AUTISM SPECTRUM DISORDERS (ASD) TREATMENT GUIDELINES

OVERVIEW OF GUIDELINE

The following guidelines apply to children and adolescents with the diagnoses of:
  o Autistic Disorder (DSM-IV-TR 299.0;
  o Pervasive Developmental Disorder NOS; and
  o Asperger's Disorder (both DSM-IV-TR 299.80).

Two additional conditions listed under the category of Pervasive Developmental Disorders in DSM-IV-TR, the rare and increasingly disabling Rett's Disorder and Childhood Disintegrative Disorder are not covered under these guidelines.

These guidelines are to be considered within the context of the child's cultural, ethnic, and spiritual values in order to maximize the accuracy of the diagnosis, the effectiveness of the treatment, and the best possible outcomes for the child and his or her family.

This ValueOptions guideline was developed and written by a workgroup consisting of the company’s senior child psychiatrists. The workgroup reviewed the available ASD literature as well as other published medical guidelines and/or practice parameters. The most important ones were those published by the American Academy of Neurology and Child Neurology, the American Academy of Child and Adolescent Psychiatry, DSM IV-TR, and the American Academy of Pediatrics.

INTRODUCTION

Autism Spectrum Disorders (ASDs) are generally believed to be biologically-based neuro-developmental disabilities representing heterogeneous disorders of development.

Individuals with these disorders display diverse neurobehavioral phenotypes recognized by qualitative impairments in reciprocal social interaction, impairments in communication, and a behavior pattern in which stereotyped behaviors, interests and activities may be present.
Most often, ASDs can be conceptualized as:

- neurological disorders related to brain development often associated with mental retardation and epilepsy;
- psychological disorders of cognitive, emotional, and behavioral development; often comorbid with mood and anxiety disorders;
- communication and language disorders; and
- relationship disorders in which there is a failure of normal socialization.

**Epidemiology:** ASDs are among the most prevalent of the serious disorders seen in childhood. The prevalence of ASDs, particularly the regressive form of autistic disorder, is increasing in the population. Surveys suggest that the rate of all Pervasive Developmental Disorders (PDD) is between 36.6 and 65 per 10,000. Autism is 13 per 10,000, Asperger’s disorder is 2.6 per 10,000, and PDD-NOS is 36.6 per 10,000. In addition, the rate of PDD NOS is decreasing as the diagnosis of Asperger’s disorder is being more commonly used.

The neurology literature estimates that only about 30% of children with autistic disorders score in the normal range of intelligence and that the prevalence of epilepsy in children with autistic disorder is between 7% and 14%, with seizure peaks in early childhood and again in adolescence. Medical disorders associated with an autistic disorder can be identified in up to 10% of cases. 90% of ASD children do not have medical disorders directly associated with ASD. The prevalence of mental health diagnoses associated with ASD is higher than in the general population.

There are conflicting interpretations of the epidemiological studies of ASDs that make it difficult to prove or disprove the notion of an increase in incidence. An increase in diagnosis could be due to a widening definition of ASD and/or frequent and improved screening methods, or to as yet unproven environmental factors interacting with genetically susceptible population subtypes.

**SCREENING**

The American Academy of Pediatrics (AAP) recommends that developmental surveillance should be done at every well – child appointment using an A.L.A.R.M. approach:
- Autism is prevalent.
- Listen to parents about developmental concerns.
Act early with the use of screening. Refer to appropriate professionals, organizations and programs such as Early Intervention. Monitor incoming information and the child and family.

During these well-child visits, the primary care clinician should:
- elicit a developmental history,
- listen to parental concerns,
- observe the child directly,
- use developmental checklists
- decide whether a need to be performed due to language, social and pretend-

Detecting developmental delays early is challenging because children develop and acquire skills asynchronously.

**Screening Tools:** It is imperative to use screening tools with good reliability, sensitivity, and specificity. Current screening tools may not identify children with milder variants of autism, those without mental retardation or language delay, those with Asperger’s disorder, or ASD in older children, adolescents, and young adults. Primary care physicians should be familiar with at least one of these tools to be used with children suspected to have an ASD. The **M-CHAT (Modified Check for Autism in Toddlers)** is the one most commonly used. Other common screening tools include:
- Childhood Autism Rating Scale—strong evidence base, combines questioning of parents and targeted observation;
- Australian Scale for Asperger’s Syndrome;
- Autism Diagnostic Observation Scale (ADOS); semi-structured interview that requires training to administer;
- Gilliam Autism Rating Scale (GARS-2); and
- Gilliam Asperger’s Disorder Scale (GADS)

Additional tools are listed in Appendix A.
**Early Identification and Intervention:** Early identification and intervention is important. Some signs of autistic disorders are usually present under 18 months of age, (e.g. lack of response to name at one year of age). Except for mild conditions, diagnosis can generally be made by age 3. There is often a significant gap between the initial expression of parental concerns (i.e., when the child is 18 months of age) and the making of a definitive diagnosis of an ASD (i.e., as late as 4 to 6 years of age). This could occur even later for Asperger’s Disorder or PDD NOS, which may not occur until school age or even adolescence, especially if normal IQ is present.

Services in early intervention programs may include: speech therapy, occupational therapy, physical therapy, specialized behavior therapy approaches, sensory integration therapy, parent training, and interdisciplinary team meetings.

