks to elicit the reinforcers previously provided. Extinction is often used with differential reinforcement to increase a learner's use of appropriate behaviors while discouraging their use of inappropriate behaviors.

Functional Behavioral Assessment (FBA) is a systematic way of determining the underlying function or purpose of a behavior so that an effective intervention plan can be developed. FBA consists of describing the interfering or problem behavior, identifying antecedent or consequent events that control the behavior, developing a hypothesis of the behavior, and testing the hypothesis. Data collection is an important part of the FBA process.

Functional Communication Training (FCT)- emerged in the mid 1980s from the literature on functional behavioral analysis (FBA) as a systematic practice to replace inappropriate or ineffective behavior serving a communicative function with a more appropriate or effective behavior or skills. It is widely used and promoted in the literature related to positive behavioral support (PBS). Within FCT, the targeted behavior is analyzed to determine its communicative function and then an alternative behavior is taught to replace it. In addition, the associated FBA identifies contingencies in the natural setting(s) that may be maintaining the undesired behavior.

Independent Work Systems promote independence by organizing tasks and activities in ways that are comprehensible to individuals with ASD. Specifically, work systems are visually structured sequences that provide opportunities to practice previously taught skills, concepts, or activities. These systems clearly communicate which activities to

complete; how many activities to complete; how to know when the work is finished; and what happens after the work is completed.

Naturalistic Interventions include techniques that closely resemble typical interactions and occur in naturally occurring settings, routines and activities. Naturalistic strategies are considered learner-centered, in that the learner plays an active role in determining multiple aspects of the instructional interaction (e.g., choice of location, materials, persons involved).

Parent Training Parents are often in a position to be the most effective teachers of their children with ASD. Many of the studies in the evidence-base for other types of instructional practices include parents as facilitators. There are some common guidelines for supporting parents to implement evidence-based practices outside of school settings.

Peer-Mediated Instruction/Intervention (PMII) is designed to increase the social engagement of children and youth with autism spectrum disorders (ASD) by teaching their peers to initiate and maintain interactions with children with autism. Specifically, the goals of PMII are to teach peers ways in which they can talk and interact with children and youth with ASD, increase the frequency with which children and youth with ASD interact with typically developing peers, extend peers' social initiations and focal children's interaction across activities in the classroom, minimize teachers'/adults' support (i.e., prompts and reinforcement), and promote interactions between typically developing peers and children and youth with ASD that are positive and natural in quality.

Picture Exchange Communication System (PECS) has been used to help children and youth with ASD develop a system for communicating with teachers, parents, and peers. PECS was initially developed at the Delaware Autistic Program by Andrew Bondy and Lori Frost as an alternative communication system and has since been demonstrated in the research literature to promote speech development and production. There are six phases of PECS instruction, with each phase building on the last. The phases are: 1) Teaching the physically assisted exchange; 2) Expanding spontaneity; 3) Simultaneous discrimination of pictures; 4) Building sentence structure; 5) Responding to, "What do you want?" and 6) Commenting in response to a question.

Pivotal Response Training (PRT) is an approach that teaches the student to respond to naturally occurring learning opportunities and to seek out such opportunities. PRT builds on children's initiative and their own interests, and it is particularly effective for developing communication, language, play, and social behaviors. PRT was developed to create a more efficient and effective intervention by enhancing four pivotal learning variables: motivation, responsivity to multiple cues, social initiations, and self-regulation.

Positive Behavioral Support (PBS) is a tiered prevention and intervention approach that uses a variety of evidence-based practices to increase positive behaviors and reduce interfering behaviors. PBS is based on the principles of ABA and focuses on identifying specific conditions in the environment that trigger interfering behaviors as well as those that support appropriate behavior.

Response Interruption & Redirection The physical prevention (e.g., blocking) of a learner's presentation of an interfering behavior and immediate redirection to another, more appropriate activity.

Self-Management is a method by which learners are taught to monitor and take data on their own behavior. This method is typically used with older, high -functioning learners who are capable of reflecting on their actions. Learners can be taught to self-monitor a variety of things such as alertness, activity level, concentration, and problematic behaviors.

Social Skills Groups Social skills are best learned in the context of social situations. Research has shown that teaching skills in a natural setting can lead to improvement in social skills. Teaching and applying social skills in a support group format where opportunities are provided for interacting and practicing social skills is also a successful approach in which participants (disabled and non-disabled) often report that they value the friendships they gain as much, if not more than, the skills learned during such programs.

Social Stories are interventions that describe social situations in some detail (highlighting relevant cues and offering examples of appropriate responding) and are aimed at helping the individual adjust to changes in routine, adapt their own behavior based on the social and physical cues of a situation, or to teach specific social skills or behaviors. They are individualized and typically are quite short, perhaps including pictures or other visual aides. Sentence types used in constructing social stories include descriptive, directive, perspective, affirmative, control, and cooperative. Refer to the work of Gray (2005) for specific instructions on creating effective social stories.

Stimulus Control and/or Environmental Modification involves manipulating aspects of the environment that are known to impact a learner's behavior. For instance, if a learner needs to access reading materials independently, then we place the materials in an obvious location and make sure that the learner has access to them. If we know that a learner is more likely to tantrum in classrooms with fluorescent lights, different lighting should be used.

Video Modeling is a teaching method that uses assistive technology (computers, digital cameras, etc.) as the core component of instruction. Video modeling is a growing evidence-based practice for teaching individuals with ASD and other disabilities. Video modeling has been used to teach a wide range of behaviors, including social/emotional skills, adaptive behavior, life skills, academics, and play skills. Video modeling can be applied in several formats, but each involves the following basic components: (a) the individual being taught or other models are videotaped performing some targeted behavior, (b) the video recording is then played back to the learner, and (c) the learner is prompted or asked to perform the behavior. Variations of video modeling include self-modeling, point-of-view modeling, and video prompting.

Visual Supports are tools that enable a learner to independently track events and activities. Visual supports may include any tool presented visually that is used to support an individual throughout his or her daily routine. Visual supports include the

use of pictures, written words, gestures, objects within the environment, arrangement of the environment or visual boundaries, schedules, maps, labels, organization systems, timelines, and scripts. There are a number of visual strategies, including first-then cards, visual schedules, visual lists, and prompt/cue cards. In addition, many other strategies include visual strategies, such as Power Cards and the 5-point scale.

Voice Output Communication Aids (VOCA)/Speech Generating Devices, sometimes referred to as Speech Generating Devices (SGD), are electronic devices that are portable in nature and can produce either synthetic or digital speech for the user. These devices may be used with graphic symbols, as well as with alphabet keys and are used to teach communication skills to learners with limited verbal ability.

Elements of Effective Programs for Children with Autism

Revised and organized by Nancy Dalrymple, 2004
For STAR Program at Weisskopf Child Evaluation Center, Department of Pediatrics,
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As part of the National Early Childhood Technical Assistance Center sponsored Forum on Autism Spectrum Disorders (1997-2001), a group of representatives from model programs reached consensus on core elements of effective programs. These have been published in various formats since they were formulated.

| Program Element | Brief Definition |
|--|--|
| Earliest Possible Start to Intervention | Children receive services appropriate to their needs as soon as they are identified as having ASD. However, the U.S. National Research Council (NRC) Committee on Educational Interventions for Children with Autism (2001) recommend entry into intervention programs as soon as an ASD diagnosis is seriously , rather than waiting until it is confirmed. |
| Individualization of Services for Children and Families | Adjustments to goals, intervention strategies, and evaluation criteria are made for each child and family receiving services, determined by the child's needs, strengths, and interests and the families concerns, priorities, and resources. |
| Systematic, Planned Teaching | Instruction or intervention that is carefully thought out, logical, and consistent with a conceptual or theoretical basis and involves planning, implementing, and assessing, intervention steps; each step is intentional, coordinated with an overall approach, and builds toward meaningful goals. |

| | |
|---|--|
| Specialized Curriculum | A core curriculum to address specific needs of children with ASD, includes these key areas: attending to elements of the environment, imitating others, language comprehension, use of language, playing appropriately with toys and interacting socially with others. |
| Intensity of Engagement | Engagement refers to the amount of time a child is attending to, and actively participating in, the social and nonsocial environment. Intensity of engagement is sometimes expressed as the percent of enrolled time that is spent in teaching interactions, or in activities in which the child is actively learning. The time that a child is engaged in learning opportunities may occur during program time and in home or community settings. |
| Family Involvement | Includes family involvement in their own child's program; services provided to families primarily because their child has ASD; services provided to families that are not directly related to ASD but may impact on overall family functioning; family support and networking; and family involvement in the overall program. |
| <i>Program Elements That Are Part of Some, But Not All Programs</i> | |
| Structured Environments | Arranging the environment, instructional materials, and teaching interactions to elicit, facilitate, or support specific skill attainment or development, including the use of environmental arrangements or visual cues to organize or schedule activities, to facilitate choices, and to define work, play, or rest spaces. |
| Developmentally Appropriate Practices | Practices that have been designed for all young children; programs are guided by information about child development and learning, each individual child's strengths, needs, preferences, and knowledge of the social and cultural contexts in which children live. |
| Intervention in Setting with Typical Children or in Natural Environments | Some or all interventions occur in settings with typical children. This may include fully integrated settings in childcare, preschools, recreation activities, and other supports in home and community. |

Additionally the **National Research Council's Committee on Educational Interventions for Children with Autism (2001)** as reported in **Educating Children with Autism**, Washington, DC: National Academy Press (available on-line at www.nap.edu/books) states:

- Active engagement in intensive instructional programming should be provided for a minimum of an equivalent of a full school day for 5 days a week (minimum of 25 hours per week), including full year programming depending on the child's chronological and developmental age.
- Teaching opportunities should be planned, repeated, and generally organized into brief periods of time for very young children (15 – 20 minute intervals), with sufficient amounts of adult attention in one-to-one and very small group instruction in order to meet individual goals.
- There should be no more than two young children with ASD per adult in a classroom.
- There should be mechanisms for ongoing assessment and program evaluation that are conducted in order to measure child progress and make adjustments in programming.

Dawson and Osterling (1997) in a chapter, Early Intervention in Autism from Guralnick: *Early Intervention*, Brookes Publishing add:

- There needs to be a functional approach to behavior where the purpose of the behavior is understood and the necessary skills to replace the behavior are taught.
- Transition planning and implementation are important for future success.

There are many theories and approaches to early intervention for children with ASD, but there is agreement that it needs to be collaborative, able to be generalized to natural environments, and be family-centered. Further, effective intervention appears to be relatively intense, intrusive and interactional, requiring adaptations from both the child and others in the child's environment (Bristol & Schopler, 1993). It's important that families and the people providing services have accurate, current information about autism as well as an understanding of the child's individual needs. These are then translated into individually appropriate strategies. Some of the debate in early childhood education for children with ASD stems from attempts to mesh strategies that are teacher-directed and behaviorally-defined with programs that are child-centered and teacher-facilitated where the environment provides much of the structure. Most children benefit from a combination of approaches and need consistency across therapist, teachers, caregivers, parents, and all who teach and interact with them daily. Children with autism are diverse and more information is needed about what works with each child. It is essential to continually assess needs and progress in a collaborative way so that the changing needs of the child are met. This requires good data keeping through a variety of means, then data interpretation to make adjustments.

Promising Practices: Models and/ or Programs

The following interventions do not meet the criteria for evidence-based practices as determined by the National Professional Development Center on ASD. Further research is needed to determine efficacy of these programs and /or models.

The following programs and /or models may be effective in supporting individuals with ASD in a variety of settings, such as home, community, and educational settings.

Integrated Play Groups The concept of Integrated Play Groups was developed by Pamela J. Wolfberg, Ph.D. Based on the nature of play among peers without disabilities Dr. Wolfberg established a format that promotes socialization and imagination in children with autism and other developmental delays. Integrated Play Groups follow rules for creating an appropriate play environment, including play areas and selected materials; preparing the typical peers for play; use of assessments and measurements of progress; as well as play guidance. Integrated Play Groups focus on social communication, especially in the autistic deficit areas of imitation, joint attention, and imaginative and creative play.

SCERTS Model™ stands for Social Communication, Emotional Regulation, and Transactional Support. The SCERTS Model™ is a comprehensive model that is based on a developmental perspective and was designed to support individuals with ASD. The SCERTS Model™ is interdisciplinary in its approach, in that it addresses social communication and emotional regulation throughout the child's daily activities and routines, and guides and supports parents and caregivers through a multidisciplinary team effort. The model uses the knowledge base and experience of general and special educators, speech language pathologists, occupational therapists, child psychologists, psychiatrists, and social workers. The SCERTS Model™ is not prescriptive, nor is it a curriculum. Instead, it is based on fundamental beliefs and values that address the core deficits of ASD. The model is systematic, semi-structured, but flexible, so that the individual goals of the family and child with ASD can be addressed at specific developmental levels. The model is based on the belief that children learn best when they are emotionally regulated and can communicate within a social context. The SCERTS Model™ was systematically developed to be implemented based on those beliefs. It does not exclude other educational models, but accepts them within its framework of intervention as appropriate.

Relationship Development Intervention (RDI), created by Steven Gutstein, Ph.D. is modeled on how typical children become competent in the world of emotional relationships. It is an intervention approach quite different from the typical social skills programs currently available. RDI uses assessment information to develop clear, specific, developmentally appropriate treatment objectives and customized activities. The RDI curriculum is composed of six levels, each representing a dramatic developmental shift in the central focus of relationships. The six levels are: Novice,

Apprentice, Challenger, Voyager, Explorer, and Partner. RDI provides a path for people on the autism spectrum to learn friendship, empathy, and a love of sharing their world with others. Language comes alive when integrated with real emotion. People with ASD learn not only to tolerate but to enjoy change, transition, and going with the flow. The path begins at the edge of each person's current capability and carefully, systematically teaches the skills needed for competence and fulfillment in a complex world.

D.I.R./Floortime Dr. Stanley Greenspan and his colleague Serena Weider created the Developmental-Individual Differences-Relationship (D.I.R.)-based model as an intervention for children with autism and other developmental delays. Greenspan and Weider (1998) specify six functional milestones of development in this order: self-regulation and interest in the world, intimacy, two-way communication, complex communication, emotional ideas, and emotional thinking. According to the authors, these milestones lay a foundation for more advanced learning since they are based upon emotional interactions usually developed early in life. The D.I.R. model uses a comprehensive evaluation, including developmental history, biomedical assessment, current functioning, child-caregiver interactions, auditory processing, sensory processing, sensory modulation, motor and perceptual motor functioning, and family patterns, to develop a comprehensive intervention plan for the child and family. The primary goal of the D.I.R.-based intervention is to enable children to form a sense of themselves as intentional, interactive individuals and to develop cognitive language and social capabilities from this basic sense of intentionality. Part of the D.I.R. method uses "floortime," which is an intensive, one-to-one experience during a 20- to 30-minute period when a caregiver physically gets down on the floor and interacts with the child. The focus is on relationships, based on Greenspan and Weider's belief that the more intellectual functions of the brain do not develop without a constant source of relating. During floortime, the adult follows the child's interest or intent, even if the interest is a self-regulatory behavior, in order to encourage interaction. For example, if the child spins the wheels on a car, the adult may help him or spin a different wheel. The adult may limit the number of toys available so that the child has to interact to get more toys. The goal is not just to follow the lead of the child but also to help the child expand his interactions. According to the authors, the four goals of floortime are two-way communication, logical thought, attention and intimacy, and the expression and use of feelings and ideas.

Priming a way of letting a child know what to expect or what is coming. You can prime for a short or a long period of time. For example, you may prime a child for a Saturday shopping trip by going over where you will go, when you will go, how long you will be there, and the things you need to accomplish at each place. You may also identify what behavior is expected for each stop. Typically, you would put the same information in a visual format to cue the child throughout the trip. For example, you may have a visual schedule for the day that you look at with the child as you discuss the day.

5-Point Scale is a technique used to help a child break down an abstract concept into a visual system that is easier to understand. For example, a concept such as using appropriate voice volume can be broken down into a 5-point scale, with 1=no voice,

2=whisper, 3=normal voice/dinnertime, 4=loud voice/playing outside, and 5=screaming. A visual representation of the scale is used as the scale is introduced and explained to the child. It is reviewed repeatedly so it becomes very familiar. A picture of the scale is later used as a visual support to remind the child to use an appropriate voice level. The teacher points first to the level the student is using, and then slides her finger down to the appropriate level for a given situation. For example, if the child was screaming while the family was in the store, the parent would point to number 5, then move her finger down to 3 – an acceptable level.

Power Cards, developed by Elisa Gagnon, is a strategy to teach a child appropriate behavior for a particular situation. The Power Card strategy relies on the power of a child's special interest. It includes a story in which the person or object of special interest behaves appropriately in a situation in which the child is having difficulty. The child is given a small card, which includes approximately three points to guide appropriate behavior, along with a picture or some visual reference to the person or special interest to cue the child.

Social Interpretation Strategies are an important element of social skills instruction. Strategies involve systematically breaking down hypothetical or past social experiences of the child in a visual manner. An adult facilitates this breakdown, and then discusses other choices the child could make in a similar situation, as well as the consequences of different choices. Examples of social interpretation strategies include: social autopsies, Situation Options Consequences Choices Strategies Simulation (SOCCSS), cartooning, and flowcharts (i.e., *The Way To A*).

Home Base For many individuals with ASD, the world, in particular the school environment can cause a great deal of anxiety. In such cases, a Home Base may be assigned. The Home Base is a place where the child feels comfortable and can relax. The child is always allowed to leave her current setting and go to Home Base when she feels her anxiety level rising. A self-calming technique, this strategy recognizes that a child may have to remove herself from an environment in order to calm down.

Graphic Organizers are visual ways to organize information or materials. These can range from idea webs and Venn diagrams to color-coding folders and books for each school subject. Graphic organizers can be effective tools for helping a child organize the environment, as well as organize information to enable learning.

Related Services

Communication Interventions

Communication difficulties, both verbal and nonverbal, are inherent in the diagnosis of ASD. The typical sequence of communication development is disrupted. As a result, communication skills can range from nonverbal, gestural, word approximations, the use of single words, to verbal conversation. When designing intervention strategies, it is important to understand both the individual's receptive (comprehension) and expressive

communication skills. Stressful situations that increase anxiety often interfere with the ability to communicate. Challenging behavior can also serve as a means of communication for children with delayed communication. A Functional Behavior Assessment (FBA) can identify the function of behavior and functional communication training can be conducted.

Difficulty understanding humor, idioms (“keep your eye on the paper”), sarcasm, and other complex forms of verbal and written expression is common. Even the highly verbal individual may understand and use literal (concrete) language, but have difficulty with abstract concepts needed for higher order thinking skills.

A person’s communication ability usually changes over time. Therefore, it is important to maintain an ongoing communication assessment from diagnosis through adulthood as this provides current information, which is necessary to support appropriate communication strategies.

Supporting all forms of communication – verbal, signing, pictorial, augmentative devices (and often a combination of more than one) – promotes learning.

Speech-Language Therapy During therapy, the child’s functional communication skills, or the child’s *intent* (such as requesting and protesting), are assessed. Programs are then developed to address communication deficits and improve communication skills. Therapy may occur in natural and individual settings or in small groups. Families will always be involved in the therapy process in order to facilitate functional communication across various situations. Parent and caregiver training is a vital component of speech-language therapy, ensuring maximization of its benefits.

Be sure to choose a speech-language pathologist (SLP) who holds a Certificate of Clinical Competence from the American Speech-Language-Hearing Association (ASHA). The SLP is a skilled professional who can address the following areas of concern:

Receptive language refers to the understanding of spoken or written messages as well as other forms of language. This includes such components as the identification of objects, actions, adjectives, prepositions, and people.

Expressive language refers to the production of language. This includes such things as sentence structure, verb tenses, regular/irregular plurals, and length of utterance.

Articulation/phonology includes developing speech sound production, the use of tongue, lips, and teeth to produce speech sounds.