**DIAGNOSTIC ASSESSMENT**

**General Information:** The assessment and diagnosis of ASDs requires comprehensive data gathering from multiple domains, including the child’s medical and developmental history and the family’s medical history. The diagnosis is based on history and observation because there is, as yet, no biologic test which identifies individuals with ASDs.

Usually, the definitive diagnosis of an ASD is made by professionals with training in child development. Although developmental-behavioral pediatricians, pediatric neurologists, child psychiatrists, and child psychologists have this training, they may not specialize in the early diagnosis of ASDs. In order to have the greatest confidence in the appropriateness and validity of the diagnosis of ASD the diagnosing professional should have both specialized training in the early diagnosis of ASD as well as general training in child development.

**Multidisciplinary Approach:** Ideally, an Autistic Spectrum Disorder Diagnostic Evaluation is a multidisciplinary approach led by a Developmental Pediatrician or Pediatric Neurologist, with a Child Psychiatrist consulting or doing the primary evaluation.

A multidisciplinary approach evaluation usually comprises the following elements:

- Clinical interview with parents/caregivers including:
  - Family History
  - Prenatal and Perinatal History
  - Developmental History
Use of a parent completed checklist, such as the Autism Behavior Checklist (ABC)
Use of a structured diagnostic interview such as the Autism Diagnostic Interview –Revised (ADI-R, see attachment)
Medical Screening for co-morbid medical issues

**Medical Co-morbidity:** Members of the multidisciplinary team observe child and family interactions and usually the pediatrician or pediatric neurologist usually performs a physical and neurological evaluation. Special attention is paid to detecting physical anomalies, seizure disorders, GI disturbances, sensory sensitivities, sleep problems, and high pain tolerance. Physicians are attuned to detecting a number of medical conditions in which symptoms of autism are seen. These medical conditions might include:

- Hearing Loss or Congenital Deafness. (May require further neurologic and ear nose and throat oto-acoustical or brain-stem auditory evoked response testing.)
- Lead or other heavy metal toxicity
- Tuberous Sclerosis – can be comorbid, est. 0.4-3% (8-14% if epilepsy present)
- Fragile X Syndrome – can be comorbid, est. 0.5-1%
- Chromosome 15 abnormalities (includes Angleman Syndrome and Prader Willi Syndrome) - can be comorbid, est. 1%
- Acquired epileptic aphasia (Landau-Kleffner Syndrome)
- Drug Influence and/or Fetal Alcohol Syndrome
- Physical CNS Damage from Earlier Physical Abuse
- Intra-uterine or Neonatal CNS Damage

**Medical Testing:**

- Laboratory testing including high resolution chromosome studies and DNA analysis for Fragile X Syndrome (FRAX) is indicated if there is a family history of FRAX, mental retardation (present or suspected), or if there are dysmorphic features.
- Selective metabolic testing is indicated if associated clinical and physical findings suggest a possible inborn error of metabolism.
- Clinical neuroimaging studies are indicated if there are specific neurological indications.
- An EEG is indicated if seizures are present or suspected or if developmental regression is present (especially under age 5).
Multidisciplinary Team Assessment: The multidisciplinary team should review assessments, testing and reports/observations from child-care workers, teachers, and relatives. Additional assessment information/activities may include:

- A family assessment (home environment, family stresses, strengths, protective and risk factors, knowledge of autism, emotional expression, interactions and discipline style, and values/spiritual beliefs);
- Additional diagnostic evaluations to assess the development of motor skills, communication skills, and cognitive and adaptive functioning;
- Psychological, speech and language, and occupational and physical therapy evaluations (usually obtained from early intervention or preschool educational programs);
- Cognitive and adaptive behavior evaluations as indicated below

  Cognitive evaluations include:
  - The Differential Ability Scales (DAS),
  - Stanford-Binet Intelligence Scales, Fifth Edition (SB5),
  - Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV), and Wechsler Preschool and Primary Scale of Intelligence-Third Edition (WPPSI-III).

  - Adaptive behavior evaluations include:
    - the Scales of Independent Behavior-Revised (SIB-R) and
    - the Vineland Adaptive Behavior Scales (VABS).

- Comprehensive speech/language/communication evaluations are obtained if language delays are present.
- Sensorimotor evaluations occur if motor development, sensory processing deficits, or mannerisms/stereotypies appear to be interfering with functioning.

Diagnostic Formulation: Upon completing the diagnostic evaluation, a 5 Axis DSM –IV-TR diagnosis should be made. (Attachment – DSM-IV-TR definitions for Autistic Disorder, Asperger’s Disorder and PDD-NOS).

It is often the role of the child psychiatrist to consider the psychiatric differential diagnoses encountered during ASD assessments. Alternative or comorbid Psychiatric Disorders include:
- Mental Retardation – estimated 50-75% prevalence with Autistic Disorder (not present in Asperger’s Disorder). With Mental Retardation, communication deficits are consistent with cognitive level and there is no qualitative impairment in the development of reciprocal social interaction.
- Obsessive Compulsive Disorder (Obsessions/compulsive behaviors seen in OCD overlap with abnormal preoccupations/ritualistic behavior of autism, but obsessional ideation causes distress in OCD and not in ASD)
- Tourette’s Syndrome and Tic Disorders
- Elimination Disorders (Encopresis, Enuresis both night-time and daytime)
- Schizophrenia can be diagnosed in individuals with Autistic Spectrum Disorders (Per DSM-IV-TR, schizophrenia diagnosis added if prominent hallucinations/delusions are present for at least one month) Note: differential diagnosis here can be difficult due to misperceptions, developmental delays with “imaginary friends” seen and talking to the individual, and traumatic memories from abuse or exposure to inappropriate material (e.g., violent, scary, sexual movies)
- Mood Disorders
- Anxiety Disorders (While social anxiety is part of the diagnosis of ASD, severe anxiety in the form of specific phobias or agoraphobia may also be present as a separate diagnosis.)