Oral-motor skills include improving the range, rate, complexity, strength, and coordination of oral motor movements. This strategy may also include massaging of cheeks, lips, and gums, brushing teeth, and methods to decrease teeth grinding.

Feeding and swallowing includes ability to close lips, manipulate food with tongue, age-appropriate chewing pattern, and safe swallowing. Other areas that can be addressed include oral desensitization to different tastes, textures, smells, temperatures, and consistencies of foods.

Social skills/play skills includes appropriate social language, the ability to read facial expressions, the ability to understand social cues/body language, and age-appropriate play skills such as sharing, taking turns, and playing independently or with others.

Pragmatics is the use of language in social context.

Cognition refers to the mental process of knowing, including aspects such as awareness, perception, reasoning, and judgment. (Source: dictionary.com)

Alternative or augmentative communication (AAC) refers to the use of any device, technique, symbol system, or combination thereof to supplement, enhance, or increase a person's communication abilities.

Sign language refers to use of signs alone or paired with speech.

Picture Exchange Communication System (PECS) involves using picture symbols to communicate wants and needs, as well as to label items. The child goes through a learning process that teaches initiation of communication and then expands to the use of sentences. Many children who use PECS develop some verbal skills and may graduate to speech as the primary form of communication.

Communication boards can be made with pictures or objects that the child points to or removes from the board to communicate wants and needs.

Other communication devices include a wide range of devices designed to enable the user to create longer messages. These devices can also act as a universal remote, allowing the user to operate electronic devices in the environment such as the TV, lights, and so on. The speech-language therapist can assess the child's abilities to use high-tech devices and make recommendations about the type of device that is best suited for the child's individual needs.

Total communication refers to a communication system that pairs simultaneous production of speech with manual signs or another augmentative devices or symbol systems. The child is encouraged to use the words/phrases that he is capable of producing and supplementing communication with signs and symbols for those thoughts he cannot communicate verbally.

Enhanced Milieu Teaching (EMT) is a naturalistic teaching strategy that incorporates both the principles of incidental teaching (Hart & Risely, 1968) and systematic principles for responsive conversational style (Kaiser & Grim, 2006). EMT is used by caregivers and professionals to teach communication skills in the context of daily routines and activities. Adults arrange the environment with materials of interest to the child and follow the child's lead. EMT consists of a set of prompting techniques which support turn taking and the child's use of language. EMT is especially useful with individuals on the autism spectrum because it focuses on the development of functional communication skills in the context of typical social interaction and utilizes behavioral techniques that are effective in teaching new skills to students with autism (Kaiser & Grim, 2006).

Physical Therapy

Physical therapists (PT) are specialists in sensorimotor development, muscle and joint function, posture, balance and coordination, as well as gait and functional mobility. They are knowledgeable about orthotic and prosthetic devices and assistive technology. Physical therapists identify movement problems and determine what issues may be interfering with a child's ability to develop age-appropriate gross-motor skills.

Physical therapists help young children with autism learn to walk, run, jump, ride a tricycle, and catch a ball. They assist preschoolers and school-aged children in becoming safe in their environments, walking up and down stairs and climbing. They help children acquire the gross-motor skills necessary to play on the playground or participate in physical education classes with their peers.

Physical therapy may work closely with occupational therapy, sensory integration and/or speech therapy to help maximize the effects of each therapy.

Occupational Therapy

Occupational therapy (OT) is concerned with an individual's ability to participate in desired daily life tasks, or "occupations," that give life meaning. If a person's ability to perform life tasks is impacted by an illness, disease, and/or disability, occupational therapy can be important.

Performance areas include:

- Activities of daily living such as grooming, oral hygiene, toilet hygiene, dressing, feeding and eating, socialization, functional communication, and functional mobility
- Work and productive activities (educational and vocational activities) and home management such as meal preparation, shopping, or clothing care;
- Play or leisure activities (play or leisure exploration and play or leisure performance).

Following an evaluation of the child's functioning, OT intervention is focused on those areas that are interfering with the child's ability to function. Tasks that may be targeted include writing, improving hand-eye coordination, buttoning a shirt, tying one's shoes, getting dressed, and feeding oneself. OT intervention with persons with autism often includes a sensory-integrative approach which focuses on providing controlled sensory input during specific activities (see next section on Sensory Integration). School-based occupational therapy is focused on educationally relevant goals and is tied to curriculum standards. For school-based therapy to be effective, a consultative approach is necessary. Therapy may encompass the more traditional "pull-out", direct service approach. This approach is comprised of working with the student within the classroom, consulting with the parent, student and educational team to ensure that interventions and accommodations (in the home as well as in the classroom) are effective.

Areas addressed by occupational therapy may include the following:

- **Fine-motor control/written output** The OT may implement a fine-motor strengthening and coordination program, and recommend adaptations (i.e., use of pencil grips, specially lined paper, use of keyboard, extended time, shortened work load, use of note-taker or adapted software programs).
- **Visual-motor and visual-perceptual skills** Occupational therapists may also address the student's ability to control eye movements to smoothly shift visual focus, track objects across midline, and perform the visual motor control needed to read and write text . Accommodations may include slant boards, copy of all work on chalkboard available at desk, paper window guided work, and colored transparencies.
- **Postural stability and control** Occupational therapists may address difficulties students may have in maintaining efficient seating postures. Recommendations may include dynamic seating using a partially inflated beach ball or camping pillow or a Move n' Sit Cushion.

Sensory Processing

A. Jean Ayres, Ph.D., an occupational therapist, first researched and described the theories and frame of reference that we now call sensory integration. Briefly, sensory integration is a process used by the brain to locate, sort, and make sense out of incoming sensory information. This process is important to the successful accomplishment of life tasks.

Ayres described sensory integrative dysfunction as a sort of "traffic jam" in the brain. Some bits of sensory information get "tied up in traffic" and certain parts of the brain do not get the sensory information they need to do their jobs. Children who have ASD may experience this.

For example, a child may scream when wearing certain clothing because her sensory system is hypersensitive to the sense of touch. This same child may crave bear hugs (deep touch) because her proprioceptive system is hyposensitive. (See "Proprioception" below.) These hypersensitive and hyposensitive sensations impact the child's independent functioning in many facets of life, including peer interaction, attention at school, and activities of daily living at home.

Proprioception (sensation from joints, muscles and tissues that lead to body awareness) is obtained by lifting, pushing and pulling heavy objects as well as by engaging in activities that compress (push together) or distract (pull apart) the joints. It is the sense that allows a person to guide his arm or leg movements without having to observe the movement to make sure it is happening.

Vestibular (the sense of movement, centered in the inner ear) is obtained by spinning and swinging and, to a lesser extent, any type of body movement or change in head position. It coordinates the movement of one's eyes, head, and body and tells the body where it is in space. The vestibular sense is central in maintaining muscle tone, coordinating two sides of the body, and holding the head upright against gravity.

Tactile (sense of touch) is obtained by providing a variety of input from textures, temperature, and pressure.

Auditory (what we hear and closely connected with the vestibular sense) is obtained by listening to various types of music or natural sounds. Some auditory input can have an organizing and calming effect. Music containing 60 beats per minute can be particularly organizing, whereas irregular beats and contrasts in volume may be energizing.

Visual (what we see), can be used to calm or alert the system. Care must be taken that the child's environment is not too visually stimulating or distracting.

Olfactory (smell) input can stimulate, calm, or send a child into sensory overload.

Taste, obtained by the use of sweet, salty, crunchy, or chewy foods, can help calm, alert, or organize the system.

Sensory Diet Once the child's sensory processing abilities and needs have been evaluated, the therapist may work with the educational team as well as the family to develop a *sensory diet*, a term coined by Patricia Wilbarger, OT. The sensory diet is a carefully designed personalized activity schedule that provides the sensory input a person's nervous system needs to stay focused and organized throughout the day. Because sensory needs vary from individual to individual and from day to day, careful monitoring and collaboration is crucial. Components of a sensory diet might include brushing, swinging, heavy work (lifting, carrying), swimming, wearing weighted vests, wrist or ankle weights, wearing earphones, tactile play, trampoline jumping, chewing hard or crunchy objects, among many others. Occupational therapists may also elect to use a system of tactile and proprioceptive input called the Wilbarger Protocol. This is a system using a soft bristle brush to provide carefully controlled sensory input, always followed by a deep pressure/joint compression system. While this protocol has been anecdotally reported to be effective in regulating sensory processing for some individuals, if done incorrectly, it can have harmful or dangerous results. Therefore, this procedure should only be used by trained personnel, and under the supervision of a trained occupational therapist.

Recreational Therapies

Recreational therapy is a general term used to describe the practice of using leisure activities as therapeutic interventions. Such therapies provide opportunities for supporting and enhancing communication and social and motor activities, and may include, but are not limited to, the following.

Additional research is needed to determine the efficacy of recreational therapies

Aquatic Therapy refers to the use of water and specifically designed activities to help restore, maintain, and increase function. Aquatic/swimming therapy focuses on therapeutic play activities that improve range of motion and increase balance, endurance, and body awareness. Swimming provides movement that can help enhance motor planning. Water pressure can be soothing and calming for individuals with ASD.

Art Therapy is an established profession that uses the creative process of art to improve and enhance the physical, mental, and emotional well-being of individuals of all ages. It can increase fine-motor, visual motor, visual perception skills, organization, planning, and artistic expression.

Music Therapy is the prescribed use of music and musical interventions to work toward specific therapeutic goals and objectives. Goal areas include communication, academic, motor, emotional, and social skills. Music therapy can also have a positive effect on self-esteem and reduce anxiety while developing appropriate expression of emotions. Music is a nonverbal form of communication. It is a natural reinforcer – it is immediate in time and provides motivation for practicing nonmusical skills. Parallel music activities are designed to support the objectives of the child as observed by the therapist or as indicated by a parent, teacher, or other professional. A music therapist might observe the child's need to socially interact with others. Musical games like passing a ball back and forth to music or playing sticks and cymbals with another person might be used to foster such interaction. Eye contact might be encouraged with imitating clapping games near the eyes. Preferred music may be used contingently for a wide variety of cooperative social behaviors like staying in a chair or remaining with a group of children in a circle.

Therapeutic Horseback Riding Hippotherapy, or therapeutic horseback riding, uses horses as a source of treatment to improve balance, posture, and mobility. It can also improve the cognitive, behavioral, and communication functions of individuals of all ages. Riding enables an individual to participate in an enjoyable activity while increasing attention span, independence, and self-esteem. While learning from the horse, riders often bond with the horse as well as the other riders, thus providing a good foundation on which to build relationships with others.

Other possibilities for recreational therapies include tumbling/dance, camping, 4H, animal therapy, peer playgroups, community sports activities, swimming/aquatics, yoga, martial arts, and tae kwon do.

When deciding on recreational therapies, the child's needs and interests must be considered

Biomedical Interventions

***Policy Statement from the AMERICAN ACADEMY OF PEDIATRICS:
Counseling Families Who Choose Complementary and Alternative Medicine for
Their Child with Chronic Illness or Disability***

Committee on Children with Disabilities

PEDIATRICS VOL. 107 NO. 3 MARCH 2001, PP. 598-601

A statement of reaffirmation for this policy was published on May 1, 2005.

The use of complementary and alternative medicine (CAM) to treat chronic illness or disability is increasing in the United States. This is especially evident among children with autism and related disorders. It may be challenging to the practicing pediatrician to distinguish among accepted biomedical treatments, unproven therapies, and alternative therapies. Moreover, there are no published guidelines regarding the use of CAM in the care of children with chronic illness or disability. To best serve the interests of children, it is important to maintain a scientific perspective, to provide balanced advice about therapeutic options, to guard against bias, and to establish and maintain a trusting relationship with families.

Medications

A variety of medications have been prescribed for individuals with ASD, and several have been researched. However, no one medication works for every person with ASD. Hyperactivity, sleep problems, obsessive tendencies, anxiety, aggression, and self-injury are some of the symptoms that may be targeted with specific medications. When medication is being discussed or prescribed, it is important to ask:

- What is the safety of its use in children with autism?
- What is the appropriate dosage?
- How is it administered (pills, liquid)?
- What are the long-term consequences?
- Are there possible side effects?
- How will my child be monitored and by whom?
- What laboratory tests are required before starting the drug and during treatment?
- Are there possible interactions with other drugs, vitamins, or foods?

Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, parents should seek out and work with a medical doctor with expertise in the area of medication management. Medications should be given on a trial basis with close monitoring of positive and negative effects. Since there are few objective measures of a person's response to a medication,

reliance on subjective information (parent, teacher, and caregiver reports) is common. This is particularly important for children with ASD, who have difficulty understanding and expressing feedback from their bodies and their emotions. The observations of parents and caregivers should be systematically collected by logs, charts, scales, or other accepted behavioral documentation. Occasionally, a trial of medication tapering and discontinuation is a way to determine its efficacy and/or whether it is still needed. Like any medical treatments, medications should be reviewed at every follow-up visit.

Nutritional and Dietary Interventions

Individuals with autism may exhibit low tolerance or allergies to certain foods or chemicals. While not a specific cause of autism, food intolerances or allergies may contribute to behavioral issues. Nutritional therapies may be used for a variety of reasons. Some parents and professionals have reported changes when specific substances are eliminated from the child's diet.

Parents wishing to pursue dietary interventions should consult a gastroenterologist or nutritionist who can help ensure proper nutrition. Be sure to consult with a doctor, nutritionist, or dietician before beginning any dietary or nutritional supplement interventions

The Gluten-Free/Casein-Free Diet (GFCF) According to theory, some individuals are unable to completely digest the protein in cereals (gluten) or in dairy products (casein). The molecular structure of the partially undigested proteins, known as peptides, resembles opiates. Such peptides are thought to have an effect much like opiates on the brain and nervous system. From this premise it follows that long-term exposure to these peptides can have damaging effects on the developing brain and can also affect behavior, just as any narcotic would.

Beginning a GFCF diet can be difficult but not impossible. Gluten is most commonly found in wheat, rye, and barley, and sometimes contaminates oats grown nearby or processed on the same equipment as gluten-containing cereals. Casein is found in dairy products. Wheat and dairy make up a large proportion of the Western diet. One of the biggest obstacles parents face is that children needing GFCF diets often crave these foods. In fact, parents often report withdrawal symptoms when gluten and casein are eliminated from their child's diet.

Although there are reports of immediate improvement, it may take as long as six months for gluten and one month for casein to clear out of the system. Advocates of the diet recommend trying it for at least a year as it can take that long for some children to show improvement. The diet affects changes in the body at a cellular level and promotes healing of the stomach and intestinal lining, both of which can take time. Calcium is very important in bone development and maintenance. Most people get their calcium from dairy sources. If your child is on a dairy- or casein-free diet, a calcium supplement may be necessary.

Specific Carbohydrate Diet (SCD) refers to a strict grain-free, lactose-free, and sucrose-free dietary regimen. Initially developed for individuals with celiac disease and other intestinal disorders, the diet may help individuals with ASD who experience gastrointestinal problems. The theory behind this diet is that carbohydrates, being forms of sugar, promote and fuel the growth of bacteria and yeast in the intestines, causing an imbalance of and eventual overgrowth of bacteria and yeast. Bacterial overgrowth can prevent the digestion and absorption of carbohydrates. This causes the carbohydrates to remain undigested in the intestines, providing even more fuel for bacteria and yeast. Toxins and acids can be formed by the bacteria and yeast and injure the small intestine lining. Excessive mucus may be produced as a defense mechanism against the irritation caused by toxins, acids, and undigested carbohydrates.

Anti-Yeast Diet This diet was developed to address the overproduction of or allergies to *Candida albicans*, a single-celled yeast that is impossible to keep out of the body. Normally, it does no harm, because it is kept in check by beneficial bacteria, but if there is an imbalance in the beneficial bacteria, *Candida* can grow uncontrolled, releasing extremely acidic toxins into the bloodstream. These chemicals slow the brain down so that it no longer works correctly. The chemicals should be cleared by the liver so that they never reach the brain. However, in some, they are apparently not cleared, causing problems. The anti-yeast diet consists of removing fermented foods from the diet. The worst offenders are alcoholic beverages and non-alcoholic beer, vinegar, barley malt, chocolate, pickles, soy sauce, and aged cheese. Some believe that individuals with ASD are likely to have an allergy to or overproduce *Candida albicans*.

Supplements Over the past 10 years or more, claims have been made that vitamin and mineral supplements may improve the symptoms of autism in a natural way. If you are considering adding vitamins or minerals to your child's diet, a laboratory and clinical assessment of her nutritional status is highly recommended. The most accurate method for measuring vitamin and mineral levels is a blood test. It is also important to work with someone knowledgeable about nutritional therapy. While large doses of some vitamins and minerals may not be harmful, others can be toxic. Once supplements are chosen, they should be phased in slowly (over several weeks), and the effects should be observed for one to two months. The reported benefits of supplements range from behavioral changes, to improved language. Supplements can include the following:

- **B6 and Magnesium**

B6, often combined with magnesium, is reported to help improve language, eye contact, brain electrical activity, behaviors, and immune system function. Magnesium is needed with high doses of B6 because, when taken alone, B6 may cause a deficiency in magnesium and other B vitamins. Also, magnesium may decrease some possible side effects, such as irritability, bed-wetting, and sensitivity to sound.

- **Vitamin B12**
Vitamin B12 deficiency is characterized by the inability to absorb food. Vitamin B12 is essential for metabolism of fats and carbohydrates and the synthesis of proteins. Vitamin B12 is involved in the manufacture of the myelin sheath, a fatty layer that insulates nerves in the brain.
- **DMG/TMG**
Dimethylglycine (commonly known as DMG) is classified as a food substance rather than a vitamin. It is found in very small amounts in brown rice and liver. Parents have reported positive results with a similar product, tri-methyl-glycine (TMG). TMG breaks down into DMG and SAmE in the body. SAmE is a nutritional supplement and is sometimes used to treat mood disorders such as depression. There are, as yet, no published reports on the efficacy of DMG or TMG for individuals with ASD.
- **Melatonin**
Melatonin is a hormone made by a part of the brain called the pineal gland. Melatonin may help our bodies know when it is time to go to sleep and when it is time to wake up. Melatonin supplements come in two pill forms, natural and synthetic (man-made). Natural melatonin is made from the pineal gland of animals. Children with ASD often have sleep disturbances, which suggests that there may be some problem associated with the body's production and use of melatonin. Children receiving melatonin regularly exhibit benefits that cannot be explained in simple terms, like better sleep. It may be a combination of better sleep and better control of biological rhythms. Especially in children, melatonin should be given only under the supervision of the regular physician.
- **Vitamin A**
For years, high doses of this vitamin have been used successfully to treat the measles virus. Using cod liver oil, Megson (2004) began vitamin A therapy with some of her patients and observed some positive results. Some patients spoke more frequently and clearly; others made gains in eye contact. Megson has reported that vitamin A in the natural form, such as cod liver oil, helps to rebuild areas in the brain, called receptors which are dramatically affected by ASD. The natural form of vitamin A is claimed to also improve cell growth, repair of epithelial cells found in the gut wall, immune system function, and gene expression and transcription. Consult your doctor if you are considering a Vitamin A supplement as too much vitamin A or D, which is also found in cod liver oil, can be toxic.
- **Vitamin C**
The benefits of vitamin C are widely known in the general public, and it may be of help for children with autism as well. Vitamin C is an antioxidant that helps the brain utilize oxygen. Without this vitamin, confusion and depression can develop. Vitamin C can also help support the immune system, aid in detoxification, and fight viruses and bacteria. Vitamin C is nontoxic, even in high doses.

- **Folic Acid**

Folic acid is a nontoxic B vitamin, and a nutrient essential to the brain's health. It has been reported as helpful in treating autism. It is widely recommended that pregnant women take extra folic acid during their pregnancy to help prevent some birth defects. It is most effective when taken with vitamins B12 and C. Other supplements can include essential fatty acids, zinc, probiotics, and cod liver oil, but should be carefully researched and taken only under the supervision of a physician.