According to DSM-IV-TR, some psychiatric disorders **cannot be comorbid with** Autism Spectrum Disorders. It is not uncommon to see some of these disorders historically. Rightfully, these diagnoses may be considered provisional or rule outs of the ASD diagnoses. These diagnoses include:

- Attention Deficit Hyperactivity Disorder (very controversial – DSM IV-TR says that ADHD cannot be diagnosed along with an ASD, but some experts suggest the contrary; in addition, treatment may be helpful even if diagnosis is not allowed)
- Personality Disorders, especially Avoidant, Schizotypal, Schizoid (Autistic disorders have an earlier onset and greater severity than these personality disorders)
- Communication Disorders – cannot be comorbid-(With Communication Disorders, there is no qualitative social impairment; receptive language impairments co-occur with autistic disorders. With Asperger’s Disorder, cognitive testing usually reveals a high verbal/low performance pattern when the FSIQ is over 85, but a separate Learning or Communication Disorder is not diagnosed)
- Reactive Attachment Disorder (Abnormal social relatedness of RAD overlaps with autism, but RAD includes a history of severe neglect/abuse and improves with consistent care-giving)
- Selective Mutism
- Stereotypic Movement Disorder
o Rett’s Disorder
o Childhood Disintegrative Disorder
o Intermittent Explosive Disorder (According to the DSM IV, this diagnosis should be used only after other mental disorders that might account for episodes of aggressive behavior have been ruled out. Autism has a range of behavioral symptoms including impulsivity, aggressiveness, self-injurious behavior, and temper tantrums noted as associated symptoms).

**CARE MANAGEMENT**

Once a diagnosis of ASD is made, there needs to be care management and treatment planning. The variety, intensity, and comprehensiveness of services needed by individuals with ASDs, as well as the participation of professionals from various disciplines, require the efforts of one clinician, usually the child’s pediatrician, to join in a family-professional partnership to facilitate care coordination over long periods of time. This clinician helps to coordinate appropriate services to maximize developmental achievement.

**TREATMENT**

Just as a Multidisciplinary Evaluation is necessary, so is Multidisciplinary Treatment important.

**Strengths-based:** There is general consensus that the best outcomes are achieved when treatment is begun early and based on an individual’s strengths. Specific strengths often found in ASD children, as suggested by the Connecticut 2005 special Education Guidelines on Autism, include:

- Understanding of concrete concepts
- Memorization of rote material quickly and easily
- Recall of visual images and memories easily
- Visual thinking
- Learning discrete chunks of information rapidly
- Hyperlexia Decoding written language at an early age
- Long term memorization capability
- Understanding and using concrete rules and sequences
- Approaching tasks perfectionistically
- Being precise and detail oriented
- Maintaining of schedules
- Being honest even to a fault
- Extreme focusing on a task others may not perceive as pleasurable
- Being charming with innocence and without deviousness
- Having an excellent sense of direction
- Being compliant to clearly understood instructions

**Evidence-based:** There are over 60 treatments and interventions that are reportedly helpful to some individuals with ASDs. Some of these treatments have a scientific evidence basis to them, while others do not. Treatments may be considered to be standard treatments when they have solid scientific evidence to support them, and non-standard when the same degree of evidence is not yet available.

As with all profound childhood-onset illnesses, many “treatments” have been developed and promoted without any evidence-based research supporting their efficacy. Researchers still do not know why a particular treatment will help one child and not another, and they are unable to predict exactly what treatment will work with what child.

**Clinicians and parents of children with ASDs should use caution before subjecting any child with this disorder to unproven treatments.**

Smith in 2000 gives the best example of what should be evaluated in evidenced based ASD research. He talks about lack of bias, random, non-retrospective samples with matched measured intellect, with a time limited interaction that does not exceed 25 hours /week. He draws from some of the measures used initially in Lovaas’ seminal Applied Behavior Analysis Reports.

There are five therapies that can fall into this category of unproven treatments:
- secretin
- dietary interventions, and
- hormonal therapies and vitamin therapies.

There are other treatments that have been known to be harmful to children. These include:
- intravenous immunoglobulin therapy, and
- chelation.

Still other treatments are dubious at best and include such strategies as:
- facilitated communication and
- auditory integration.

the best example of what should be evidenced based ASD research. He talks random, non-retrospective samples with intellect, with a time limited interaction 25 hours /week. He draws from some of initially in Lovaas’ seminal Applied Reports.

elements, with measurement tools, that
1. Intelligence Quotient-Wechsler, Bayley, and Merrill-Palmer
2. Academic Achievement-WAIT
3. Language Development-Reynell
4. Adaptive Functioning-Vineland
5. Socioemotional-Achenbach

The following table outlines some of the most frequently used interventions with information about evidence-basis, typical provider, and other information.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Evidence Basis</th>
<th>Risks Reported</th>
<th>Lead Professional</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applied Behavioral Analysis (ABA)</td>
<td>Controversial and non-replicable</td>
<td>Overuse; high financial risk; extended timeframes and non-delineated ages</td>
<td>Special Education/Psychologist</td>
<td>Requires a coordinated team, a trained parent, and a credentialed ABA Therapist; better than traditional psychotherapy for changing abnormal, maladaptive behaviors</td>
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<tr>
<td>Chelation</td>
<td>None</td>
<td>Significant</td>
<td>MD</td>
<td>Mostly Testimonial</td>
</tr>
<tr>
<td>Intravenous Immunoglobulin</td>
<td>None</td>
<td>Significant</td>
<td>MD</td>
<td>Mostly Testimonial</td>
</tr>
<tr>
<td>Dimethyl glycine</td>
<td>None</td>
<td>unclear</td>
<td>MD or nutritionist</td>
<td>Mostly Testimonial</td>
</tr>
<tr>
<td>B6-Magnesium</td>
<td>None</td>
<td>unclear</td>
<td>MD or nutritionist</td>
<td>Some attempts at controls</td>
</tr>
<tr>
<td>Casein and gluten-free</td>
<td>None</td>
<td>Can make dietary</td>
<td>MD or nutritionist</td>
<td>The wrong child can get</td>
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<tr>
<td>Treatment</td>
<td>Description</td>
<td>Provider</td>
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<tr>
<td>Secretin Enzyme</td>
<td>None</td>
<td>GI Problems</td>
<td>MD or nutritionist</td>
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<tr>
<td>Cranio-sacral Therapy</td>
<td>None</td>
<td>Can cause spinal complications with incorrect manipulation</td>
<td>Chiropractor</td>
<td></td>
</tr>
<tr>
<td>Speech and Language Therapies including Auditory and Sensory integration, Sign Language</td>
<td>None alone</td>
<td>None reported</td>
<td>Speech and Language Therapists</td>
<td>May be useful as ancillary treatment approaches</td>
</tr>
</tbody>
</table>

**Additional Treatment Considerations:** The treatment of ASD is not straightforward. There is no identifiable etiology or known cure. Neurological factors are extensive. Treatment options for Autism and other Autistic Spectrum Disorders are not easily chosen.

As outlined above, the treatment of ASDs is so complex that it is best to have one person identified as the lead coordinator of treatment for the child and family. This individual should be involved in the development of a strengths-based Individualized Treatment Plan that addresses ongoing evaluation, symptoms, needs, interventions goals, and an assessment of available resources.

Educational, psychosocial, behavioral, and targeted symptom management interventions should be addressed in the Treatment Plan. For the purposes of this set of guidelines, treatments will be subdivided into three primary categories: Psychosocial Interventions, Pharmacological Interventions, and Alternative Interventions (represented by those discussed above demonstrating little or no evidence basis).

**Psychosocial Interventions**

Psychosocial interventions may include a multitude of options: educational services, parent training and education, support-groups, skills training, speech and language therapy, physical therapy and occupational therapy, among others. It is important to note that while numerous specific treatment models exist for ASDs, the most successful and well-established programs would fall under the
category of therapeutic behavior modification. These approaches are best viewed as an educational day behavioral training methodology that is typically provided in an early intervention, pre-school or school-based setting. As with all behavioral interventions, it is critical that there are clearly defined intervention targets that aim to increase a specific positive behavior or to diminish a specific maladaptive, socially unacceptable behavior.

**Pharmacological interventions**

Pharmacological interventions may also contribute to the overall improvement and functioning of patients with ASDs. Target symptoms should be specified in both psychopharmacologic and behavioral treatments. Target symptoms should be specified with an estimate of the frequency, intensity, duration and impact of the behavior.

While nearly all types of psychopharmacological agents have been utilized in these individuals, studies supporting their efficacy are limited. As in other areas of psychiatry and mental health, symptom-based treatment appears to be the most beneficial at this time. Attention must be paid to the development of potential side effects and adverse reactions to any medication utilized in the treatment of ASD and its co-morbid conditions. Choice of medications should be based on the specific symptoms exhibited, as well as any co-morbid conditions and diagnoses. Some side effects may be due to neurological factors and multi-brain system involvement. The use of lower doses and incremental slow increased doses is recommended when psychopharmacological intervention is used. Medications used and their approximate symptom effectiveness are presented in the following two tables. Atypical Antipsychotics, such as Risperidone, have undergone studies in ASDs and show promise in individual patients, as well as in one scientific double-blind study.

Treatment by a Child Psychiatrist, Pediatric Neurologist, or Developmental Pediatrician with specialization in ASD is essential. Slow dosage increases, high risk of unusual reactions to medications, and necessity for interdisciplinary team approach all require more intensive treatment.
## Effectiveness of Medications Prescribed for ASD Symptoms