Defeat Autism Now! Protocol (DAN)

The Defeat Autism Now!, or DAN, protocol is a guide for clinical assessment of individuals with autism developed by participants in the DAN conferences organized originally by the Autism Research Institute. ARI is the Autism Research Institute, a non-profit organization, founded in 1967 by Dr. Bernard Rimland. ARI is focused on conducting research and providing information on ASD to both parents and professionals. Some practitioners who know the DAN! protocol regularly use the medical tests to assess a child's health. There are also practitioners who will be willing to read the DAN! protocol and implement it. The basic premise of the DAN! protocol is that heavy metal toxicity in the form of thimerosal in vaccines, amalgams, or some other source, is the cause of the symptoms of autism. Most also recommend the use of the GFCF diet.

CHAPTER 4

Accessing Educational Services: Navigating Through the School System in Kentucky

Through collaboration between parents and schools, excellence is fostered in education for all students. Cooperative team efforts can help to identify students' strengths and needs for effective programming. Areas to consider when planning might include communication, social skills, stereotypical/repetitive behaviors, sensory needs, and academic issues. Working as a team, we can put the pieces of the ASD puzzle together one piece at a time.

This chapter describes how a child receives an educational identification of autism to qualify for special education services under the Individuals with Disabilities Education Act (IDEA). The chapter also provides an explanation of the Individualized Education Program (IEP) and offers tips for participating successfully in the ARC meeting, including suggestions for communicating effectively with school personnel.

Please refer to the Glossary at the end for a description of the terms used in this chapter

Educational Identification

Under the Individuals with Disabilities Education Act (IDEA), all children with disabilities have the right to a free and appropriate public education (FAPE). The local school district is responsible for locating, identifying, and evaluating all children who may be eligible for special education services from 3 to 21 years of age. This process is called Child Find.

If you are concerned about your child's development and the child is 3 years old or younger, you can contact the First Steps program in your county, as discussed in Chapter 2. If you are concerned about a child who is 3 and older, you can request support from your local school district. If your child is in preschool or kindergarten, request a meeting with your child's teacher to discuss your concerns. Ask the teacher to observe your child's performance in social as well as academic situations and compare those observations with your own.

Pre-Referral

If your child does not attend school and does not currently have a diagnosis, discuss your concerns with your pediatrician or contact your local school district. Your school

district is responsible for identifying all children with disabilities. Ask to speak to someone in the special education department. When you explain your concerns, your child will be referred for screening to determine if further evaluation is necessary. If your child is in school and needs help to be successful in the classroom, school personnel will initiate one of the following to identify the type of support your child needs:

- **Assistance Team (AT)** This is a group of school personnel who meet to support classroom teachers in addressing issues with an individual student, whether the issues are behavioral or educational. The team identifies supports the student may re-quire to be successful in the classroom. Parents are included in the AT process for their child.
- **Student Intervention System (SIS)** This is the process of identifying and assessing the effectiveness of interventions identified to support a student who is experiencing learning difficulties. The interventions will be identified and carried out by school personnel.

In both instances, the accommodations and supports are carried out for a specific length of time while data is being collected on the student's progress. The AT/SIS team will meet to review the data and then determine whether to continue the intervention process by adding and/or adapting supports. If the team feels that the student is not responding to the intervention or showing expected progress, the team must request a multi disciplinary evaluation.

The Admissions and Release Committee (ARC)

The ARC team is a group of individuals responsible for making all decisions about the identification, evaluation, placement of children with disabilities, and the provisions of FAPE. The ARC team can also be called the Individual Education Program (IEP) team. The ARC team consists of the following people:

- **Parents/guardians**
You, the parent(s), are a very important and equal member(s) of the ARC. There is no other person who knows your child better.
- **General education teacher**
Under IDEA, a general education teacher should attend the meeting to share information about the general curriculum or same aged peers if the child is or may be participating in the general education environment.
- **Special education teacher**
This should be your child's special education teacher or a special education teacher with knowledge of the suspected disability. He/she should attend to share information about how your child learns. The special education teacher will help the general education teacher assess what accommodations and/or modifications your child will need to be successful in the general education classroom.

- **Representative of the school district or Placement Specialist**
The district representative/placement specialist is able to provide or supervise the provision of specially designed instruction, has knowledge of the general curriculum, and has the ability to commit resources.
- **Psychologist/Individual who can interpret test results**
For any testing or evaluation that may have been done, IDEA requires that someone attend the meeting who can interpret test results and how the results may impact instruction. The results must be explained so that everyone involved understands their implications.
- **Individual with expertise of child**
At your discretion, an individual with knowledge or special expertise of your child should attend.
- **Related service personnel**
If the ARC identifies a need for related services, such as speech-language therapy, occupational therapy, social work services, etc., it is important that the relevant related service personnel attend the meeting. His or her expertise is vital to planning a program.
- **Your child**
When appropriate, the child should be a member of the team. Students should be involved when they are capable of participating in the decision-making, and should always be involved when issues regarding transition are discussed. If the student cannot be present or does not want to attend, efforts must be made to establish the interests and concerns of the child before the meeting.
- **Representative of public agency**
When appropriate, a representative of a public agency to discuss community programs and transition services may attend. This agency may be involved in paying for transition services.
- **Representative of preschool program**
When the child is in the preschool program a representative of that program should be included in the meeting.

While each of these people may not be in attendance at your child's ARC, the team needs his/her expertise. If your child's needs indicate that a specific area of knowledge is needed, the team can request their input in writing prior to the meeting.

ARC Members-The IEP is developed by a team that consists of the following:

- You as the parents
- The child, if appropriate

- The child's general education teacher
- The child's special education teacher
- A school district representative who is qualified to provide or supervise the specially designed instruction, is knowledgeable about the general education curriculum, and can commit resources (i.e., school principal, counselor, specialist)
- A person who can interpret test results and how the results may impact instruction, if applicable
- Related service personnel (Speech/language pathologist, Occupational Therapist)
- If the child is being served in early intervention programs, a representative from the preschool program.

Who else can attend ARC meetings?

IDEA allows parent or the school district to bring anyone to a meeting who has working knowledge about the child or the child's disability.

Identification, Evaluation, and Placement Process

Federal and state laws and regulations have specific steps to make sure the rights of children with disabilities are protected. These rights include making sure that you have a chance to work as part of a team with the school district in making decisions about your child's education.

The following steps are carried out in the process of identification, evaluation, placement and provision of FAPE:

1. Referral
2. Evaluation
3. Eligibility
4. Development of the IEP
5. Placement
6. Implementation
7. Program Review

Referral

When parents, school staff, or other individuals think that a child might have a disability and need special education services, they give that information to the office of the Special Education Director. This is known as a referral.

If your child is referred for special education services, you will be notified in writing, invited to attend an Admissions and Release Committee (ARC) meeting, and asked for permission to evaluate your child.

Evaluation

In order to best serve the needs of your child, the ARC team uses the information from the full and individual evaluations to decide if your child meets the eligibility guidelines for a particular type of disability and whether your child may need special education and related services.

The school collects information about your child from many different people and in many different ways. Evaluation sources include:

- Your child's educational history
- The observations and opinions of professionals who have worked with your child
- Your child's medical history when is related to their performance in school
- Psychological evaluations
- Your knowledge of your child in relationship to his/her school experiences, abilities, strengths, challenges, and behavior outside of school.

The evaluation process involves several tasks:

- Reviewing existing information
- Deciding if more information is still needed
- Collecting more information about your child using various assessment tools.

Once you have given your written consent for your child to be individually evaluated, qualified professionals will be chosen to help assess your child's abilities and needs. Professionals will observe your child. They may give your child formal assessments or conduct informal interviews with your child. They are trying to get a picture of the "whole child."

In most cases, your school district will be able to conduct your child's entire evaluation within the district. In a few cases, a school district may not have the staff to do all of the evaluations needed. These districts will have to hire or contract with outside people or agencies to do some or all of the evaluation. If your child is evaluated outside the school, the school must make the arrangements at no cost to you. The school will inform you in writing exactly what type of testing is to be done. Evaluations done at the recommendation of the ARC are done at no cost to parents.

The total amount of time from the date the school receives your written consent to evaluate your child until the date the individual education program is started cannot exceed sixty (60) school days. When the evaluation is completed, you will receive a written invitation to an ARC meeting to discuss the results of the evaluation. As a member of the ARC, you and other members of the ARC should have access to the evaluation information to be used for making educational decisions prior to the ARC

meeting. Ask to obtain your copy of the evaluation report before the ARC meeting. You have the right to have the results of your child's evaluation explained to you. You may ask any questions you have in order for you to fully understand the results and help make decisions for your child.

If you do not understand the evaluation, you cannot give informed consent. Parents must know what the evaluation results mean to make good decisions about their child's identification and the IEP.

Eligibility

If the ARC, with parents as members, decides your child is eligible--which means that your child has a disability and needs specially designed instruction (SDI) and related services-- you will be given a written notice explaining that decision. The ARC must develop a written IEP. The ARC uses the full and individual evaluation results to determine if a child is eligible under the IDEA. The school district will do its best to have you take part in all decisions about your child. This includes asking you to attend the ARC meeting to discuss the results of the evaluation and to decide if your child is eligible under the IDEA.

Development of the Individual Education Plan

What is an IEP?

When your child is determined to be eligible for special education services, an Individual Education Program (IEP) is written. The IEP is a plan developed by the ARC to identify the services and supports necessary for a child to be successful in school. It is a written agreement between parents and the school of what constitutes FAPE for the child, which is required by IDEA.

If the ARC decides that your child has an educational disability and needs SDI and related services, the ARC will develop an IEP for your child. An IEP is a written plan of action describing the specially designed instruction and related services needed to meet the individual educational needs of your child. The district is obligated to provide a FAPE for all children with disabilities. Remember, you should always be given the opportunity to be a part of the ARC process that plans and reviews the IEP. The ARC should include you, your child (when appropriate), staff from the school district and other people invited by you or the school. The district will want to ensure you are able to fully participate by arranging for an interpreter or a translator if needed.

Placement

After the IEP is written, the ARC will decide how the IEP will be implemented. The ARC will consider what the least restrictive environment (LRE) is for your child based on his/her IEP. This is called placement. Remember, the LRE is not the same for every

child. Your child has the right to receive instruction and to take part in school activities in the LRE. This means that, as much as possible, your child has a right to participate in school programs and activities with children who do not have disabilities.

The KEY questions in determining the least restrictive environment are:

- What does the IEP say your child needs?
- Where can your child receive the programming he/she needs and can this be with other children who do not have disabilities? If not, why?

The ARC will consider a variety of educational settings where your child could receive specially designed instruction and related services, but the first place considered is always general education classes.

Where your child receives educational services depends on the kind of support he/she needs. Some children with disabilities will receive educational services in general education classes in regular schools, while other children may receive educational services in separate special education classes or schools.

Implementation

Once you have given written permission for placement, your child will begin to receive specially designed instruction and related services based on the IEP. Qualified teachers and related service providers will provide the instruction and services stated in the IEP. "Qualified" means that the individuals are certified or licensed by the state to perform the services. Specific names of IEP implementers are not written on the IEP; only the titles of the persons who will be providing the service(s) (e.g. teacher of special education, teacher of general education, OT, PT) are listed.

Implementers are responsible for providing instructional activities to help your child achieve the goals stated in the IEP. Implementers are also responsible for keeping records and reporting on how your child is progressing during the year. These records show that services were provided and how your child progressed toward reaching goals and objectives. These records also are used to make decisions at the annual ARC meeting when the IEP is reviewed.

Review

Federal and state regulations require the ARC to periodically review your child's IEP.

This ARC meeting must be held at least once per year to determine if annual goals have been met. This review is called the annual review.

Even though an ARC meeting must be held at least once a year to review your child's IEP and placement, you or any member of the ARC may request a review at any time, should a new issue arise. The parent may request an ARC meeting to discuss issues/questions regarding the evaluation, eligibility, IEP, or placement. The parent may call the school counselor, special education teacher, or principal to arrange the meeting.

When it is time for the annual review of your child's IEP, the school district will notify you in writing about the ARC meeting. The ARC reviews your child's IEP and recorded data kept by teachers and related service providers to decide if goals have been met. The ARC also must decide if your child still needs specially designed instruction and related services. If services are still needed, the ARC reviews your child's IEP, revises it if necessary and decides where services will be provided.

Regulations also require the school district to re-evaluate your child on or before the third anniversary of the meeting when the ARC determined your child eligible for specially designed instruction and related services. You or any ARC member may ask for a re-evaluation sooner than every three (3) years, but not more often than once a year unless agreed upon by the parent and local district, under the 2004 IDEA Reauthorization.

Components of the IEP

The IEP form is broken into several sections, and discussion of each section provides an agenda of topics to be addressed at the meeting. After members of the ARC have discussed each topic, the information is added to the form. The team may come with draft information written, but anything can be added or changed as the team discusses each section. The components of the IEP and the information they include are as follows:

- Present Levels of Educational Performance (PLEP) – information from the evaluation or from prior IEP data and from observation must be retrieved to address your child's strengths, areas of need, current level of functioning, and how the disability may impact his/her involvement in and progress in the general curriculum. If your child is in preschool, the IEP will state how the disability affects participation in appropriate preschool activities.
- Special Factors – This is a list of factors that fundamentally affect a child's educational performance. The team should consider and discuss how these factors will be addressed if they are pertinent to the child's needs related to school performance. Special factors include:
 - ü Behavior
 - ü Limited English proficiency
 - ü Visual impairment
 - ü Communication
 - ü Assistive Technology
 - ü Extended School Year Services
- Measurable annual goals – goals developed to address each of the significant needs identified in the PLEP. These goals, derived from PLEP statements, are goals that your child should reasonably accomplish in one school year. Goals should be written according to your child's current level of functioning as the measurable starting point and identify where the child will be functioning after one school year.

There must be a description of how the district is going to measure progress on the goals.

- Special education – specially designed instruction (SDI) and related services must be stated in the IEP. SDI means changing and/or adapting the content or delivery of instruction to address the unique needs of your child and make sure your child has access to the general curriculum. This includes stating the supplementary aids and services, modification to the program, and supports for personnel that will be provided to assist your child.

Educationally Relevant

When a child has related services on his/her IEP, the goal is to enable that child to benefit from special education services in order to ensure FAPE. Related services should be educationally relevant, meaning that they ensure that the child benefit from services. There are some factors to consider with educational relevance: educational program, eligibility, present levels of performance, and skill levels. The goal of the services is to enable a child to complete instructional activities and to make the child independent in the educational environment.

- Related services – all related services included on the IEP should be accompanied by a designation of the amount of time per week/month the child will be receiving the services and where the services will take place. Related services can include: speech-language pathology and audiology services; psychological services; physical and occupational therapy; counseling services; orientation and mobility services; transportation; and other services. The related service personnel should be included in the development of the IEP.
- Participation with non-disabled children – this identifies the least restrictive environment (LRE) for your child to receive his/her educational program.

If the district representative/placement specialist states that he/she is unable to commit resources during the meeting, the ARC may have to reconvene another meeting when he/she can commit resources.

Autism Speaks offers a School Tool Kit to provide information about autism -- the features, challenges and strengths -- as well as some of the tools and strategies that may result in more positive interactions for all members of a school community.

http://www.autismspeaks.org/community/family_services/school_kit.php

Accommodations vs. Modifications

Accommodations refer to "whatever it takes" to make sure that a child with a disability can participate as fully as possible in the general education curriculum and achieve the academic content standards. Accommodations are changes in the way that material is presented (for example, a child may listen to a reading passage on tape instead of reading it) or in the way a student responds to the material (a student may dictate their responses to questions instead of writing them), as well as changes in setting, timing, and scheduling.

Accommodations involve many kinds of techniques, strategies, and support systems. They help students work around limitations related to their disability. An accommodation refers to "how" the general education curriculum will be presented to the student with disabilities so that he can understand the general education curriculum.

Accommodations may include:

- Visual schedules
- Scribe
- Note-taker/assistive technology
- Calculator
- Sensory regulation items
- Paraphrase
- Visual organizers
- Reader
- Supplemental aids and services

Modifications are changes that can be made to "what" students are expected to learn. For most students with disabilities, modifications should be considered only after all types of accommodations have been exhausted. Modifications involve partial completion of program or course requirements. When determining a modification, the IEP team should ask the following question: "What part of the curriculum does this child need to know that will help them in their adult life?" Because the purpose of special education services is to prepare children with disabilities for further education, employment, and independent living...that is, for life as adults.

Participation in state and district-wide tests – Individual accommodations and modifications that will be provided for your child to participate in state and district-wide assessment must be stated on the IEP. There are three ways that children can participate in assessment:

- § Take the test without accommodations
- § Take the test with allowable accommodations that are provided daily in the general education classroom
- § Take an alternate assessment as determined by the ARC

Dates and places – A statement of when the services and modifications will begin, how often they will be provided, where they will be provided, and how long they will last.

Transition service needs – The ARC identifies a set of activities that promote movement from:

- § preschool to school
- § school to school
- § school to post secondary education
- § vocational training
- § integrated or supported employment
- § continuing adult education
- § adult services
- § independent living
- § community experiences and participation.

If the child is 16 years or older, the IEP transition service statement will focus on the child's course of study. The purpose of the transition plan is to assist students with disabilities in becoming independent adults, making a smooth transition from school to competitive employment and/or postsecondary education, independent living, and community involvement.

Measuring and reporting your child's progress – A statement of how often you will be informed (at least as often as students without disabilities) and how you will be informed of his/her progress.

The IEP concludes with the signatures of all participants. Your signature does not indicate that you agree or disagree with the IEP, but that you attended the meeting.

The format of the IEP document is designed specifically to guide a step-by-step process of development with each section building on the previous section. It is important to remember that the information listed in the PLEP must be accurate in order for the team to write appropriate measurable goals. When written properly, the IEP documents the provision of a free, appropriate public education (FAPE).

Helpful Hints for Preparing for the IEP Meeting

- Talk to a parent mentor or an advocate before the meeting. They can give you suggestions on how to work effectively with the team at the meeting and explain your rights under IDEA.
- Familiarize yourself with educational jargon and acronyms; ask for clarification of any you don't fully understand.

- Ask for and review evaluation and present levels of educational performance (PLEP) data before the IEP conference. Ask the school for clarification of anything you do not understand. If necessary, meet with evaluator/teacher before meeting to discuss.
- Before the meeting, write down your priorities and questions.
- Make an agenda for the IEP meeting to guide the discussion of the points you want to cover.
- Tell the school who you will bring to the meeting and ask who will attend from the school. This information should be on the meeting notice. As a courtesy, inform the school as soon as you know of a new participant; surprise guests are usually not appreciated.
- Gather information you want to share, including medical or other assessments. If possible, disseminate this information to participants prior to meeting.
- Bring a friend to the meeting to help in taking notes and clarifying information that is discussed.
- Let the school know if the meeting time or location does not work for you. Offer alternative suggestions in writing to the school.
- Ask the question "How is this going to help my child?" This will help focus the discussion of services and supports being considered.

IEP Questions to Consider

- Are my child's goals measurable? That is, does the IEP state his/her level of functioning now so that it can be compared to his/her functioning in the future to determine how much progress has been made?
- Does the IEP identify the modifications, accommodations, and other supports my child needs to succeed?
- Does the IEP identify who will provide what service and how much time will be spent on those goals?
- How do you measure where my child is currently performing now?
- Are we setting reasonable and realistic expectations of progress for my child?
- How often will my child's IEP goals be reviewed and how often will we meet to review progress?