<table>
<thead>
<tr>
<th>Target Symptoms</th>
<th>Stimulants</th>
<th>Alpha Adenergics</th>
<th>SSRI’s</th>
<th>Remeron</th>
<th>Anti-Convulsant Mood Stabilizers</th>
<th>Glutamatergics</th>
<th>Neurolepic-Haldol</th>
<th>Atypical Antipsychotics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperactivity and impulsivity</td>
<td>Possibly Effective</td>
<td>Possibly Effective</td>
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<td>Occasionally Effective</td>
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<tr>
<td>Explosivity Aggressivity and Poor Conduct Control</td>
<td>Occasionally Effective</td>
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<td>Occasionally Effective</td>
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<tr>
<td>Perseveration, Compulsive Behavior and Stereotypic Behavior</td>
<td>Occasionally Effective</td>
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<tr>
<td>Psychotic Thinking</td>
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<td></td>
<td>Occasionally Effective</td>
<td>Occasionally Effective</td>
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<tr>
<td>Social Isolation</td>
<td>Occasionally Effective</td>
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<td></td>
<td>Occasionally Effective</td>
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<tr>
<td>Anxiety, Depression and Self Injury</td>
<td>Possibly Effective</td>
<td></td>
<td>Occasionally Effective</td>
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<td></td>
<td>Occasionally Effective</td>
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<tr>
<td>Irritability and mood instability</td>
<td>Occasionally Effective</td>
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<td></td>
<td>Possibly Effective</td>
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<tr>
<td>Sleeplessness</td>
<td>Occasionally Effective</td>
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<td></td>
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<td></td>
<td>Occasionally Effective</td>
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**ValueOptions**

*Autism Spectrum Disorder Guideline*

October 12, 2006

Reviewed October 9, 2008, 10/18/10
### Most Common Side Effects Reported with Medications Prescribed for ASD

<table>
<thead>
<tr>
<th>Side Effects</th>
<th>Stimulants</th>
<th>Alpha Adenergics</th>
<th>SSRI’s</th>
<th>Remeron</th>
<th>Anti-Convulsant Mood Stabilizers</th>
<th>Glutamatergics</th>
<th>Neurolepic-Haldol</th>
<th>Atypical Anti-psychotics</th>
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<tr>
<td>Agitation and Hypomania</td>
<td>Mild</td>
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<tr>
<td>Suicidal Thoughts</td>
<td>Mild</td>
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<td>Sedation</td>
<td>Moderate</td>
<td>Mild</td>
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<td>Mild</td>
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<td>Weight Gain</td>
<td>Mild</td>
<td>Mild</td>
<td>Mild</td>
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<td>Mild</td>
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<td>Mild</td>
<td>Significant</td>
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<td>Increase Prolactin Effect</td>
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<td>Mild</td>
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<td>EPS</td>
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<td></td>
<td>Severe</td>
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<td>Mild</td>
<td>Moderate</td>
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<td>Higher Sugar and Lipid Profile</td>
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<td>Moodiness</td>
<td>Moderate</td>
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<tr>
<td>Irritability</td>
<td>Moderate</td>
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<td>Tics</td>
<td>Mild</td>
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<tr>
<td>Poor Appetite</td>
<td>Moderate</td>
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<tr>
<td>Poor Sleep</td>
<td>Moderate</td>
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<td>Changed Pulse</td>
<td>Rapid</td>
<td>Slowed</td>
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<td>Arrhythmia</td>
<td>Mild</td>
<td>Mild</td>
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</table>

**SPACE INTENTIONALLY LEFT BLANK**
PARENT AND FAMILY CONCERNS

As with other serious and debilitating childhood disorders, physicians need to prepare and educate parents and families on long-term treatment efforts. Physicians need to be prepared for parent questions, such as:

- “What is ASD and how can we be certain that the diagnosis is correct?”
- “Were the professionals making the diagnosis qualified to do so?”
- “How will we ever understand the disorder?”
- “How will we be able to determine what treatment our child needs?”
- “How will we know if the treatment is working?”
- “What do we do if it is not working?”
- “How can we make sense of it all when we are trying to cope with our own emotions and the demands of everyday family life?”
- “Will we ever be able to accept that our child is “different” from typical children?”
- “What treatments are available?”
- “What is available in the school for the special needs of my child?”
- “What help is available for the out-of-control behaviors?”
- “How do we get help for the rest of the family who has to live with this also?”

These and other similar questions are often asked by parents at some point. Even when not verbalized, the physician and other treatment providers can assume that these and similar questions are on the parents’ minds.

Although all children are unique, including those with ASDs, the journey parents must take to help their child has been mapped out and can be navigated successfully. Many have taken the journey and stand ready to be of service. There are at least 13 national organizations, 86 internet resources, and books and publications for parental use. These resources will help the parent to advocate for the child where necessary. It is important that parents not receive the impression or the message that ASD is about bad parenting.

Parents should be informed about treatment options, including the need for family counseling or therapy. Parents need to know what the treatment is and what it is supposed to do, such as:

- How many hours does it take a day and how many days a week?
- What role do parents and family members play in the treatment?
- Where is treatment provided?
How is progress measured?
What does it cost?

Many experts advise that parents should pay attention to a few basic principles that are helpful to most children:

- establish consistent routines and prepare a child in advance for deviations from those routines;
- support a child’s interests,
- listen to feelings, and
- “catch them being good” with lots of praise.

Treatment for ASD is most effectively accomplished by a multidisciplinary team make up of a variety of a system representatives. Providers and assigners of care need to gain skills in coordinating within the systems of care.