Navigating Rough Waters

When You Disagree with the School District's Decisions

The Individuals with Disabilities Education Act (IDEA) values the input of parents regarding their child's education. It provides for actions parents can take when they disagree with school district personnel about their child's educational program. The following are options parents have:

- 1. Request a case conference** – This is a meeting with school personnel to discuss concerns and explore how to resolve the issues.
- 2. Request an administrative review** – This is a meeting that will include the district superintendent or designee to review the issues of disagreement. This person is able to reverse the decision of school personnel.
- 3. Request mediation** – This occurs when parents and schools cannot agree after both the case conference and administrative review. You and the school must both agree to mediation. A trained, qualified and impartial representative hired by the Kentucky Department of Education will be assigned to conduct the mediation between you and the school district representatives. A mediation time that you, the mediator, and the school district representatives agree upon will be scheduled.
- 4. File for an impartial due process hearing** – This is a formal, administrative procedure that is held to resolve disagreements between the parents and the school district. The district will contact the Kentucky Department of Education and a list of potential impartial hearing officers will be sent to the district. In Kentucky, all hearing officers must be attorneys and all hearing officers must have completed training on the process through the Kentucky Department of Education. Parents and the school have to agree upon a hearing officer to hear the case.

Complaint Process

Parents may also file an official complaint with the Kentucky Department of Education. This is an official notice that a school district may have violated one or more of the federal or state special education laws. Complaints must be about students, or groups of students who are eligible or thought-to-be eligible for special education services.

This does not require a hearing officer. The complaint is reviewed by staff of the Kentucky Department of Education who investigates the complaint by talking with both the parent and the school districts to establish the facts of the case. An official decision is made regarding the complaint and the parent and the school district are informed in writing of the decision of the Kentucky Department of Education. If the district is found in violation of federal or state law, the district is required to correct the violation.

Complaints must be made in writing and sent to the Kentucky Department of Education, Division of Exceptional Child Services (DECS), 8th Floor Capital Plaza Tower, 500 Mero Street, Frankfort, Kentucky 40601.

Types of Disagreements

School district denies the request to perform a multi-factored evaluation (MFE)-

In order for a child to be eligible for special education services, the child must meet two conditions. The child must:

- Have a disability under one of the 13 IDEA categories
- The disability must have a documented adverse affect on the child's educational program

If the school does not observe an adverse affect on the child's educational performance based upon educational data, the school may refuse to perform an evaluation when parents request one.

If the school district refuses to perform an MFE, it must provide the parents with a *prior written notice* letter. The letter must contain information regarding why the evaluation will not be provided and what documentation was used to determine that an evaluation is not needed.

In response the parents may do one of the following:

- Request a mediation with an Kentucky Department of Education-appointed mediator to review the issues of disagreement and make a decision
- File a complaint with the Department of Education, Office for Exceptional Children.

School district determines that the child is not eligible for special education services after the MFE is performed-If this happens, parents can refuse to agree with the results of the MFE and request an *independent educational evaluation* at public expense. A request for an independent evaluation should be made in writing.

The district can agree to provide for an independent educational evaluation and provide parents with a list of approved evaluators that parents can use at the school's expense. Parents may choose an evaluator from the list or choose someone else.

For a publicly funded evaluation, the school must agree to the evaluator that the parent chooses. IDEA requires that the school agree to the location of the evaluation and the qualifications of the examiner (they must be the same as the criteria for evaluators that the district uses (such as a licensed psychologist).

The school district can initiate a due process hearing to show that its first evaluation is appropriate and, therefore, deny the independent educational evaluation. In this case, a hearing is scheduled before a hearing officer while the school presents evidence to support its position and the parents do the same. The hearing officer then decides if the school must provide for an independent educational evaluation.

Any time a district refuses the independent evaluation at the school's expense, parents have the option of obtaining an independent evaluation at their own expense. When the parents receive the results of any independent educational evaluation, they must request a case conference in writing with school district personnel to consider (and discuss) the results of the evaluation. At this meeting, parents are requesting school district personnel to review any decisions related to the child's eligibility or educational programming based on the new information provided.

If parents and the school district disagree after a review of the independent evaluation results-If you and the district cannot come to an agreement about how to address your child's needs, parents can file for an impartial due process hearing, as described in option number 4 above.

The IEP is not appropriate or is not being implemented appropriately-If this is the case, request in writing a review of your child's Individual Educational Program with the team and identify your concerns. At this meeting the team can address your concerns and make revisions to the IEP, if appropriate, or identify additional areas of assessment and programming needed to address your concerns.

In addition, IDEA funds parent training and information centers in every state and territory specifically to answer parents' questions about special education issues and provide training to give parents the information they need to advocate for their child's educational interests.

Section 504

If you do not want to pursue a due process hearing to challenge the school district's decision about your child's eligibility for special education services, another mechanism is available to obtain accommodations for your child. When a child has an identified disability that does not meet the criteria under one of the 13 IDEA categories or that does not adversely affect the child's educational performance, parents can request that the district provide the child with a 504 Plan. This may be the case for children with Asperger Syndrome.

Section 504 of the Rehabilitation Act is a broad civil rights statute that prohibits discrimination on the basis of disability. It states that no person with a disability can be, by reason of his or her disability, denied access to or excluded from participation in or denied the benefits of a public program or service.

Upon request, a 504 Plan is developed to provide the accommodations necessary for the individual with a disability to access an identified service or program. Each local district is required to identify procedures to implement the requirements of Section 504. A district is also required to identify individual(s) responsible for the coordination of Section 504 services. Ask for information regarding your district's procedures for compliance with Section 504.

The Importance of Knowing Your Educational Rights

It is important to approach the educational planning for your child with the school team from a positive perspective. Be open to ideas and solutions as long as they meet your child's needs. Still, understand that you have the right under IDEA to question the school district's decisions and that there are procedural safeguards written into the law to help you protect your child's right to a free and appropriate public education.

Several resources are available to help parents understand their rights regarding the education of their child. The KY PIRC, the Autism Society of Kentucky, and other local autism groups provide parent trainings on educational rights on a regular basis. These groups also offer assistance to families by phone and through their websites. There are many websites available that also provide information for parents on advocating for their child's educational rights.

(Information adapted from materials developed by the Kentucky Coalition for the Education of Children with Disabilities, Marion, Kentucky. Used with permission).

Glossary of Terms

Admissions and Release Committee Meeting (ARC) - The ARC is made up of the parent, child (if appropriate), regular education teacher, special education teacher, administrator or designee and others as appropriate. This group is responsible for identification, evaluation, placement and developing, reviewing, or revising an individual Education Program for a child with a disability.

Alternate Assessment (Portfolio) - The alternative assessment is an option for children who have the cognitive inability to complete a regular course of study leading to a traditional diploma.

Assistive Technology Device - any piece of equipment or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.

Assistive Technology Service - is any service that directly assists an individual with a disability in the selection, acquisition, or use of an AT device.

Free Appropriate Public Education (FAPE) - public education provided at no cost to the parent, and in accordance with an Individual Education Program.

Individuals with Disabilities Education Act (IDEA) - The federal law that requires states to provide children with disabilities a free appropriate public education that modifies and extends the Education for all Handicapped Children's Act.

Individualized Educational Program - A written plan of action which includes a student's present levels of performance; annual goals directly related to each area of need; short-term instructional objectives; all necessary specially designed instruction and related services; transition services; extent of participation in regular education; dates for initiation and anticipated duration of services; amount of time child shall spend receiving each service; evaluation procedures; implementers or persons responsible.

Related Services - transportation and such developmental, corrective, or supportive services required to assist a child with a disability to benefit from special education. For example, speech therapy is considered a related service.

Least Restrictive Environment - The educational setting in which the child with a disability can learn effectively, based upon unique needs and capabilities.

Present level of Performance (PLOP) - the first component of the IEP that describes the current performance level, abilities, and disabilities of a child with a disability.

Referral - written information about a student suspected of having a disability that may include: personally identifiable data; a description of the areas of concern; an appropriate instruction; support services and interventions provided for any area of concern that adversely affects educational performance.

School Records - (cumulative and other available records) are documents and other written information directly related to a child, which are collected, maintained or used by the school district to make IEP decisions.

Specially Designed Instruction (SDI) - adapting, as appropriate, the content, methodology, or delivery of instruction to address the unique needs of the child with a disability and to ensure access to the general curriculum.

Transitions - a coordinated set of activities for a child with a disability that is designed within an outcome-oriented process, promotes movement from school to post-school activities, and is based on the student's needs.

CHAPTER 5

Social Service Programs: Kentucky Resources

This chapter will discuss ways to explore and access resources specific to the state of Kentucky. The main focus is to provide easy-to-read information concerning available resources and to provide immediate contact information for the purpose of applying for resources and/or locating additional information. You may notice that many of the resources listed in this manual are directly linked to regional Comprehensive Care Centers. Often (and especially with children under the age of three and adults), a local Comprehensive Care Center will be the point of entry for an individual to gain access to many programs and services. For school-aged children and adolescents, the most direct route to services is often through the local public school system.

This product is a version of the resource manual created by the Human Development Institute. The list of resources provided here is not meant to be exhaustive. The purpose is to focus on resources available to individuals with developmental disabilities, though other related resources have been included.

This chapter is organized in the following sections: *Services for Youth and Children, Services for Adults, and Services for All Ages*. You may wish to consult all of the sections as you look for potential services and programs within this Guide.

Services for Children and Youth

The Commission for Children with Special Health Care Needs

What is the CSHCN?

The Commission for Children with Special Health Care Needs is an agency that provides diagnosis and treatment for persons with certain disabilities, both congenital and acquired (i.e. cerebral palsy, spina bifida, etc...).

Do I qualify for services from CSHCN?

You must be a resident of Kentucky. You must be under the age of 21 years (exception: adults with Hemophilia). You must have a condition usually responsive to medical treatment provided by our program. You must meet financial guidelines.

How do I apply?

To find the regional office that serves your area:

Commission for Children with Special Health Care Needs
310 Whittington Parkway, Suite 200
Louisville, KY 40222
Phone: (800) 232-1160 or (502) 429-4430

How can I learn more? <http://chfs.ky.gov/dms/Consumer+Directed+Option.htm>

Early Periodic Screening Diagnostic and Treatment Special Services (EPSDT)

What is EPSDT?

The EPSDT Screening Program provides routine physicals or well-child check-ups for Medicaid eligible children at certain specified ages. It is considered preventive care. Children are checked for medical problems early. Specific tests and treatments are recommended as children grow older. The areas of health care that are checked include: preventive check-ups, growth and development assessments, vision, hearing, teeth, immunizations, and laboratory tests.

Do I qualify?

You must be age 21 or under and be eligible for Medicaid. Services must be deemed medically necessary by peer review organizations and must be prior authorized by these organizations.

Medical necessity is determined by Kentucky Health Choices.

How can I apply for EPSDT services?

Application forms must be submitted by the service provider. Required information for patient application of services includes a physician's order, product information, prices from different providers with comparable products, and a letter from the physician or other professional including:

- Patient history
- Diagnosis and prognosis
- Medical justification for each item/service
- Description of the benefit to the patient
- Length of time that the patient will need the item/service.

Often, the application process can be facilitated through a home health agency, nurse's registry, dental agency, or equipment provider. Your local Comprehensive Care Center (see Appendix A) may have a listing of local EPSDT providers. If you are refused service through EPSDT, there is an appeal process. For questions about appealing a decision, contact Kentucky Protection and Advocacy at (800)-372-2988 or (502) 564-4527 (Voice/TTY).

How can I learn more?

Department of Medicaid Services

Phone: (800) 635-2570 TTY (800) 775-0296

<http://chfs.ky.gov/dms/epsdt.htm>

First Steps

What is First Steps?

First Steps is an early intervention program that serves children from birth to age three who have a developmental delay or a physical or mental condition that may cause a delay in development. Services include, but are not limited to, evaluation of the child's development, home visits, and an Individual Family Services Plan (IFSP).

Does my child qualify?

Child must be younger than age 3.

Child must have a developmental delay or disability, or an established risk condition (Down Syndrome, etc...).

Areas of concern in child development:

- Communication
- Motor skills
- Cognitive development
- Personal social skills
- Adaptive or self-help skills

If you have a concern about your child in any of the areas listed above, you can apply for the First Steps program. An evaluation of your child's development will be available.

How do I apply?

Contact the First Steps Program: (800) 442-0087 or TTY: (502) 564-5777
You will then be directed to your local point of entry office.

How can I learn more? <http://chfs.ky.gov/dph/firststeps.htm>

IMPACT Plus**What is IMPACT Plus?**

IMPACT Plus is a collaborative effort of the Department of Mental Health, Developmental Disabilities and Addiction Services (DMHDDAS). This program provides a network of short-term care and services for Medicaid/K-CHIP-eligible children with complex treatment needs. Services include behavioral health evaluations, individual & group therapy, child support services, after school or summer programs, day treatment services, partial hospitalization, intensive outpatient behavioral health services, therapeutic foster care, parent-to-parent support, and targeted case management. Services also include short-term placements in a hospital, psychiatric treatment facility, group or foster home or other court-placed facility.

Does my child qualify?

Must be under the age of 21 and fit one of the following requirements:

- Currently in the custody or under the supervision with risk of being in the custody of the Department for Community Based Services or Department of Juvenile Justice; or
- Must be at risk for immediate and extensive institutionalization (hospitalization, out-of-home placement).

Must have documentation to prove:

- A severe and continuing DSM-IV-R Axis I diagnosis, other than dementia or substance abuse
- A serious behavioral health problem related to the diagnosis that has lasted in the home, school, and community for the past 6 months and has been determined by a behavioral health professional to be at high risk of continuing for 6 months

- A plan of medically-necessary community based behavioral health services that can reasonably be expected to improve the child's condition so that the child may discontinue the intensive services and be discharged to a less intensive behavioral health service or program within 6 months
- Other intensive services within the child's community are not enough to meet the child's needs or are not available.

How do I apply for IMPACT Plus services for my child?

Contact the IMPACT Plus Program Office, DMHDDAS: Phone: (502) 564-4797
TTY (502) 564-5777

How can I learn more? <http://www.mhmr.ky.gov/mhsas/Impact%20Plus.asp?sub1>

Kentucky Children's Health Insurance Program (K-CHIP)**What is K-CHIP?**

K-Chip's mission is to provide health insurance coverage to low income, uninsured children in Kentucky. The K-CHIP staff understands that access to health care is very important and that preventive care is a large part of health care. Immunizations, well child checkups and other preventive services help children get and stay healthy.

Does my child qualify for K-CHIP?

- Must be less than 19 years of age
- Must not be eligible for Medicaid
- Must not have had health insurance for at least six months
- Must not have voluntarily dropped child's insurance within the past 6 months
- Family income must be at or below 200% of the Federal Poverty Line.

How can I apply for my child to obtain medical coverage through K-CHIP?

Contact the K-CHIP Program, Department for Medicaid Services where eligibility and services are determined by local offices in the county where the applicant resides:
Phone: (877) 524-4718 Spanish: (800) 662-5397

Kentucky IMPACT Program**What is the Kentucky IMPACT Program?**

Kentucky IMPACT is a statewide program which coordinates services for children with severe emotional disabilities and their families. Service coordination between teachers, physicians, individual counselors, and the family is offered; intense in-home family services are available; and the IMPACT team is sometimes able to provide funds for the purchase of miscellaneous items needed by the child. Support groups are also available.

Do I qualify?

- Child must be younger than 18.
- Must have a diagnosis of a psychiatric disorder. Diagnosis of chemical dependency, mental retardation, or other brain disorder may be present, but cannot be the primary diagnosis

- Must be severely limited in at least two of the following areas: self-care, interpersonal relationships, difficulty in daily life activities, self-direction, must have been disabled for at least one year
- Must require service planning from two or more agencies.

How can I apply for IMPACT services for my child?

You may contact the state office for Kentucky IMPACT, and you will be directed to the appropriate regional office:

100 Fair Oaks Lane, 4E-D

Frankfort, KY 40621-0001

Phone: (502) 564-4456 TTY: (502) 564-5777

Or you may contact your local Comprehensive Care Center

How can I learn more? <http://mhmr.ky.gov/mhsas/KY%20Impact.asp>

Or you may contact your local Comprehensive Care Center to determine if there are providers in your area.

Services for Adults

Acquired Brain Injury Waiver Program

What is the ABI Waiver Program?

This program is designed to provide intensive services and supports to adults with acquired brain injuries as they work to re-enter community life. Services include case management, personal care, respite care, environmental modifications, behavior programming, counseling and training, structured day programs, specialized medical equipment and supplies, supported employment, community residential services, occupational services, and speech and language services. Services can only be provided in community settings.

Do I qualify for ABI?

You Must:

- Be 21 to 65 years of age and require nursing facility level of care;
- Have a primary diagnosis of an acquired brain injury;
- Meet nursing facility level of care;
- Be expected to benefit from waiver services;
- Be able to remain in the community upon discharge; and
- Be financially eligible for Medicaid services.

How do I apply for ABI?

You may call for an application: (502) 564-5198 **or toll free:** (866) 878-2626

Or you may write: Brain Injury Services Branch, 275 E. Main Street, 6W-B
Frankfort, KY 40621.

How can I learn more about ABI? <http://chfs.ky.gov/dms/Acquired+Brain+Injury.htm>

For members who would like to choose Consumer Directed Option Services for ABI, visit the DMS CDO page: <http://chfs.ky.gov/DMS/Consumer+Directed+Option.htm>

Centers for Independent Living (CIL)

What are Centers for Independent Living?

CILs are typically non-residential, private, non-profit, consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. The goal is to assist individuals with disabilities achieve their maximum potential within their families and communities.

What services to CILs offer?

CILs work to assure physical and programmatic access to housing, employment, transportation, communities, recreational facilities, and health and social services. CILs offer services including: information and referral, peer counseling, advocacy, and independent living skills training which teach self-help skills, inform people about other disability programs, and create new services. CILs treat housing, transportation, attendant services, employment and discrimination as the interlocking problems that they are. CILs can help you learn more about transportation in your community and how to use it, as well as provide assistance in completing the Assistive Technology Loan Board application.

How can I learn more?

Center for Accessible Living

305 W. Broadway, Suite 200,
Louisville, KY 40202

(502) 589-6620 or (800) 813-849 (502) 589-6690 (TTY) <http://www.calky.org>

Center for Accessible Living

1051 N. 16th Street, Suite C
Murray, KY 42071

(270) 753-7676 (voice)/ 888-261-6189 (270) 753-7729 (TDD) <http://www.calky.org>

Disability Coalition of Northern Kentucky

525 W Fifth Street, Ste 219
Covington, KY 41011

(859) 431-7668 (800) 648-6057 (TTD/TTY voice) www.dcnky.org

BEST CIL Inc

624 Eastwood Avenue
Bowling Green, KY 42103

(270) 796-5992 www.bestcil.org

Pathfinders for Independent Living, Inc.

105 E. Mound Street
Harlan, KY 40831

(606) 573-5777

Independence Place

836. Euclid Avenue, Suite 101
Lexington, KY 40502

(859) 266-2807 www.independenceplaceky.org

Homecare Program

What is the Homecare Program?

The Homecare Program helps adults who are at risk of institutional care to remain in their own homes by providing supports and services to ensure daily needs are provided by. This is accomplished primarily by coordinating the help of caregivers and provider agencies. Assessment and case management, home management and personal care, home delivered meals, chore services, home repair, and respite for family caregivers and home health aide service are among the assistance provided.

Do I qualify for this resource?

You must be 60 or older and unable to perform two activities of daily living or three instrumental activities of daily living You must be at risk of going to an institution; or You must be in an institution, but would be able to return to a private home environment if needed services are provided.

How do I apply?

You may request an application from the Office of Aging Services in Frankfort by calling: (502) 564-6930, or you may contact your local Comprehensive Care Center to determine if there are Homecare Program providers in your area.

How can I learn more?

Department for Aging and Independent Living
275 E. Main St., 3W-F
Frankfort, KY 40621 Phone: (502) 564-6930/TTY (888) 642-1137

Medicare

What is Medicare?

Medicare is the nation's largest health insurance program, which covers more than thirty-nine million Americans 65 or over, some people with disabilities under 65, and people of all ages with End State Renal Disease. Medicare has two parts:
Part A (Hospital Insurance) - Most people do not have to pay for Part A.
Part B (Medical Insurance) - Most people pay monthly for Part B.

Do I qualify for Medicare?

- Must be a citizen or permanent resident of the United States
- Must be 65 years of age and older OR
- You or your spouse must have worked for at least 10 years in Medicare-covered employment
- Be under 65 with End Stage Renal Disease OR
- Have received Social Security or Railroad Retirement disability for 24 months.

If you are not a U.S. citizen or a lawfully admitted alien who has lived in the U.S. continuously for a five-year period, please contact the Social Security Administration at (800) 772-1213 for your Medicare enrollment and eligibility.

How can I apply for Medicare coverage?

If you are not yet 65 and already getting Social Security or Railroad Retirement Board

benefits, you do not have to apply for Medicare. If you are disabled and have been receiving disability benefits under Social Security or Railroad Retirement Board for 24 months, you will be automatically enrolled in Part A and Part B beginning the 25th month of benefits. If you are not receiving Social Security or Railroad Retirement Board benefits you must apply for Medicare Part A and Part B. You can apply by contacting the Social Security Administration (or Railroad Retirement Board). You should apply three months before the month you turn 65.

How can I learn more?

Social Security Office:

Phone: (800) 772-1213

<http://www.medicare.gov/Basics/Overview.asp>

Michelle P. Waiver**What is the Michelle P. Waiver?**

In 2002, some people with developmental disabilities sued the Commonwealth of Kentucky because the state didn't provide enough help for them to live in the community instead of an institution. Kentucky finally agreed to provide extra services and settled the suit. It then created the Michelle P. Waiver. The Michelle P. Waiver is a Medicaid program that helps people live in the community or go back to the community after living in an institution. It is for anyone with mental retardation or a developmental disability who is eligible to receive services at an ICF/MR, like Oakwood, Hazelwood, or Cedar Lake Lodge. To get the waiver, you must also have a medical card or be eligible for one.

What services are provided through the Michelle P. Waiver?

- Case Management Supported Employment *
- Homemaker * Attendant Care *
- Personal Care * Behavioral Supports *
- Respite Assessment/Reassessment
- Adult Day Health * Occupational Therapy *
- Adult Day Training * Physical Therapy *
- Environmental and Minor Home Adaptations Speech Therapy *
- Community Living Supports *

A case manager or support broker will help you decide the services you need. The services with a star are limited to 40 hours a week altogether. There are no residential services with the Waiver. It was designed to help people who live in their own homes or a family member's home, but need help to continue living in the community.

Who provides the services?

Once you receive the Waiver, you can get services from any Supported Community Living (SCL), Home and Community Based Waiver (HCBW) or Adult Day Health Care (ADHC) provider. You can even hire someone you know to provide some of the services through the Consumer Directed Option. For more information about the Consumer Directed Option, see the *Services for All Ages* section in this Guide.

How do I apply?

To apply, contact your local Community Mental Health Center. It will provide an assessment to determine if you are eligible. You can find your Center by visiting <http://mhmr.ky.gov/cmhc> or by calling (502) 564-5560.

How can I learn more? www.kypa.net

Personal Care Attendant Services Program**What is the Personal Care Attendant Services Program?**

Attendant services are provided for people 18 and older with functional loss of two or more limbs and who have the ability to hire and supervise an attendant. Services include assistance with personal care, housekeeping, shopping, travel, self-care procedures, meal preparation, and other daily activities. State and local funds are used by local organizations to provide services and programs that help maintain older persons in their own homes. Please contact the Department Aging and Independent Living to determine whether or not there is a waiting list for services.

Do I qualify?

- Must be 18 years of age or older
- Must be severely physically disabled with permanent or temporary recurring functional disabilities
- Loss of two or more limbs
- Must need at least 14, but no more than 40, hours of personal care attendant services per week
- Must be mentally capable of instructing and supervising attendants
- Must be able to prepare attendant payroll reports and employer tax statements

How can I apply for these services?

Contact the Office of Aging Services, Cabinet for Health Services:
Department for Aging and Independent Living
275 E Main St., 3W-F
Frankfort, KY 40621
Phone:(502) 564-6930 TTY: (888) 642-1137

Supplemental Security Insurance (SSI)**What is SSI?**

SSI is a need-based program designed to provide a minimum income to people unable to work due to disability or retirement who are otherwise uninsured or underinsured and have insufficient income from other sources.

Do I qualify for SSI?

To receive SSI, you must be 65 or older or blind or disabled. SSI is based on financial need. You must be determined disabled by the Social Security Administration Disability Determination Office. SSI recipients are automatically eligible for Medicaid.

How can I apply for SSI?

Call the Social Security Administration (SSA) office to schedule an appointment at your local office: Phone: (800) 772-1213.

How can I learn more? <http://www.ssa.gov>

Supported Employment**What is Supported Employment?**

Supported Employment service assists persons with severe disabilities find and maintain employment in an integrated setting with long-term support. This program is meant for individuals who need ongoing support to be successful in their job.

Do I qualify for Supported Employment services?

If you receive SSI benefits, you qualify. It is not necessary to receive SSI to qualify for this program. If you have a severe mental or physical disability, you can apply. If your disability has interfered with getting and/or keeping a job, you may be eligible for this service.

How can I apply for these services?

Call the Kentucky Office of Vocational Rehabilitation in Frankfort:
Phone: (800) 372-7172 or (502) 564-4440

What can I expect during this phone call?

An appointment will be made for you to meet with a counselor. You will apply for DVR services, specifying Supported Employment. You can also access a list of service providers by calling the number above.

How can I learn more? <http://www.ihdi.uky.edu/kyseweb>
http://ovr.ky.gov/programs_services/supported_employment_program.htm

Supports for Community Living (SCL)**What is the Supports for Community Living Program?**

SCL provides services to individuals with disabilities that enable them to live in the home or in the community rather than in an institution. SCL services include the following: support coordination, residential supports, supported employment, behavior supports, psychological services, occupational therapy, physical therapy, speech therapy, respite care, as well as specialized medical equipment and supplies. There is often an extended waiting list for SCL, so it is very important to contact the Supports for Community Living Office to have your name added to this list.

Do I qualify for SCL?

You must have a developmental disability or mental retardation. You must meet Medicaid requirements.

How can I apply for SCL?

The first step is to complete an application form.

You can get an application form by calling or by visiting the Web site.

How can I learn more?

Phone: (502) 564-7702 TTY: (502) 564-5777 <http://mhmr.ky.gov/mr/scl.asp>

Services for All Ages

Assistive Technology

What is Assistive Technology?

Assistive technology refers to devices and tools that are created to help those with disabilities participate more fully in the activities of daily life. Assistive technology can be funded by private insurance, public funding, other private sources, or through loans.

How can I apply for Assistive Technology?

Assistive technology may be provided through several agencies, each with its own application process. Call the Kentucky Assistive Technology (KATS) Network for information on local providers in your area:

KATS Network

Charles McDowell Center

8412 Westport Rd

Louisville, KY 40242

Voice: (502) 429-4484 / (800) 327-5287

What can I expect from KATS NETWORK?

KATS helps people of all ages. A KATS representative will ask a few questions to help determine your need. KATS will direct you to the right agency or service provider. KATS publishes a handbook which is available upon request.

How can I learn more? <http://www.katsnet.org> (Kentucky KATS Network)
<http://katlc.ky.gov/> (Assistive Technology Loan Corporation)

Consumer Directed Option

What is the Consumer Directed Option?

The Consumer Directed Option (CDO) gives Medicaid waiver members more choices in the way some Medicaid services are provided. With CDO you can choose who will provide services you need as well as how, when and where services will be provided. You can choose a friend, family member, or support broker to help you direct your services. You can blend services and may return to traditional service delivery at any time with no loss of services. A support broker will help you design your plan of care which is based on your particular needs.

Do I qualify for services from Consumer Directed Option?

You must be a Medicaid eligible and enrolled in one of the following Medicaid Waiver programs:

- Home and Community-Based (HCB) waiver
- Supports for Community Living (SCL) waiver
- Acquired Brain Injury (ABI) waiver

Residential and medical services are not covered under the Consumer Directed Option. Your support broker can advise you about CDO eligible services.

How do I apply?

To find the office of Aging and Independent Living that serves your area:

KY Health Choices

Consumer Directed Option

Department for Aging and Independent Living

275 E. Main St., 3W-F

Frankfort, KY 40621

(877) 293-7447

How can I learn more? <http://chfs.ky.gov/ccshcn/>

Home and Community-Based Waiver (HCB Waiver)

What is the HCB Waiver?

The Home and Community-Based Waiver program provides Medicaid coverage to eligible persons who are aged or disabled, who would otherwise require nursing facility level of care. Services include but are not limited to the following: assessment and reassessment, case management, homemaker services, personal care services, respite care, minor home adaptations, attendant care, and adult day health care.

Do I qualify for this service?

If you receive Medicaid, you qualify for this program. (Qualifying for HCB may enable you to become eligible for Medicaid. Some families choose to pay for the first month of HCB. The second month of service eligibility is determined by the financial eligibility of the individual instead of the family.) A physician must certify that without these services, the physician would order nursing facility care. There is no age requirement for the HCB Waiver.

How can I apply for the HCB Waiver?

Your local Comprehensive Care Center may have a listing of Home Health Agencies that perform as HCB providers in your area. You may contact your local Comprehensive Care Center or the Department for Medicaid Services: (502) 564-5707.

How can I learn more? <http://chfs.ky.gov/dms/hcb.htm>

Hart-Supported Living Program

What is Hart-Supported Living?

The Hart-Supported Living program is for Kentuckians with disabilities to request grants for supports so they can live in, contribute to and participate in their communities. Any Kentuckian with a disability recognized under the Americans with Disabilities Act (ADA) is eligible to apply for a Hart-Supported Living grant. The program is administered

through the Department of Mental Health, Developmental Disabilities, and Addiction Services (DMHDDAS), but it is a program for people with all disabilities.

Do I qualify?

You (and your family, friends, and the people who support you) should consider applying for a Hart-Supported Living grant if:

- You want to live in a home of your choice that is typical of the homes where people without disabilities live
- You want to participate in your community with all members of the community.
- You want to decide for yourself what supports and services you need to live in the community
- You want to arrange for and manage your own supports

How can I apply for Supported Living Services?

Contact your Regional Supported Living Coordinator for an application and for assistance in completing the application. Applications must be received by April 1st in the office of Regional Hart-Supported Living Coordinator for funding for the upcoming fiscal year, beginning July 1st.

Contact the State Hart-Supported Living Coordinator:

DMHDDAS

275 E Main St., 3W-F

Frankfort, KY 40621

Phone: (502) 564-6930

How can I learn more? <http://mhmr.ky.gov/mr/supportedliving.asp?sub1>

Medicaid (KyHealth Choices)

What is Medicaid?

KyHealth Choices is the new name for Kentucky Medicaid, which is a joint federal-state program that pays for medical services on behalf of certain groups of low-income persons. Members of families with children, pregnant women, elderly, blind, or persons with a disability are eligible for Medicaid if they meet certain financial criteria.

Do I qualify?

Individuals or families with dependent children may be eligible for Medicaid if they meet one of the following requirements:

- a pregnant woman
- a dependent child under age 19
- a parent of a dependent child, if one parent has left the home, cannot work due to sickness or disability or has died
- Parents (both) living with the dependent child, if the parent who earned the most income in the last 24 months is unemployed
- Income requirements are based on family size, pregnancy, and age of the youngest child.

How can I apply for Medicaid coverage?

An application for Medicaid may be filed at your local Department for Community Based

Services Office. Applicants will be required to show proof of identity, proof of citizenship, proof of health insurance, proof of income, Social Security number, and a doctor's statement verifying pregnancy, if applicable. For more information, call the Cabinet for Health Services of Kentucky, Department for Medicaid Services: (800) 635-2570.

How can I learn more? <http://chfs.ky.gov/dms/>

Additional Medicare and Medicaid Guides

The Kaiser Family Foundation released new guides that explain the role of Medicare and Medicaid for roughly 20 million children, adults and seniors with disabilities. These guides offer basic introductions to the Medicare and Medicaid programs, including things such as:

- How do people with disabilities apply for coverage under Medicare or Medicaid?
- What is Medicare's policy for covering durable medical equipment?
- Where can people with disabilities turn if they need help in applying for Medicaid?
- How do people with disabilities appeal Medicare coverage decisions?
- Can a person with a disability who has Medicare and/or Medicaid be employed and still keep their coverage?

How can I learn more?

The guides and additional information are available in PDF and HTML formats at: <http://www.kff.org/medicare/disabilities.cfm>

Social Security Disability Income (SSDI)

What is SSDI?

Social Security Disability Insurance (SSDI) is a federal cash benefit that may be available if a person is disabled.

Do I qualify for SSDI?

Social Security Disability eligibility is determined on having a disability and SSDI payments are based on your prior work. Your spouse and other dependents may be eligible for SSDI payments based on your work history. Their income may affect their amount, but their income does not affect the amount that you draw for yourself. Eligibility for both SSI and SSDI is possible if SSDI benefit rates are low enough. If you qualify for SSDI benefits you will be eligible for Medicare after receiving benefits for two years. At age 65 your SSDI benefits automatically roll over to Social Security Retirement benefits.

How can I apply for SSDI?

Call the Social Security Administration (SSA) office to schedule an appointment at your local office: Phone: (800) 772-1213.

How can I learn more? <http://www.ssa.gov>

State General Funds

What are State General Funds?

State General Funds are dollars that Comprehensive Care Centers can use flexibly. These versatile dollars can fund short-term supports that include but are not limited to respite, crisis intervention, and case management.

Do I qualify and how do I apply?

Due to the flexible nature of these funds, you will need to contact your local Comprehensive Care Center to determine if funds are available for the services you need. A Comp Care Center listing is included later in this chapter.

Traumatic Brain Injury (TBI) Trust Fund and Benefit Management Program

What is TBI?

This program offers flexible, funding and support for people with traumatic brain injuries.

Do I qualify?

Must have:

- Partial or total disability caused by injury to the brain.
- Damage to the brain from physical trauma, lack of oxygen, allergic conditions, toxic substances and other medical incidents.
- Impaired cognitive abilities or impaired brain function resulting from allergic conditions, toxic substances, or other acute medical clinical incidents.
- There is a benefit limit of \$15,000 per individual per year, with a lifetime maximum of \$60,000.

Exclusions-The following services are not covered under this program:

- Medications
- Institutionalizations
- Hospitalization
- Services for anyone who is a hospital or institutional resident.

How can I apply for TBI?

Contact the program administrator for additional information. (800) 447-4984

How can I learn more? <http://www.kybraininjuryfund.org/>

Vocational Rehabilitation (Voc Rehab)

What is Voc Rehab?

The Kentucky Office of Vocational Rehabilitation assists Kentuckians with disabilities to achieve suitable employment and independence.

Do I qualify for Vocational Rehabilitation services?

If you receive Social Security disability benefits, you are considered to be an individual with a significant disability and are presumed to be eligible for services. Your impairment must result in a substantial impediment to employment. It is not necessary

to receive SSI to qualify for this program. You must be of employable age by completion of rehabilitation.

How can I apply for Vocational Rehabilitation?

Contact the Office of Vocational Rehabilitation:

Office of Vocational Rehabilitation

209 St. Clair

Frankfort, KY 40601

Voice: (502) 564-4440 / (800) 372-7172 (in Kentucky)

TTY (888) 420-9874

What can I expect during this phone call?

An appointment will be made for you to meet with a counselor. Your eligibility will be determined within 60 days of your application.

How can I learn more? <http://ovr.ky.gov/index.htm>

Kentucky Comprehensive Care Centers

Four Rivers Behavioral Health

425 Broadway

Paducah, KY 42001

(270) 442-7121

24 hour Crisis and Information Line: (800) 592-3980

<http://www.4rbh.org>

Counties served: Ballard, Calloway, Carlisle, Fulton, Graves, Hickman, Livingston, Marshall, and McCracken.

Pennyroyal MH / MR Board

735 North Drive

Hopkinsville, KY 42240

(270) 886-5163 or

24-hour line: (877) 473-7766 or in Christian County (270) 881-9551

<http://www.pennyroyalcenter.org>

Counties served: Caldwell, Christian, Crittenden, Hopkins, Lyon, Muhlenberg, Todd, and Trigg.

River Valley Behavioral Health

1100 Walnut Street

Owensboro, KY 42301

(800) 737-0696 <http://www.rvbh.com>

For all first appointments and referrals to River Valley Behavioral Health outpatient services, call Point of Entry: (270) 683-4039 or (800) 737-0696

Counties served: Daviess, Hancock, Henderson, McLean, Ohio, Union, and Webster.

Life Skills

380 Suwanee Trail Street

Bowling Green, KY 42102

(270) 901-5000

24 hour Crisis line: (800) 223-8913 (Outside Warren County) <http://www.lifeskills.com/>

Counties served: Allen, Barren, Butler, Edmonson, Hart, Logan, Metcalfe, Monroe, Simpson, and Warren.

Communicare, Inc.

107 Cranes Roose Court
Elizabethtown, KY 42701

(270) 765-2605 www.communicare.org

Counties served: Breckinridge, Grayson, Hardin, Larue, Marion, Meade, Nelson, and Washington.

Seven Counties Services, Inc.

101 W. Muhammad Ali Blvd.
Louisville, KY 40202-1451

24-hour crisis line: (800) 221-0446 or (502) 589-4313/ TDD (502) 589-4259

<http://www.sevencounties.org>

Counties served: Bullitt, Henry, Jefferson, Oldham, Spencer, Shelby, and Trimble.

North Key Community Care

503 Farrell Dr.
Covington, KY 41011

(859) 781-5586

24-hour crisis line: (859) 331-1792 or toll-free (877) 331-3292 www.northkey.org

Counties served: Boone, Campbell, Carroll, Gallatin, Grant, Kenton, Owen, and Pendleton.

Comprehend, Inc.

611 Forest Ave.
Maysville, KY 41056
(606) 564-4016

After Hours Emergency: (877) 852-1523 www.comprehendinc.com

Counties served: Bracken, Fleming, Lewis, Mason, and Robertson.

Pathway, Inc.

P.O Box 790
Ashland, KY 41105-0790

(606) 329-8588 or (800) 562-8909 www.christiancarecommunities.org/p_centralKY.asp

Counties served: Bath, Boyd, Carter, Elliott, Greenup, Lawrence, Menifee, Montgomery, Morgan, and Rowan.

Mountain MH / MR Board

150 South Front Ave.
Prestonsburg, KY 41653

(606) 886-8572 www.mtcomp.org

Counties served: Floyd, Johnson, Magoffin, Martin, and Pike.

Kentucky River Community Care

115 Rockwood Lane

Hazard, KY 41701

(800)262-7491 TTY/TDD: (800) 787-5043 <http://www.krccnet.com>

Counties served: Breathitt, Knott, Lee, Leslie, Letcher, Owsley, Perry, and Wolfe.

Cumberland River MH / MR Board

P.O Box 568

Corbin, KY 40702

(606) 528-7010 www.cumberlandriver.com

Counties served: Bell, Clay, Harlan, Jackson, Knox, Laurel, Rockcastle, and Whitley.

Adanta MH / MR Board

259 Parkers Mill Rd.

Somerset, KY 42501

(606) 679-4782 Emergency Crisis Line (TDD/TTY): (800) 633-5599

<http://www.adanta.org>

Counties served: Adair, Casey, Clinton, Cumberland, Green, McCreary, Pulaski, Russell, Taylor, and Wayne.

Bluegrass MH /MR Board

1351 Newtown Pike

Lexington, KY 40511

(859) 253-1686 24-hour crisis line: (800) 928-8000 <http://www.bluegrass.org>

Counties served: Anderson, Bourbon, Boyle, Clark, Estill, Fayette, Franklin, Garrard, Harrison, Jessamine, Lincoln, Madison, Mercer, Nicholas, Powell, Scott, and Woodford.