Parents need to be apprised of their legal rights to obtain appropriate early intervention services and a free and appropriate public education for their child with ASD. As a cautionary note, it is very important to emphasize that the word “appropriate” does not necessarily mean “the best”. Parents may need assistance to negotiate for what is obtainable to meet their child’s unique needs.
SUMMARY AND CONCLUSIONS

ASDs are chronic, extensive neurological disorders characterized by pervasive impairments occurring across several domains of development. They are first detected in early childhood. ASDs have well known Axis I, Axis II, and Axis III co-morbidities. Despite the increase in the number of cases, the diagnosis is often not precise. After decades of research, the pathophysiologic and etiologic mechanisms underlying these disorders are only now being elucidated.

The evaluation, diagnosis and treatment of ASD is extremely complex, often involving multiple professionals and supported by a myriad of funding sources. With respect to treating medical professionals, pediatricians and pediatric neurologists are usually consulted before child psychiatrists and mental health professionals. Interventions for ASD can occur in early intervention programs, various classrooms (therapeutic pre-school, special education schools, special education classrooms in regular schools and in-support special services in regular classrooms), outpatient medical and mental health offices, specialty clinics, family homes, treatment and group homes, residential treatment centers and hospitals specializing in care for children with developmental disabilities. Treatment for ASD is typically quite costly and private insurances usually provide minimal coverage. Because of its complexity and high cost, treatment for ASD requires major funding sources. These include EPSDT, IDEA, Medicaid (both regular and waiver programs), and Medicare.

The needs of individuals with ASDs may change during their lifetimes. Early identification and early intervention offer the best opportunity to maximize developmental potential. Educational training and later vocational training must be individualized in order to capitalize on strengths and talents. Communication problems need to be addressed through language and speech therapies. Coordination and motor deficits benefit from occupational therapy, physical therapy, and adaptive physical education. Behavior problems and co-occurring psychiatric disorders are the domains of the varying mental health specialists.

Family members of individuals with ASDs may experience considerable stress. This stress may be lessened by community support, and parent training.

ASDs are quite difficult to treat. The basic strategy calls for early intervention and preschool programming, with consistent, coordinated treatment planning and follow-through. The major area that reduces morbidity is very early secondary prevention in the context of early intervention. Much research still needs to occur in actual causality and diagnosis that could lead to primary prevention initiatives.
APPENDIX A

Additional ASD Screening Tools

Developmental Screens

Ages and Stages Questionnaire (ASQ)
- Jane Squires, Ph.D. and Diane Bricker, Ph.D. et al
- Series of 19 questionnaires for ages 4 to 60 months, 30 questions in each,
- completed by parents/caregivers in 10-20 minutes, scored by non-
  professionals in 1-5 minutes;
- inclusive cost estimated at $25 per year

Brigance Screens
- Albert Brigance
- Four instruments, ages birth to 6 years,
- completed by clinicians - observation and parents/caregivers report, take 10 minutes to administer, scored by
  clinician, available in Spanish
- inclusive costs about $12 per visit,
- http://www.curriculumassociates.com/products/BriganceOverview.asp?source=homelink-
  Brigance&Type=SCH&CustId=3547147411604261311523

Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP) Infant-Toddler Checklist
- Amy M. Wetherby, Ph.D., and Barry M. Prizant, Ph.D.
- Ages 6 to 24 months, 24 multiple choice questions,
- completed by parents/caregiver in 5-10 minutes, scored by clinician;
- free (other components of the CSBS DP can be purchased)
Parents’ Evaluation of Developmental Status (Peds)

- Frances Page Glascoe, Ph.D.
- Ages birth to 8 years, 10 questions
- completed by parents/caregivers in 2 minutes, available in Spanish
- materials cost 36 cents per visit,

Secondary Developmental Screens

Child Development Inventories (CDI)

- Harold Ireton, Ph.D.
- Three separate instruments for ages 3 to 72 months, 270 yes/no questions, available in Spanish
- completed by parents/caregivers,

Autism Screening Tools

Autism Diagnostic Observation Schedule (ADOS)

- Catherine Lord, Ph.D., Michael Rutter, M.D., FRS, Pamela C. DiLavore, Ph.D., and Susan Risi, Ph.D.
- Standardized behavioral observation and coding
- Administered and scored by clinician; administration time 35-40 minutes
- Ages toddler to adult
Checklist for Autism in Toddlers (CHAT)
- Simon Baron-Cohen, Ph.D., Tony Charman, Ph.D. et al
- Nine questions asked of parents/caregivers by clinician, five observations by clinician, administered at 18 month checkup,
- scored by clinician,
- free.

Gilliam Autism Rating Scale (GARS-2)
- J.E. Gilliam
- Behavioral Checklist with 4 sub-scales consisting of Stereotyped Behaviors, Communication, Social Interaction, & Developmental Disturbances
- 3 to 22 years of age.
- Administered by teacher, teacher’s aide, or parent to a group of children
- 5-10 minutes
- http://ags.pearsonassessments.com/group.asp?nGroupInfoID=a9220

Gilliam Asperger’s Disorder Scale (GADS)
- J.E. Gilliam
- Normed behavioral rating scale
- Preschool through adult
- Administered by trained professional
- 5-10 minutes

Modified Checklist for Autism in Toddlers (M-CHAT)
- Diana L. Robins, M.A., Deborah Fein, Ph.D. et al
- 23 yes/no questions completed by parent/caregiver at the 18 month checkup,
- scored by clinician,
- free
- http://www.firstsigns.org/downloads/m-chat_scoring.PDF
Pervasive Developmental Disorders Screening Test – II (PDDST-II)
- Bryna Siegel, Ph.D.
- Age 18 months and older, completed by parents/caregivers, takes 10-20 minutes, available in Spanish.
- scored by clinician,
- materials cost about $1.50 per visit,

Secondary Autism Specific Screens

Childhood Autism Rating Scale (CARS)
- Eric Schopler, Ph.D., Robert J. Reichler, M.D. and Barbara Rochen-Renner, Ph.D.
- Ages 2 years and older, 15 items completed by clinician based on observation and interview with parents/caregivers, takes 10-20 minutes,
- materials cost about $1.50 per visit.