Advocacy Resources

AUCD - Association of University Centers on Developmental Disabilities- American Association of University Affiliated Programs for persons with Developmental Disabilities.

(301) 588-8252 <http://www.aucd.org/>

Americans with Disabilities Initiative - This is a good site for general information on the ADA as well as other resources.

(502)564-6606 Toll free: (877) 423-2933 TDD: 711

<http://w.usdoj.gov/crt/ada/> or <http://ada.ky.gov/>

Bluegrass Regional Mental Health and Mental Retardation Board

(859) 253-1686

1351 Newtown Pike.

Lexington, KY 40511 <http://bluegrass.org>

Arc of Kentucky

706 E. Main Street, Suite A

Frankfort, KY 40601

(800) 281-1272 or (502) 875-5225 <http://www.arcofky.org>

Arc of the United States - The national organization of and for people with mental retardation and related developmental disabilities and their families.

(800) 433-5255 / (301)565-3842 <http://www.thearc.org/>

The Council for Exceptional Children - is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted.

(888) 232-7733 TTY: (866) 915-5000 <http://www.cec.sped.org/>

The Council on Mental Retardation (CMR) - is an association of families and friends of persons with mental retardation with a 50 year history of advocacy involvement including parent outreach and citizen advocacy programs.

(502) 584-1239 www.councilonmr.org

Human Development Institute at the University of Kentucky - The mission of HDI is to promote independence, productivity, and integration of all people through numerous research, training, and outreach activities.

(859) 257-1714 <http://www.ihdi.uky.edu>

Kentucky Autism Training Center - works to enhance supports for persons with autism by providing information and technical assistance to families and services providers across Kentucky.

(800) 334-8635 / (502) 852-5555 <http://louisville.edu/kyautismtraining/>

Family Voices - a national grassroots network of families and friends, advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs; promotes the inclusion of all families as decision makers at all levels of health care; and supports essential partnerships between families and professionals.

(888) 835-5669 (National office) or (502) 595-4459, Ext. 279 (KY office)

<http://www.familyvoices.org>

FIND (Family Information Network on Disabilities) of Louisville is a Community Parent Resource Center, which is a federal grant program of the US Dept. of Education. FIND of Louisville serves families with children who have disabilities and attend Jefferson County Public Schools. FIND of Louisville serves all disabilities.

(502) 587-6500 <http://www.findoflouisville.org/>

Kentucky Disabilities Coalition - A statewide alliance of consumer, family, and professional groups for a better life for all Kentuckians with disabilities.

(502) 875-1871 <http://www.geocities.com/kydisabilitiescoalition/>

Kentucky Consumer Advocate Network - "Building Better Lives Together"

A non-profit state funded organization that offers services for people statewide.

(800) 564-8034 / (502) 245-5281

Kentucky Education Rights Center, Inc. - is comprised of individuals who as advocates and attorneys have represented children with disabilities with school-related problems for a number of years. The endeavor of this organization is to provide this

identical assistance, but to do so without families incurring financial hardships.
(859) 983-9222 <http://www.edrights.com>

Kentucky Council on Developmental Disabilities – The mission is to create change through visionary leadership and advocacy so people have choices and control over their own lives.

Toll Free: (877) 367-5332 TTY: 800-627-4702 <http://chfs.ky.gov/kcdd/>

KY ADA – The State office of the Americans with Disabilities Act provides technical assistance, consultations and training to government agencies and programs regarding the Americans with Disabilities Act. Technical assistance and training areas include: employment, programs, services, and facilities. The office also responds to inquiries by local governments, businesses and individuals throughout the Commonwealth.

(877) 423-2933 / (502) 564-3850 TDD: 711 <http://ada.ky.gov/>

KY SPIN – Located in Louisville, works to empower and support individuals with disabilities and their families to effectively advocate for and access needed information, resources, and support networks in order to enhance the quality of their lives.

(800) 525-7746 / (502) 937-6894 <http://www.kyspin.com/>

KY Protection and Advocacy – an independent state agency, mandated by federal law, whose mission is to protect and promote the rights of Kentucky residents with disabilities through legally-based individual and systemic advocacy and education.

(800) 372-2988 (Message Line & TTY) / (502) 564-2967 <http://www.kypa.net>

PASRR Preadmission Screen and Resident Review - the Department of Mental Health, Developmental Disabilities and Addictions Services (DMHDDAS) mandates the state mental health and mental retardation authority to establish a preadmission screening and resident review (PASRR) for all persons applying for admission to or residing in a nursing facility.

(502) 564-4527 TTY: (502) 564-577 <http://mhmr.ky.gov/KDMHMRS/pasrr.asp>

TASH Disability Advocacy Worldwide – An international association of people with disabilities, family members, other advocates and professionals working for a society in which inclusion of all people in all aspects of society is the norm.

(202) 263-5000 <http://www.tash.org>

TASH, Kentucky Chapter – Located in Louisville.

(502) 239-4805 <http://www.tash.org/dev/TashPublic/Chapters.aspx>

Accessibility Information

Often, the most immediate issue facing an individual with disabilities is accessibility.

Employment Services

Office of Vocational Rehabilitation provides services to individuals with disabilities to prepare for, secure, retain or regain appropriate employment. <http://ovr.ky.gov>

KY Cabinet for Workforce Development: Connecting Kentucky to employment, workforce information, education and training. <http://www.state.ky.us/agencies/wforce>

Supported Employment assists persons with disabilities to find and maintain employment. http://ovr.ky.gov/programs_services/supported_employment_program.htm

Assistive Technology refers to devices and tools that may be available to persons with disabilities that allow them to participate more fully in the activities of daily life. <http://www.katsnet.org> or <http://katlc.ky.gov>

Accessible Faith Organizations

Issues to consider when looking for a place of worship:

- Are the buildings and sanctuary accessible?
- Are the programs and ministries accessible?
- Are the social activities accessible?

Contact the following for further information:

Catholic Diocese of Lexington: (859) 253-9803
Coordinator for Ministries for Persons with Disabilities www.cdlex.org

Temple Adath Israel: (859) 269 2979 www.lextai.org

Accessible Housing

HUD Federal Rental Assistance - HUD funds several rental assistance programs. <http://www.hud.gov/renting/index.cfm>

Kentucky Assistive Technology Loan Program – Loan program for individuals with disabilities for the purpose of vehicle modifications (van lifts, etc...) <http://www.katlc.ky.gov>

Accessible Transportation

Human Development Institute at the University of Kentucky - Getting around town for either medical or personal ventures can be fulfilling for someone with a disability when the right services are available. The HDI staff has worked diligently to locate and list these accessible services. We have compiled a list of statewide transportation services available to individuals with disabilities, constructed the list by county to enable individuals to quickly and efficiently find their area and transportation services provided within it. In addition we have listed the transportation services offered through Medicaid. These services are categorized by region and county. With the ever-changing size and quality of transportation services, we will routinely update and modify any changes necessary. To obtain a hard copy of the transportation manual, please call HDI at (859) 257-2569 or (859) 257-1714. www.ihdi.uky.edu

Kentucky Assistive Technology Loan Corporation – Loan program for individuals with disabilities for the purpose of vehicle modifications (van lifts, etc...)

<http://www.katlc.ky.gov>

Special Services and Equipment Fund – The State General Fund may have funds available for vehicle modifications or transportation services.

Accessible Education

Schools cannot discriminate based on disability. If you have a child with a developmental disability and have concerns about educational programs that your child may be entitled to or eligible for, contact your local public school system.

If you have concerns about state laws and education, contact:

Kentucky Department of Education

500 Metro Street, 6th Fl. CPT

Frankfort, KY 40601.

(502) 564-2000

www.kde.state.ky.us/KDE

If you wish to file a dispute over educational programs that you believe your child is entitled to but does not receive, contact:

Kentucky Protection and Advocacy

100 Fair Oaks Lane, Third Floor

Frankfort, KY 40601

(800) 372-2988 / (502) 564-2967 (Voice and TTY)

www.kypa.net

Accessible Recreation

Accessible recreational activities are available through a variety of agencies and organizations. The Human Development Institute does offer a Recreation Manual with available activities offered across the state. For more information or to request a copy, call (859) 257-1714 or visit the Website at www.ihdi.uky.edu

Contact your local **Parks and Recreation Department** or your local **YMCA** for information about the programs and activities that they offer.

<http://www.ymca.net/maps> to find the YMCA closest to your location

Kentucky Horse Park - also offers some accessible recreational activities, and its campus is widely accessible for touring.

4089 Iron Works Parkway

Lexington, KY 40511.

(800) 678-8813 / (859) 233-4303

<http://www.kyhorsepark.com>

Please Note -

When asking about accessible recreational activities, you may want to remember to ask whether the activity is integrated or segregated.

Accessible Respite Care

Respite Care consists of short term and temporary care to families with members who have disabilities so that the caregivers and other family members can take a break from their daily routine of care giving. Respite care can also be offered overnight or for an extended period of time. Respite care help alleviate the stress and consistent nature of caring for relatives with disabilities. Respite care also helps assuage burnout on behalf of the caregiver and family members. Furthermore, respite care also provides a change of daily schedule for the child cared for which can help strengthen both their independence and relationships with others.

Most respite care programs are managed by The Arc, The Easter Seal Society and United Cerebral Palsy in cooperation with local hotels. Depending on the organization or volunteer(s), respite caregivers either visit the homes of these families or require visiting a day care center or a respite group home. "Host families" or exchange programs consist of other families who also have a member with a disability temporarily caring for a friend or neighbor's child and vice versa.

Life Skills, Inc - offers respite care relief for individuals and families affected by mental illness, developmental disabilities and substance abuse. For more information, please call (270) 901-6499

Corporate Office

992 State St., PO Box 6499

Bowling Green, KY, 42102-6499

(270) 901-5000

www.lifeskills.com

Bluegrass Regional Mental Health and Mental Retardation Board - can arrange respite care services for individuals with developmental disabilities.

1351 Newtown Pike

Lexington, KY 40511

(859) 253-1686

<http://bluegrass.org>

Wells Health Systems Inc - provides short stay respite care services for individuals with special needs.

(270) 926-9355

725 Harvard Drive

Owensboro, Kentucky 42301

www.wellshealthsystems.com

Christian Appalachian Project Rainbow Respite Center's CAP Disabilities Service in Lancaster - provides respite care either in their residential setting or within the family's home or community.

(866) 270-4227 / (859) 792-3051

The Christian Appalachian Project

P.O. Box 511

Lancaster, KY 40444-0511 www.christianapp.org

Audubon Area Community Services, Inc - offers respite care services for families receiving benefits from KTAP.

800 W Fourth Street
Owensboro, KY 42304
(270) 686-1600 www.audubon-area.com

Seven Counties Services, Inc – located in Louisville. Provides respite care services for children with developmental disabilities.

101 W. Muhammad Ali Blvd.
Louisville, KY 40202-1451
(800) 221-0446 / (502) 589-4313 www.sevencounties.org

Independence Place - accepts information and makes referrals for families seeking respite care services.

824 Euclid Ave., Suite 101
Lexington, KY 40502
(859) 266-2807 www.independenceplaceky.org

BEST CIL Inc - offers personal care attendants for individuals 18 years or older who have lost the use of two or more limbs.

624 Eastwood Ave.
Bowling Green, KY 42103
(270) 796- 5992 www.bestcil.org

Cumberland River Comprehensive Care Center - in Corbin, KY offers respite care for individuals supported by Cumberland River Care Center. Emergency respite care request is accepted and handled on a case by case basis.

Kim Wake or Chad Jackson: (606) 528-7010 <http://www.cumberlandriver.com/crccc.html>

First Steps - Kentucky's Early Intervention System which offers respite care for children with developmental disabilities (aged 0-3 years). Also offers emergency respite care services.

First Steps
275 E. Main St., - HS2W-C Frankfort, KY 40621 (502) 564-8003

Legislator Information

Some of the resources listed in this manual include excellent programs that are unfortunately limited in availability. It is important to let your legislators know your thoughts about these programs and services as well as your thoughts about future services.

State Legislators:

For a complete listing of State Legislators: <http://www.lrc.state.ky.us>

Federal Legislators:

For a complete listing of Federal Legislators: <http://www.usa.gov/Contact/Elected.shtml>

Kentucky Autism Training Center (KATC)

The mission of the Kentucky Autism Training Center is to enhance supports for persons with autism by providing information and technical assistance to families and service providers across Kentucky. The serves as a statewide clearinghouse for information about ASD; maintains a collection of resources, including books, CDs and DVDs for loan at no cost to parents and professionals. It provides professional development opportunities on ASD and; maintains a service and supports database that is searchable online. For more information, contact KATC at 502-852-4631 or check the website: <http://louisville.edu/education/kyautismtraining>

Federal Assistance Programs**Supplemental Security Income (SSI)**

Based on parents' income, some children with disabilities are eligible to receive a cash benefit through Supplemental Security Income (SSI). Eligibility requirements are related to family income, including income from salary or wages, as well as savings and property. In other words, the amount of money or property a family has determines how much SSI a child can receive each month. Children may become eligible to receive benefits themselves when they reach the age of 18 if they cannot work.

To be eligible under the disability rules, a child must have a "marked and severe" functional limitation from a physical or mental condition. Children who are eligible for SSI benefits are also eligible for medical care under Medicaid.

Apply for SSI for your child by contacting your local Social Security Administration office or by calling the following toll free number (800) 772-1213. Have your social security number available when you call.

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) is a program that provides for a worker who becomes disabled and who has paid into social security. Sometimes SSDI also pays for the worker's dependents. When a worker retires, becomes disabled, or dies, any dependent children will get monthly cash benefit. How much the child receives depends on the size of the benefit the worker received. There is a cap or a maximum amount one family can receive, when both the worker and dependent children get benefits.

Apply by contacting your local Social Security Administration office or by calling the following toll free number (800) 772-1213.

Internal Revenue Service: Tax Deductions and Tax Credits for Families

According to IRS rules, a federal tax credit is available for eligible low- and moderate-income individuals and families who work. The Earned Income Tax Credit (EITC) reduces the amount of tax you owe. In 2001, workers with one eligible child could apply if their income was less that \$27,413. You can complete an assessment online to determine if you are eligible at: <http://apps.irs.gov/app/eitc2005/SetLanguage.do?lang=en>

Tax Deductions for Medical Expenses

Eligible medical expenses may be used as a tax deduction under IRS rules. The deduction can be taken only for unreimbursed medical expenses that amount to more than 7.5% of the adjusted gross income. To be eligible, parents must itemize deductions and not take the standard deductions.

Eligible expenses include health insurance payments, dental payments, transportation and hotel costs associated with getting medical care, and costs for assistive technology and durable medical equipment. You can combine the costs of medical care for yourself, your child with a disability, and any other family member to reach the 7.5% limit required.

For more information, contact the IRS at (800) 829-3676 or visit the IRS website at www.irs.gov/taxtopics/tc502.html

Non-Profit Organizations**Lions Club International**

The organization has a rich history of helping low-income individuals with disabilities, mostly with vision and hearing disorders, by providing grants for medical equipment, surgeries, glasses, hearing aids, and so on. To find the club closest to you, visit www.lionsclubs.org/EN/index.shtml (630) 571-5466.

Rotary International

Rotary is a worldwide organization of business and professional leaders that provides humanitarian service. Rotarians worldwide provide individuals with disabilities with education, employment, accessibility, and equal participation opportunities. Each club develops its individual service program from nine areas – one of which is helping people with disabilities. To find the club nearest you, contact the headquarters. (847) 866-3000 <http://www.rotary.org/en/Members/RunningAClub/Pages/ridefault.aspx>

Kiwanis Club

Service projects also address other needs within the community, such as working to stop substance abuse, helping the elderly, promoting literacy, supporting youth sports and recreation, responding to disasters, and supporting specific persons in need. The purpose of the clubs is to provide a way for adults with disabilities to develop leadership skills, to serve their communities, to be integrated into society and to demonstrate the value and dignity of citizens living with disabilities. Contact the Kiwanis headquarters for more information. (317) 875-8755 or www.kiwanis.org/clubloc/

Parent and Family Support Programs**Regional and Local Autism Groups**

Several regional and local autism organizations and parent support groups exist around the state. Contact the KATC at (502) 852-4631 for a list of local groups.

KY-SPIN

The mission of **KY-SPIN, Inc.** is to empower and support individuals with disabilities and their families to effectively advocate for and access needed information, resources and support networks in order to enhance the quality of their lives.

<http://www.kyspin.com>

United Partners in Kentucky (UP in KY)

UP in KY members are committed to work together, and share information and expertise in order to enhance and improve the quality of life of persons with disabilities and their families. We are dedicated to providing accurate, timely, and pertinent information to children, youth, and young adults with disabilities and their families so they can make informed decisions.

<http://www.up-in-ky.com>

The Arc

The Arc of the United States advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with our network of members and affiliated chapters, we improve systems of supports and services; connect families; inspire communities and influence public policy. <http://www.thearc.org>

Partnership for Families and Children

The Kentucky Partnership for Families and Children (KPFC) has a 30-member board that consists of agency-affiliated professionals and caregivers of children with emotional, behavioral, and/or mental health challenges.

<http://www.kypartnership.org><http://louisville.edu/education/kyautismtraining/resources/Services%20for%20Youth%20and%20Children.pdf> A Kentucky Autism Training Center's link to the guide to "Kentucky Services for Children and Youth", a Directory of Services for Children and Youth with Special Health Care, Educational, and Vocational Rehabilitation Needs through the Kentucky Commission for Children with Special Health Care Needs.

<http://louisville.edu/education/kyautismtraining/resources/flowchart.pdf> The Kentucky Autism Training Center's link to a PDF "Flowchart on Access to Mental Health Services for Children Birth to Age 5" by Kentucky Child Now.

CHAPTER 6

Advocacy: Raising Awareness and Influencing Service Delivery

Definition of Advocate:

- To ad-vo-cate: 1. to speak or plead the cause of another
2. to support or promote the interests of another

The above definition of advocacy is plain, simple, and easy to understand. However, the "process" of advocating is not that simple unless you are well educated about your child's disability, knowledgeable about your child's rights especially within the educational system, and firmly believe that that you are your child's natural advocate. No one can be a better advocate for your child than you.

We all have heard the saying, "I had no choice in the matter." Well, this is certainly the case with respect to advocacy. As parents, we have no choice but to advocate for our children. We cannot sit and wait for someone else to do it for us. As parents, we need to develop a sense of urgency that will help set the standards for our child's future.

One choice you do have is the "level" of advocacy you want to take on. You can advocate at the individual level (e.g., for your child only) or at a local or state-wide level. Advocating at a local or state level takes more time and coordination with other advocates for the same disability. You can take on a very important role in your community by getting more actively involved in this manner and create real change for all individuals affected with autism.

You will always receive advice from others around you.....family, doctors, teachers, and other professionals who have your child's best interest at heart. While the advice of others is important, always remember, "*You know your child the best.*" You are living and breathing your child's disorder on a daily basis. As a result, you should feel confident and competent about what you should be advocating for--whether it's during structured meetings with professionals or casual conversations with family members.

Believe not only in your child, but in your ability to advocate at all times!

"Parents are the true educators of their children. Teachers, psychologists, and other support staff are consultants to those parents".
-Nichols Hobbs

How Do I Become a Strong Advocate for My Child?

Become informed –learn what resources exist to help your child

- Join groups who have meetings and newsletters- they have lots of information to share
- Attend trainings-to find out about upcoming training opportunities, visit the KATC website <http://louisville.edu/education/kyautismtraining> or contact your local parent support group
- Visit websites

Know and understand your rights

Contact Protection & Advocacy for free information and assistance
www.kypa.net

Read books such as *From Emotions to Advocacy* by Wrightslaw
www.wrightslaw.com

Read the article, “Beyond IEPs: Eight Ways Parents Can Help Advocate for Children With Autism” by Autism Speaks
www.autismspeaks.org/docs/family_services_docs/BeyondIEP_s.pdf

Learn how to play the role of advocate

- Be prepared
- Write down your thoughts: prepare an agenda and speaking points before a meeting
- Keep your files and records organized
- Know what you want...and be specific
- Build positive, respectful relationships with professionals
- Ask questions about anything you don't understand
- Be a good listener
- Write down details
- Practice beforehand what you're going to say in meetings
- Get professional opinions in writing
- Don't personalize statements made by others...focus on your child and not the personalities of others
- Offer help and support to professionals when you can
- Pick your “battles” wisely
- Realize that sometimes advocacy fails. Know when to stop and try something else
- Thank people for their time

Parents go through many normal feelings when they have child with a disability. There may be anger, denial or depression. Becoming an advocate can help with some of the feelings of powerlessness that you may feel. Even after coming to acceptance we can find ourselves experiencing negative feelings at different times in our child's life.

Know that this is normal and understand that your ability to be an effective advocate can be challenging at these times. You may need to reschedule meetings or make sure you have a strong, supportive advocate to help you.

Advocacy by parents and family members is essential to ensure that children with ASD have an opportunity to achieve their fullest potential. As important as professionals are in furthering our knowledge of individuals with ASD and how to meet their needs, parents and family members have been critical in the role of educating professionals and policy makers.

As parents, we evolve from the time we first encounter the diagnosis of our child- from needing information and support to becoming educated and providing support and information to others. Because we communicate what is important to us, we naturally become advocates as we talk with other parents about our experiences.

Levels of Advocacy

Advocating for your child

The first step in becoming an advocate is learning to advocate for one's own child. Parents must learn about the diagnosis and what it means for their child's development. We must be aware of the services and supports available to address our child's needs, and about how to work with professionals to ensure that our child's needs are met. These skills are learned by:

- Learning to ask appropriate questions
- Reading pertinent articles, books, and websites
- Participating in IEP meetings and other service planning meetings
- Talking with other parents who are willing to share what they know
- Attending training and discussions offered by parent support groups and parent organizations

Sharing information with other parents

The next level of advocacy is sharing information with another parent who needs it. This can be done informally in the hallway at school, in a parent support group,

or over the phone. It can also be done more formally by leading a parent support group discussion on a topic or by providing a training session to a group of parents on a particular topic.

Supporting a parent in a service planning meeting

The third level of advocacy is when a parent chooses to attend an IEP meeting with another parent. This support can help a parent who is unfamiliar with the process or is feeling that concerns are not being fully addressed.

Participating in activities to influence how services are delivered

At this level parents advocate to change or influence the laws, regulations, and policies that affect the provision of services needed by their child and other children with ASD or other disabilities. At that point, child advocacy becomes systems advocacy.

Encouraging your child to advocate for himself

It is important that parents of a child with autism work with their child to be his/her own advocate. Individuals with autism need to be encouraged to share their strengths and unique talents with others. One such venue for self-advocacy is the IEP meeting. According to the provision under IDEA 1997, the student with a disability should be a member of the IEP Team when the focus is on transition services, which is required when the child reaches age 16. This will allow others to better understand what individuals with ASD can contribute to their communities.

We need advocates at all levels. Parent-to-parent support is critical for parents when all they have is a diagnosis and a lot of questions. No one is more effective at answering those questions than another parent who has been in the same place. The Individuals with Disabilities Education Act (IDEA) acknowledges the importance of parents providing information to other parents by providing funding to support at least one parent training and information center run by parents in each state. Many parents have served in an advocacy role by helping to create this document to provide information to other parents.

When parents are educated about their child and about the service system, they are able to take an active role in supporting other parents. They are also able to provide input to public agencies and policy makers about effective ways of supporting individuals with ASD. By making their voices heard, parents can help create the schools and communities where the people they love can live, work and play.

Kentucky Protection and Advocacy

P & A provided information/technical assistance, education, and training on legal rights of persons with disabilities. They also have written materials on a variety of disability issues. They provide some legal counsel based on yearly priorities.

(800) 372-2988 www.kypa.net

The Arc of Kentucky

The Arc of Kentucky holds a Vision of a positive future for individuals with intellectual and developmental disabilities, a future of communities with services and supports that will promote lives of value for Kentuckians with intellectual and developmental disabilities.

(502) 875-5225 or (800) 281-1272 arcokfy.org

FIND of Louisville

Community Parent Resource Center (CPRC)

Funded by the Department of Education, provides training and information related to education laws. (502) 594-6813 www.findoflouisville.org

Kentucky SPIN

Parent Training and Information Center (PTI)

Funded by the Department of Education, assists families with concerns related to education.

(502) 937-6894 www.kyspin.com

Where to Advocate

There are many areas related to aspects of service delivery where parents' voices need to be heard. At the local school district or at the state level, here are some issues that parents have identified as important:

Education

- Increasing the number of educators who understand the complexities of ASD
- Providing placements to students with ASD that best support their needs
- Providing accommodations and/or modifications tailored to the student's needs and not according to the student's label
- Using research-based methods for instruction
- Providing social skills training and development
- Encouraging the full participation of children with ASD during the school day as well as in after-school activities

- Providing effective transition services to ensure jobs and community living outcomes
- Provide more opportunities for parental involvement in schools
- Increasing partnerships with families

Medical

- Increasing early screening and diagnosis opportunities
- Educating medical personnel who may come in contact with children with ASD
- Increasing the availability of specialists knowledgeable about ASD
- Encouraging medical personnel to work in partnership with families

Social Services

- Increasing the number of providers who specialize in the unique needs of children and adults with ASD
- Making providers more easily accessible
- Encouraging providers to work in partnership with families
- Providing government-funded programs that assist families in addressing ASD needs

The Importance of Parent-to-Parent Support in Advocacy

Parent-to-parent support offers not only emotional support, but also serves as a step in learning to advocate effectively. Concerned family members originally created many organizations working to improve supports for those with disabilities. In any way you can, online or through parent support groups, stand with other parents and family members. When you do that, you become involved in systems advocacy.

We make countless decisions in the process of living with ASD. Since such decisions are individualized, you may find yourself choosing different treatment options than other parents. You may become involved with an organization that is different from what other parents or family members prefer. Your child may be significantly affected by autism and you may know families who have children that are only mildly affected and, therefore, feel you do not have that much in common.

It is unrealistic to expect everyone to agree on every choice and it is important to respect each family's decisions. However, there are probably many issues that you agree on, even if at least partially. It is imperative that we seek commonality that will enable us to stand together to support policy and legislative changes that can make a difference in our communities, our state, and our nation. A strong, united voice cannot be ignored. Here are some pointers for systemic advocacy.

- Get involved in efforts that impact the entire ASD community
- Be publicly supportive of programs and services that may help any person affected by ASD, even if it does not affect your family directly
- Respect each individual's level of commitment to advocacy, however small or large it may be.

- Give first priority to being the best advocate you can for your child and family.

Individuals with ASD are entitled to rights and services. This statement sounds simple and straightforward, but as many parents and family members know, it can get complicated and frustrating when you are working with a system that does not understand your family member's needs. People with their own agendas are often urging law-makers to make decisions that are not appropriate for our ASD community, such as mandating one specific type of intervention be used with all children with ASD. At these times, your voice needs to be heard. You have the personal experience that others may not. Let your locally elected officials know how you feel on certain issues and suggest how they should vote on proposed policies, budgets, and legislation.

Ways You Can Advocate: Home, School, and Community:

- Advocate for your child
- Advocate for other children
- Join an advocacy organization
- Call/write/email your legislators
- Vote
- Call a radio station to explain your position on a particular topic
- Write a letter to the Editor of your local paper
- Hold a town meeting to discuss issues of concern
- Attend a school board meeting to discuss your concerns
- Attend local/state social services board meetings to discuss your concerns
- Join local or state committees that address what you are trying to accomplish
- Visit your senator
- Attend a rally at the State House to raise awareness of ASD

Tips for Talking with Leaders

- Always be respectful, courteous, and professional
- Thank them for the job they are doing
- Educate yourself on the issues
- Be brief and to the point
- When possible, bring your child or a photo of your child with you.
- Ask for reasonable objectives
- Don't be negative
- Get to know contacts on their staff
- Write letters thanking them for their time and efforts
- Offer to serve as their "autism expert."

Grassroots Advocacy

"Grassroots advocacy" refers to people working together to write letters, place calls, send emails, and visit officials to communicate ideas and opinions to

government officials. Most of the time, efforts are concentrated to Senators, Representatives, and agency personnel. As a constituent, you have the right to express your opinion and advise your elected officials about the issues that you are knowledgeable about.

Start small. Begin with your own child. This means working with your child's teacher, school district and/or even school board on issues that arise regarding your child's educational progress.

Awareness Campaigns

An awareness campaign is slightly different from advocacy work because it is geared toward educating a particular group of people or the general public. A good example of an awareness campaign is the annual Autism Awareness Month promoted by the Autism Society of America (ASA) and celebrated every April. Each ASA chapter is encouraged to hold events, obtain proclamations, and distribute literature to the local community to inform them of the issues related to autism.

Local organizations often plan public events like runs and walks, community festivals, or open houses to help community members learn about autism and raise money for research or other projects. If you are interested in planning an event in your town, talk with other parents and family members to get their support. You may also contact a state organization like the Kentucky Autism Training Center. They can link you with national organizations that may provide materials and guides for planning and staging events. Some national organizations are the Autism Society of America <http://www.autism-society.org> and Autism Speaks (www.autismspeaks.org)

Ways to Spread Autism Awareness

Sponsoring a community-wide campaign is a major undertaking. But there are many other less time-consuming ways to spread awareness, including the following:

- Arrange to give a presentation to students at your local public school
- Volunteer to educate local first responders (police, firefighters and paramedics) on how to handle individuals with ASD
- Take time to educate your own family so they can also become advocates for your child with ASD
- Write a letter to the Editor of your local paper during Autism Awareness Month to outline the severity of the problem and what needs to be done
- Wear the autism awareness ribbon, autism awareness bracelets, or awareness pendants every day
- Stick an autism awareness ribbon magnet or bumper sticker on all your vehicles.
- Buy a Kentucky autism awareness license plate

- Distribute informational literature from national groups like ASA and Autism Speaks to local doctors, human service agencies, professionals, therapists, etc.

On March 18, 2005, the Governor signed House Bill 296 into law establishing the Kentucky Commission on Autism Spectrum Disorders. Sponsored by state Rep. Scott Brinkman (Louisville), the legislation charges the agency with the development of a comprehensive statewide plan for an integrated system of training, treatment and services for individuals of all ages with an ASD.

The 22-member commission first met August 22, 2005 and named subcommittees to address the following issues: identification and intervention; services/transition; best practices and training; and funding. The commission is composed of members from key state agencies and nine appointed community members. The appointed members ensure broad representation of Kentucky's citizens concerned with the health and quality of life for individuals with an ASD.

Learn more about the Kentucky Commission for Autism Spectrum Disorders at: [http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.h](http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.htm)
[tm](http://chfs.ky.gov/kcdd/HB+296+KY+Commission+on+Autism+Spectrum+Disorders.htm)

It is important for you to make your voice heard by your state and federal legislators. You can identify your current state legislators by visiting <http://www.lrc.state.ky.us/Legislators.htm>. Contact your legislators and make them aware that you have a family member with ASD. Describe the challenges faced by individuals with ASD and their families in Kentucky and the barriers they encounter in getting needed services. Remember to always be constructive and considerate.

Our legislators represent us – and they want to hear from us. The best way to do so is via post card, letter, or fax. They are bombarded with email so it is not always effective.

You can also hold a “candidates’ forum” and invite several candidates to meet with families dealing with autism in their district to hear their stories and learn about their needs. Don’t invite legislators in for a complaint session, but for positive dialogue on the issues. Remember, we want them thinking about how to be a part of the solution.

Finally, when you find candidates who support your positions you might help them with their campaigns or support them financially.

CHAPTER 7

Future Planning: Growing into Adulthood

My sons have reached the age where we need to plan for their future, but this process is only happening on a limited basis. I have to push for all these services and I'm not sure what all is available for them. I am frustrated as this is critical for their future!

-Donna Littrell

This chapter is critical for planning for the future related to your child's life after high school. Parents should work with school personnel throughout the middle and high school years to develop a person-centered plan for the future. This chapter includes many suggestions for planning for the transition of your child from a school program to adult services, including employment and living in the community. It also introduces important legal and financial planning issues that every family should think about.

Life after High School

Thinking about the future should begin immediately, and it is important to formulate plans for the future throughout your child's school experience.

One of the most challenging times for individuals with ASD and their families is when an adolescent is about to transition from a school program to the uncertainty of adult services. Questions about postsecondary education, vocational training, employment, community living, and sources of financial support for the individual with ASD must be addressed.

The Individuals with Disabilities Education Act (IDEA) requires that transition planning for this shift to adulthood and adult service systems begin by age 16, although it may begin earlier than age 16 if the IEP team agrees.

The student, parents, and members of the IEP team should work together to help the student make choices about his path for the future. This will involve discussions about where he wants to live, what kind of work he wants to do, and what recreation and leisure time activities he would like to be involved in when not working. Transition planning through the IEP process identifies the student's goals and a plan for reaching these goals in each of these areas:

Mandated Services versus Eligibility-Driven Services

One of the biggest changes that parents face at the time of their child's transition from education to community services is the shift from the mandated services of education to the eligibility-driven services of the adult service system. All children are entitled to educational services. In the adult service system, however, there are no entitlements. Individuals must "qualify" or be determined eligible for

services. Transition services within education should support parents and their children in applying for the services for which they are eligible.

In addition to the transition planning within the IEP process, IDEA also requires that the school develop a document called the Summary of Performance (see the chapter about Education) to help with this planning. When a student is no longer eligible for educational services, the school district must provide the student with a summary of their academic achievement and functional performance. This summary of performance must include recommendations on how to assist the child in meeting the student's postsecondary goals (IDEA §300.305(e)(3)).

As mentioned in the chapter about Social Service Programs under the section of the Kentucky Department of Mental Retardation and Developmental Disabilities (MRDD), at age 16 a child who has been determined eligible for MRDD services will have to be re-evaluated using adult standards. Your child's Service and Support Administrator should discuss this re-evaluation with you. If not, or if your child has not received MRDD services, call the MRDD intake worker to schedule an appointment for evaluation for eligibility.

Remember, you have the right to be present during this assessment. If your child is deemed eligible, he/she will be assigned a Service and Support Administrator who will serve as a case manager. The case manager will assist you in identifying the range of services needed and in helping you establish his/her eligibility.

Ask your service and support administrator to explain all of the services your child may be eligible for. Make sure you ask to have your child placed on waiting lists as early as possible for any services your child may wish to access in the future. You can always decline these services when they are offered if he/she does not need them. These lists are very long so it is never too early to be placed on these waiting lists.

The Ohio Center for Autism and Low Incidence (OCALI) has published "Transition to Adulthood Guidelines for Individuals with ASD"

You can read and download the guide at:

http://www.ocali.org/transition/trans_guidelines.php

Transition Planning

All students receiving special education services in public schools have regular meetings with family and school staff to discuss the student's IEP. Once a student is in high school, these meetings should begin the planning for transition from high school to adult life. This may be an area that you will need to advocate for your child. If transition planning is not discussed, please do not hesitate to discuss this important topic with your child's IEP team.

IDEA defines transition services as a coordinated set of activities for a student that promotes movement from school to post-school activities, including:

- Education after high school
- Job training
- Range of employment opportunities
- Help with coordinating support services (“case management”)
- Preparation for living independently in the community
- Recreation and volunteer opportunities

According to IDEA, these activities must be based on the individual student’s needs, preferences and interests and include activities in the areas of:

- Instruction
- Community experiences
- The development of employment and other post-school adult living objectives
- Acquisition of daily living skills and functional vocational evaluation

It is important that families and schools begin planning early to ease the transition for the person with ASD to increase success and independence in adult life. According to IDEA, this should begin by age 16. Beginning earlier, however, can only benefit the child and is highly encouraged.

Individualized Transition Planning

Because transition planning is the foundation for a student’s adult life, IDEA has provided much guidance to school districts on the content and process for developing an individualized transition plan to support students with disabilities.

In transition planning the following four points should be considered:

- The plan, including goals and services, must be based on the individual needs, preferences, and skills of the person with an ASD.
- Planning should be oriented to life after high school, not limited to what will be accomplished before leaving school
- There should be a master plan that includes long-range goals and a coordinated set of activities for each goal.
- The services provided should promote positive movement toward a life after school (Autism Society of America)

Interagency Planning

Interagency collaboration is an important part of a student’s transition planning. Other agencies and organizations may provide training or direct services to individuals with disabilities that will help schools support a student’s transition to community life. Ask your school district to involve other agencies in developing your child’s plan for transition. This can include the local office of the Office of Vocational Rehabilitation (OVR) and the county board of MRDD (see the Social Services chapter for more information on these agencies).

Schools may also seek support from other local agencies and organizations such as independent and supported living centers if they are located in your area. Parents should strongly encourage interagency collaboration as part of transition planning.

Transition planning can involve finding opportunities for job experiences for your child. These can be arranged for the school year and during summer breaks. When a student is given the opportunity to experience different settings and develop work-appropriate skills, he will be able to choose the best path. A good transition plan will allow the student's parents, school officials, and agency personnel to work together to make these opportunities available.

Questions to Guide the Transition Process

Parents can begin thinking about transition planning as early as when the child enters middle school. It can be helpful to start the process with a list of questions to act as a springboard for discussion. These questions can be similar questions parents develop when preparing for an IEP meeting (see the chapter about Education). Some families hold family meetings with siblings and the adolescent with ASD so that they can all share in the planning.

Below is a list of questions developed by a mother whose son has autism (from the Autism Society of America):

- What can your child do?
- What does your child like to do?
- What are your child's interests?
- What does your child need to explore?
- What does your child need to learn to reach his/her goals?
- What about college (four-year University, two-year community college), vocational education, or adult education?
- How about getting a job (competitive or supportive employment)?
- Where can your child go to find employment and training services?
- What transportation will your child use?
- Where will your child live?
- What living skills has your child mastered?
- How will your child make ends meet?
- Who will be involved in your child's life?
- Where will your child get health insurance?

Many people think of adulthood in terms of getting a job and living independently, but having friends and a sense of belonging in a community are also important. Transition planning through the IEP process is designed to help students and parents plan for this aspect of community life as well. To address these areas, additional questions have been included to guide discussion and decision-making in this area.

- Are supports needed to encourage friendships?
- Do people in the community know your son or daughter?
- Are supports needed to structure time for recreation? Exercise?
- Does your child have any special interests that others may share as a hobby?
- Can you explore avenues for socializing such as religious affiliations or volunteer work?

Make sure the IEP team is reminded that the pattern of strengths and weaknesses in ASD is unique. Don't design a plan that relies heavily on the individual's weaknesses.

Taking Action

It is also important that the transition process involve taking action even though it may be a number of years before your child graduates. After identifying areas of interest and setting goals, school personnel, parents, and the student should take active steps to meet those goals.

For example, the Vocational Rehabilitation representative arranges a job experience for a student with ASD who has particularly sharp computer skills. The student is dismissed from school early a few days a week and is accompanied by a job coach to work at a data processing office. In preparation for this job, the student's school program is designed to teach the student appropriate office skills, office procedures (such as using a time clock), and social skills.

Another student, who prefers to be outdoors, would be better suited to work with a community clean-up project than in an office. Her school program is designed to teach landscaping and horticultural skills, as well as social and job skills. The team would identify a job experience site that would allow the student to work in a local nursery. The transition plan must be tailored to each individual's skills and preferences.

Experience with three or four different work activities during transition planning is helpful in assessing a student's interests and capabilities while she is still in high school. For some students, transition activities will be designed to prepare them for further education. The transition plan should address the student's goals for life after high school-whatever the goals may be.