Social Communication Questionnaire (SCQ, previously known as the Autism Screening Questionnaire or ASQ)
- Michael Rutter, M.D. FRS, Anthony Bailey, M.D. and Catherine Lord, Ph.D.
- Ages 4 years and older, 40 yes/no questions completed by parents/caregivers in 10 minutes, available in Spanish.
- scored by clinician,
- cost about $2 per visit,

Australian Scale for Asperger’s Syndrome (ASAS)
✓ M. S. Garnett, and Anthony J. Attwood, Ph.D.
✓ Ages 6 to 12 years, 24 multiple choice plus 10 yes/no questions, completed by parents/caregivers,
✓ scored by clinician,
✓ free
✓ http://www.udel.edu/bkirby/asperger/aspergerscaleAttwood.html
Resources for Families

Resources

Resources are also available through the Center for Disease Control National Center for Birth Defects and Developmental Disabilities, 1-800 - CDC-INFO and online at: www.cdc.gov/ncbddd/autism/actearly/

Local resources can also be found by contacting the Autism Society of America (ASA) at 1 -800 -3AUTISM or online at: www.autism-society.org.

To locate the appropriate resource in specific states, parents can call 1-800-695-0285 or log on to the National Dissemination Center for Children with Disabilities at www.nichey.org/

ADI-R

Summary of components of the Autism Diagnostic Interview – Revised (ADI-R). This standardized interview requires extensive training to administer, but is considered the “gold standard” of accuracy in autism screening, so the following summary is provided to allow clinicians to incorporate elements of this instrument into their clinical evaluation. The questions in the ADI-R are asked of parents/caregivers.

Qualitative Impairment in Social Interactions

Direct gaze: Does the child look at you directly in the face while talking to you?
Social smiling: Does the child smile in meeting? In response to others?
Showing and directing attention: Does the child show/bring things?
Offering to share: Food, toys, favorite objects?
Seeking to share enjoyment with others: Does the child direct attention to things (he) likes?
Offer comfort: Spontaneously?
Quality of social overtures: Coordinated eye gaze – pointing?
Range of facial expressions used to communicate: Full range?
Inappropriate facial expression: Related to context?
Appropriateness of social responses: Responses to the approaches of others?
Imaginative play: Pretend games?
Imaginative social play: Initiates and responds to simple social games?
Interest in other children: Interested in children (he) doesn’t know?
Response to approaches of other children: Responsive?
Group play with peers: Actively seeks and plays cooperatively?
Friendships: Does (he) have a particular friends or a best friend?

Qualitative Impairment in Communication

Use of another’s body to communicate: Uses others as a tool?
Age of first single words: Under 24 months; phrases under 33 months
Social vocalizations/chat: Small talk?
Stereotyped utterances and delayed echolalia: Saying the same thing over and over.
Reciprocal conversation: Able to carry on a conversation?
Inappropriate questions or statements: Seems to lack the understanding of the social impact of questions or statements?
Pronominal reversals: Mixing up you/l/he/she and inappropriate inflection.
Neologisms/idiosyncratic language: Made up words.
Verbal rituals: Insisting on saying or others saying the same thing the same way
Spontaneous imitation
Pointing to express interest: Uses conventional/instrumental gestures?
Nodding: Nodding to mean yes or shaking head to mean no.

Restricted, Repetitive and Stereotyped Patterns of Behavior, Interests and Activities

Circumscribed interests: Unusual in intensity and causing social impairment
Unusual preoccupations: E.g. metal objects, traffic lights, street signs, toilets. etc.
Repetitive use of objects or interest in parts of objects: *E.g. spinning wheels, lines*
Compulsions/rituals: *Fixed sequence of activities, intrude on family life*
Unusual sensory interests: *Sight, touch, sound, taste, smell.*
Hand and finger mannerisms: *Flicking, waving, flapping, etc.*
Other complex mannerisms or stereotyped body movements: *spinning, bouncing, running in circles, body rocking.*

**DSM-IV-TR Criteria for Autistic Spectrum Disorders**

**(299.00) Autistic Disorder**

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. Qualitative impairment in social interaction, as manifested by at least two of the following:
   a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
   b. failure to develop peer relationships appropriate to developmental level
   c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   d. lack of social or emotional reciprocity

2. Qualitative impairments in communication as manifested by at least one of the following:
   a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   c. stereotyped and repetitive use of language or idiosyncratic language
   d. lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level

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

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

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

(299.80) Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
   1. 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
   2. failure to develop peer relationships appropriate to developmental level
   3. 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)
   4. lack of social or emotional reciprocity

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

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
E. 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.
F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

(299.80) Pervasive Developmental Disorders Not Otherwise Specified (Including Atypical Autism)
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 at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.
APPENDIX B

NATIONAL AND STATE PERSPECTIVES ON FUNDING AND RESOURCES

The murky areas of assigning and funding multiple services to clients with ASD led to a Road Map Initiative and a National Interagency Committee. The most important key services are medical, educational and early prevention service often tied to speech and language and social skill development. The knowledge base needs of cause, effect, diagnosis nomenclature and treatment has fostered a quintupling of NIH research in ASD. The need for early identification spawned a CDC Autism Awareness Campaign in 2004.