The National Information Center for Children and Youth with Disabilities (NICHCY) has published a Transition Summary series to help families and students with disabilities focus on taking definite steps toward a successful transition. Below we have adapted a portion of NICHCY Transition Summary page: This is an excellent site to visit for more information besides transition. www.nichcy.org/resources/transition_students.asp

Middle School: Start Transition Planning

- Involve your child in career exploration activities
- Visit with a school counselor to talk about interests and capabilities
- Have your child participate in vocational assessment activities
- Along with your child, use information about interests and capabilities to make preliminary decisions about possible careers (academic versus vocational or a combination of the two).
- Along with your child, make use of books, career fairs, and people in the community to find out more about careers of interest.

Keep in mind that while self-determination needs to be considered, students with ASD may mature more slowly than others. Therefore, their timetables for independence may be longer. Beware of eliminating options too early based on academic and behavioral expectations they may not have been achieved at the same age as their peers.

High School: Define Career/Vocational Goals

- Make sure the IEP includes a transition plan and work with school staff and community agencies to define and refine the transition plan.
- Help identify and make sure your child takes high school courses that are required for entry into college, trade schools, or careers of interest. Also, make plans for taking college entrance assessments, such as the ACT starting in the junior year of high school (These tests can be taken with the required modifications as outlined on his/her IEP).
- Help identify and make sure your child takes vocational programs offered in high school, if a vocational career is of interest.
- Encourage your child to become involved in early work experience, such as job try-outs, summer jobs, volunteering, or part-time work.
- Reassess interests and capabilities based on real-world or school experiences. (Is the career field still of interest? If not, redefine goals).
- Make sure your child participates in ongoing vocational assessment and identify gaps of knowledge or skills that need to be addressed. Address these gaps.

After High School: Achieve Your Goals

- If eligible for Vocational Rehabilitation services, make sure your child works with a VR counselor to identify and pursue additional training or to secure employment (including supported employment) in her field of interest.
- If your child is not already receiving Supplemental Security Income, contact the local Social Security Administration office shortly before she turns 18. Family income is no longer considered in determining eligibility for benefits after the person's 18th birthday. If eligible for social security benefits such as Supplemental Security Income, find out how work incentives apply.

- Contact your county board of MRDD to determine your child's eligibility for services, including Medicaid and waiver services. (See Chapter 6 for contact information.) Even if your son or daughter can be maintained on your medical insurance plan, Medicaid can be useful as supplemental insurance. In addition, Medicaid eligibility is required for many adult MRDD services.
- Contact agencies that can help, like disability-specific organizations such as the state or local chapter of the Autism Society of America. Ask about all services the student may be eligible for.
- Continue to work through the plan by following through on decisions to attend postsecondary institutions or obtain employment.

Education and Training Prior to Employment

- Have the IEP team and other disability support organization help identify postsecondary institutions (colleges, vocational programs in the community, trade schools, etc.) that offer training in a career of interest for your child.
- Identify the accommodations that would be helpful to support your child. Make sure that documentation is current on your child's IEP. This will support your child's request for accommodations at an educational institution. Find out if the educational institution makes, or can make, these accommodations. Some colleges such as Western Kentucky University, through the Kelly Autism Program, offer additional assistance for individuals with ASD.
- Write or call for catalogues, financial aid information, and request an application.
- Help identify and make sure your child takes any special tests (e.g., PSAT, SAT, ACT) necessary for entry. Deadlines to apply for this testing are generally earlier when accommodations are requested.
- Visit the institution, contact the office of disability services at the institution, and confirm that the accommodations needed for college coursework are available.

Other Future Planning Issues

There are other aspects of planning for your child's future that are not covered in the transition planning process through the IEP. These address issues like quality-of-life support for your child if you are not available and legal issues such as guardianship, and financial planning to protect government benefits.

Despite the growing number of persons with ASD in this country, fewer than 20% of families have done any futures planning to address these issues. Like all of us, your child with a disability will be an adult longer than she will be a child, so future planning is critical.

The following planning topics need to be addressed:

1. Quality-of-life issues
2. Legal
3. Financial
4. Government benefits
5. Guardianship

To guide decision-making when you are not available, discuss information regarding the needs and desires of the child with ASD and compose a directive document. This document should address lifestyle, financial, legal, and government-benefit issues. Whether people with ASD function entirely on their own or need assistance, such a directive can provide instruction for their daily care, as well as provide guidance for unexpected contingencies. Some of the questions this directive should cover include:

- How would your child like to be bathed and dressed?
- Does your child have special dietary needs and requirements?
- Does your child have any chronic medical conditions? Who monitors your child's medication?
- What leisure activities (music, computer, hobbies) does your child enjoy?
- What things can help your child live with dignity, quality, self-esteem and security?

While most people realize they need to plan, for a variety of reasons many fail to do so. Some believe the task is overwhelming and don't know where to find qualified professionals who understand their needs and how to resolve their concerns. The cost of professional services can also be an issue, as can privacy concerns.

Establishing an Advisory Team

As families begin to develop their plan, they should begin by identifying a group of people who will act as an advisory team. This should include, when possible; family members, the person with an ASD, an attorney, a financial advisor, caseworkers, medical practitioners, teachers, therapists, and anyone involved in providing services to the individual. Having input from each of them can help ensure that all parts of the plan are coordinated and complete.

Letter of Intent

Lifestyle planning is a process in which a family records what they want for the future of their loved one in a document called the "letter of intent." Although not a legal document, it is as important as a will and a special needs trust. This letter of intent will include information on a variety of important issues.

Quality of Life

Quality-of-life issues are those everyday things that need to be in place for each of us to be comfortable in our daily lives. Addressing quality-of-life issues for our loved one with ASD requires decisions and information regarding:

- Where the person will live
- Religious affiliation
- Continuing education programs desired
- Employment preferences
- Social activities preferred
- Medical care required
- Behavior management practices
- Advocacy and/or guardianship needs
- Trustees identified for financial planning purpose
- Final arrangements desired
- Detailed instructions for assisting the person with the typical activities of daily living such as bathing, dressing, feeding, and toileting
- Description of any special ways of communicating that only the immediate family knows and understands are included

TIP: Use videotape to record the individual performing activities of daily living, including communicating. Consider taping the individual having a meltdown and demonstrate the best ways of responding if that tends to be a relatively common occurrence.

Should parental support no longer be available, imagine how much easier and less traumatic it will be for the person with ASD and his or her care providers if they have detailed instructions immediately available, rather than having to figure things out on their own. What could take weeks or months to adjust to, could be shortened to a few days.

The ultimate goal of the letter of intent is to make the transition from parental care to independent or supported living or moving in with other family members as easy as possible, bearing in mind the comfort and security of the individual.

Guardianship

As each child approaches age 18, parents need to research guardianship issues and decide which options are appropriate for their young adult. Guardianship is a legal determination that involves your child's ability to make decisions regarding her own affairs, including financial, medical, and educational decisions. If you do nothing when your child turns 18, you legally lose the right to make decisions and sign legal documents for your child. Determining guardianship can sometimes be

a difficult decision. Parents should discuss the issue with professionals and with other parents to learn about all the implications.

Estate Planning

“Who will care when you are no longer there?” is an overwhelming question that parents of children with disabilities must address, but solutions and help are available.

Estate planning allows the family to state its wishes regarding the distribution of the family's assets and to appoint executors to settle the estate. In conjunction with estate planning, a trust should be established to provide supplemental funds for the individual with ASD, but in a way that maintains the individual's eligibility for government benefits. An estate planning team should include:

- Attorney
- Accountant
- Life underwriter/financial services provider
- Trust officer

A comprehensive estate plan should:

- Provide lifetime supervision and care if necessary
- Maintain government benefits
- Provide supplementary funds to help ensure a comfortable lifestyle
- Provide for management of funds
- Provide dignified final arrangements
- Avoid family conflict

Once you have decided to prepare a plan, find someone to help you or hire a professional planner. Referral sources are available through governmental agencies, organizations, or local support groups. Use a life-plan binder. Place all documents in a single binder and notify caregivers/family where they can find it. At least once a year, review and update the plan and modify legal documents as necessary.

Establishing a Trust

Government entitlements play a key role in the lives of many persons with autism spectrum disorders by providing money and health care benefits under SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), Medicaid, and/or Medicare. A basic understanding of federal and state entitlement programs is essential in order to be sure that an individual gets all that he or she is qualified to receive. That said, laws change, so it is crucial to hire professionals with up-to-date legal expertise.

In establishing a trust, financial planning is used to determine the supplemental needs of the person over and above the government benefits they may receive. First, a monthly budget is established based on today's needs while projecting for

the future. Then, by using a reasonable rate of return on the principal, the family identifies how much money is needed to fund the trust. The life expectancy of the person must be considered and then the need projected into the future using an inflation factor.

Once this is done, the family must identify the resources to be used to fund the trust. They may include stocks, mutual funds, IRAs, 401(k)s, real estate, and home or life insurance. Professional management for investing the assets may be done by the trustee, or the trustee may hire advisors.

Legal language has changed over time as state policies and legal decisions have evolved. When carefully drawn according to strict legal guidelines, trusts have been able to provide spending money to enhance the individual's daily life. Trusts can be a valuable tool for families, regardless of the size of their estate.

Make sure that the attorney and other planning professionals you hire have specific expertise in planning for people with disabilities.

CHAPTER 8

Introducing Your Child to ASD: How and When to Talk to Your Child About the Diagnosis

I received my diagnosis of Asperger syndrome as an adult. This was a turning point in my life, as it explained the relationships between what I had previously seen as a large collection of strange behaviors, thoughts and preferences. Realizing that I was neurologically different helped me to finally see myself as a whole person. It also gave me a purpose and direction for my life. Advocating for respect and resources for adults on the autism spectrum has become my primary interest. I am a student in the College of Social Work at the University of Kentucky, and will graduate in May, 2008. I coordinate the statewide Social Club for Teenagers with Asperger Syndrome through Kentucky Partnership for Families and Children. I have presented information on autism to a variety of groups and maintain an advocacy related blog, Asperger Square 8.

Autism is not a detachable part of a person and it is not an outer shell behind which someone entirely different hides, waiting to be set free. Autism is intrinsic and cannot be removed. Even if it could, this would alter every aspect of the individual's being; he or she would no longer be recognizable as the person you know. This is the very meaning of the word "pervasive."

There can, then, be no "war on autism" without waging war on the person who is autistic. This does not mean that I don't believe parents should do everything possible to improve their autistic child's quality of life. But promises to "cure" autism should be viewed through a lens of skepticism. There are many schemes waiting to drain the bank accounts of parents. Worse yet, some of these unproven "treatments" may actually cause harm to children. The best source of information is peer reviewed literature found in established journals and written by scientists who have no financial interest in any particular therapy or treatment.

Without a doubt, being viewed by one's family as a tragedy is harmful. Many people believe that if a child does not respond verbally or show obvious signs of understanding speech, that this indicates he is "in his own world," oblivious to what is said about him.

This is not true. Many, many reports exist from autistic people who have acquired means of communication later in life, revealing the extent of harm done by this belief.

Lack of speech or of typical response does not indicate lack of understanding.

Autistic adults need to have a voice in all discussions concerning autism services. This has not been the policy of the large, well-known "charity" groups. A slogan borrowed from the general Disability Rights Movement expresses this most succinctly, "Nothing About Us Without Us." This is what I believe.

Bev Harp

A frequently discussed topic on autism message boards is “How and when do I tell my child about his or her diagnosis of an autism spectrum disorder?” How young is too young? Will my child understand? Will it add to his/her anxiety? Will it help him/her understand his/her differences? What about explaining to others, siblings and other family members, teachers, and peer groups? How does a parent go about helping others to understand autism without creating stigma or contributing to false beliefs about the condition?

These are a few of the questions parents will need to answer for themselves before approaching the subject with the child or teen that has been diagnosed. A growing collection of literature addresses this subject and is available to aid in the discussions. Included here are a few of the best resources for talking about the diagnosis.

For Children:

Elder, J and Thomas, M. (2005). *Different Like Me: My Book of Autism Heroes*. London: Jessica Kingsley Press.

This book introduces historical figures and other famous persons who fit the profile we now know as autism. Included are Einstein, Newton and Kant as well as Andy Kaufman, Andy Warhol and Temple Grandin. Suggested for ages 8 to 12, this book is also a joy to read as an adult, and would make an ideal introduction to the autism spectrum for a newly diagnosed child. Illustrated.

Elder, J and Thomas, M. (2007). *Autistic Planet*. London: Jessica Kingsley Press. A rhyming book for the younger set, this one is recommended for ages 4 to 8. *Autistic Planet* is a great book for building positive perspective from an early age, and would be appropriate for siblings of ASD kids, too. Here Elder envisions a world where children matter-of-factly prefer the weather report to cartoons, and where “We don't do something one time, when we can do it over and over again!” Illustrated.

Faherty, C. (2004). *Asperger's: What Does it Mean to Me?* Arlington, TX: Future Horizons.

This is an excellent workbook for older children, pre-teens and young teenagers. The sections are well formatted and designed to help the child explore issues of identity, self-esteem, learning styles and more. At just over 300 pages, the book is thorough, a great resource for teachers and parents as well. Foreword by Gary Mesibov.

Hoopman, K. (2006). *All Cats Have Asperger Syndrome*. London: Jessica Kingsley Press.

This is a small picture book which uses cats to illustrate some features of people with Asperger syndrome. It's cute and well-intentioned if not terribly informative. If you are going to buy just one kid's book about AS, this probably is not the one. However, it does a good job of what it sets out to do, and would be a nice addition to a small library or to leave on the coffee table for curious visitors to flip through.

Schnurr, R. (1999). *Asperger's, Huh?: A Child's Perspective*. Ontario: Anisor. Some children with Asperger syndrome will relate to this first-person narrative, while others will find its language too simplistic. While the publisher recommends this for ages 8 to 12, it is most appropriate for the younger end of that scale. It might be good for siblings of the AS child.

Strand, V.(2006). *I am Utterly Unique: Celebrating the Strengths of Children Asperger Syndrome and High Functioning Autism*. Shawnee Mission, KS: Autism Asperger Publishing.

This is an alphabet book for kids on the spectrum, ages 4 to 8. It presents a very positive perspective, celebrating the strengths and unique qualities of autism with humor and respect. 56 pages with color illustrations.

Welton, J., Newson, E., and Telford, J. (2004). *Can I Tell You About Asperger Syndrome?: A Guide for Friends and Family*. London: Jessica Kingsley Press.

Told from the perspective of a ten year old boy, this is a great little book for “bridging the gap” between AS kids and their peers or siblings. The author does an excellent job of explaining how people with AS struggle to learn those things which seem so automatic to others—body language, tone of voice, etc. Simple and direct without being condescending. For ages 8-13.

For Teens:

Ledgin, N. (2002). *Asperger's and Self Esteem: Insight and Hope through Famous Role Models*. Arlington, TX: Future Horizons.

Many teens on the autism spectrum could use a good self-esteem booster. Ledgin suggests that a number of scientists, artists and musicians have had much in common with young people now diagnosed with Asperger syndrome. Autistic traits of Marie Curie and Albert Einstein are discussed, as well as those of Glenn Gould and Mozart. For teens and adults. Foreword by Temple Grandin.

Jackson, L. (2002). *Freaks, Geeks and Asperger Syndrome*. London: Jessica Kingsley Press.

Luke Jackson wrote this book when he was just 13 years old, and offers one of the best and most thorough explanations to be found in the popular literature on AS. Jackson offers his experience and advice to other teens on such topics as class work, bullying, dating and hygiene. A great introduction for a young teen exploring the meaning of the Asperger diagnosis from a peer who writes with confidence and self-acceptance. Foreword by Tony Attwood.

For Teens and Adults:

Attwood, T. (2006). *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley Press.

More than an expanded version of Attwood's 1996 *Asperger's Syndrome*, this book combines up to date research and clinical experience with personal insights from people on the spectrum. Chapters on marriage and career acknowledge the often ignored fact

of AS in adulthood. Written in accessible terms, this is a must have guide for family members, therapists and educators by one of the world's most respected authorities on the subject.

Attwood, T , Grandin, T., Bolick, T. and Faherty, C. (2006). *Asperger's and Girls*.
Arlington, TX: Future Horizons.

Asperger syndrome, like other conditions on the autism spectrum, is thought to occur four times more frequently in boys than girls. Therefore, the bulk of the research so far has focused on males. This book considers the questions specific to girls with AS as well as the possibility that AS is frequently overlooked or misdiagnosed in this population. Girls and young women with Asperger syndrome will appreciate this opportunity to read the personal perspectives included here.

Murray, D. (2005). *Coming Out Asperger: Diagnosis, Disclosure and Self-confidence*.
London: Jessica Kingsley Press.

This important book explores the impact of diagnosis and offers a number of strategies for disclosing autism. Learn the art of the "soft" disclosure and how to evaluate the level of risk for disclosing in various situations. This is an anthology offering viewpoints from professionals, family members and people on the autism spectrum.

Prince-Hughes, D. (2002). *Aquamarine Blue 5: Personal Stories of College Students with Autism*. New York: Swallow.

For the young adult considering college, here are some terrific first-hand reports of autism at the university level. Addressing social, communication and sensory issues from a variety of perspectives, each student describes his or her own experience with college life. Editor Prince-Hughes has a PhD in anthropology and is autistic as well.

Grandin, T.(1986). *Emergence: Labeled Autistic*. New York: Warner.

The first published book by the world's most famous autistic woman, Dr. Temple Grandin. Grandin talks about her childhood, sensory issues and her mother's work to have her included in mainstream schools.

Grandin, T.(1995). *Thinking in Pictures: My Life with Autism*. New York: Random House.

Further descriptions of life with autism from animal scientist Dr. Temple Grandin. This book includes more details of Grandin's thought processes and her work to bring more humane practices to the cattle industry.

Grandin, T. and Barron, S., (2005). *The Unwritten Rules of Social Relationships*.
Arlington, TX: Future Horizons.

What are autistic people thinking? What do neurotypicals (non-autistic people) expect? This is the book that explains it all. This is the key to understanding the "other" across the spectrum, separating the "musts" from the "shoulds" in social relationships, the secret codes everyone "just knows" but people with autism must be taught. Important. Invaluable. Every family with an autistic member should have this one.

Kearns-Miller, J. (2003). *Women from Another Planet?: Exploring Our Lives in the Universe of Autism*. First Books Library.

This anthology, written by women on the spectrum, offers a range of insight you rarely find in a single book. In addition to the individual chapters representing each author, there is a section in which several of the women discuss their perspectives on issues of importance to autistic women. In depth, varied and unique; highly recommended.

Newport, J. (2001). *Your Life is Not a Label: A Guide to Living Fully with Autism and Asperger's Syndrome*. Arlington, TX: Future Horizons.

Practical advice from an adult with Asperger syndrome. Much of this book focuses on basic life skills—riding a bus, opening a checking account, etc. Also included are chapters on dating and marriage. Not everyone will appreciate the author's emphasis on self-reliance and or his disdain for "labels." Newport also wrote the novel, *Mozart and the Whale*.

O'Neill, J.L. (1999). *Through the Eyes of Aliens: A Book about Autistic People*. London: Jessica Kingsley.

A book about acceptance by an autistic woman. The author views autism as a neurological difference to be respected, not marginalized or eradicated. Read this only if you love someone with autism and want to understand him or her better.

Williams, D. (1994). *Nobody Nowhere: The Extraordinary Autobiography of an Autistic*. New York: Times Books.

This is a unique story of one autistic individual and her ways of coming to terms with a world which often seems harsh and confusing. Williams has written a number of books on autism and consults widely on related topics.

Zaks, Z. (2006). *Life and Love: Positive Strategies for Autistic Adults*. Shawnee Mission, KS: Autism Asperger Publishing.

Zosia Zaks shares her strategies on everything from grocery shopping with sensory issues to dressing for job interviews. Step by step details on subjects like cleaning an apartment will appeal to linear thinking Aspies who are struggle with executive functioning problems.