In general, early education and school-based services are the entry to treatment for children with autism. Federal level decisions mostly emanated out of the federal Department of Education starting with 1975’s PL94-142, transforming into the Individuals with Disabilities Education Act (IDEA) in 1990. Autism was listed as a category in the early ‘90s and tracking of data on children with an ASD diagnosis was begun at that time. Now newborns, pre-schoolers and school-aged youngsters up to age 21 receive varying forms of help in the least restrictive environment in a free appropriate public education (FAPE). In 2002 and 2003, 163,000 children were diagnosed with an ASD. There may be an additional 30,000 children who are not diagnosed, but receive special education and may have an ASD.

- IDEA-The Individuals with Disabilities Education Act (20 U.S.C. §§ 1400 et seq.; Implementing Regulation: 34 CFR Part 300) is an entitlement for individuals with a disability who are at least 3 years of age to receive a “free appropriate public education” or “FAPE.” Here is a summary of the act provided by the Department of Justice:

“The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP’s) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student. IDEA also mandates that particular procedures be followed in the development of the IEP. Each student’s IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child’s teacher; the parents, subject to certain limited exceptions; the child, if determined
appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents’ or agency’s discretion. If parents disagree with the proposed IEP, they can request a due process hearing and a review from the State educational agency if applicable in that state. They also can appeal the State agency’s decision to State or Federal court.”

According to the National Institute of Mental Health: “for every child eligible for special programs, each state guarantees special education and related services…” under the Individuals with Disabilities Education Act (IDEA). “Usually children are placed in public schools and the school district pays for all necessary services. These will include, as needed, services by a speech therapist, occupational therapist, school psychologist, social worker, school nurse, or aide.”

**IEP**
“By law, the public schools must prepare and carry out a set of instruction goals, or specific skills, for every child in a special education program. The list of skills is known as the child’s Individualized Education Program (IEP). The IEP is an agreement between the school and the family on the child’s goals.” Once an IEP is in place, a follow up meeting occurs once a year to review progress and to make changes based on the child’s needs.

**Early Intervention Program**
If a special needs child is less than three years old, an early intervention program is available in every state. “Each state decides which agency will be the lead agency in the early intervention program. The early intervention services are provided by workers qualified to care for toddlers with disabilities and are usually in the child’s home or a place familiar to the child. The services provided are written into an Individualized Family Service Plan (IFSP) that is reviewed at least once every six months. The plan will describe services that will be provided to the child, but will also describe services for parents to help them in daily activities with their child and for siblings to help them adjust to having a brother or sister with ASD.”

**IEP vs. 504 Accommodation Plans**
In some cases, school aged children with disabilities will not necessarily be eligible to receive an Individualized Education Plan under IDEA; instead they may receive a 504 Accommodation Plan, which is a less intensive plan authorized under the Americans with Disabilities Act and which is for general education to provide reasonable accommodations to students for equal opportunity and access. The distinction is between guaranteeing the student a specialized education from which they receive educational benefit (and an IEP) vs. a general education with accommodations for access and opportunity (via a 504 plan).
Federal Entitlements

Much of the service covered outside of the educational settings is financed by Medicaid’s Early and Periodic Screening Diagnosis and Treatment (EPSDT) program where regular evaluations and medically necessary treatment services are prescribed as a result of the examinations of children and youth under the age of 21 even if it is not covered under regular state Medicaid coverage. The Medicaid system is the second main system assisting children and youth with ASD and is the largest insurance payer of service. 50,000 children with ASD receive services in this way.

Below is a summary of EPSDT abstracted from the CMS web site:

“EPSDT service is Medicaid’s comprehensive and preventive child health program for individuals under the age of 21. EPSDT was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA ‘89) legislation and includes periodic screening, vision, dental, and hearing services. In addition, Section 1905(r)(5) of the Social Security Act (the Act) requires that any medically necessary health care service listed at Section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State’s Medicaid plan to the rest of the Medicaid population. The EPSDT program consists of two mutually supportive, operational components:

(1) Assuring the availability and accessibility of required health care resources; and
(2) Helping Medicaid recipients and their parents or guardians effectively use these resources. These components enable Medicaid agencies to manage a comprehensive child health program of prevention and treatment, to seek out eligibles and inform them of the benefits of prevention and the health services and assistance available and to help them and their families use health resources, including their own talents and knowledge, effectively and efficiently. It also enables them to assess the child’s health needs through initial and periodic examinations and evaluations, and also to assure that the health problems found are diagnosed and treated early, before they become more complex and their treatment more costly.”

Medicaid and Medicaid Waiver Program

With Medicaid, a person with ASD can receive coverage for medical services and service coordination if a child qualifies for Supplemental Security Income, based on income criteria. A child may also be eligible for Medicaid if his or her parent receives public assistance through the welfare program. Adults with ASD (older than 18), may also qualify for SSI if they are unable to work.
Finally, if a child is younger than 18 and the parent does not meet the income guidelines for SSI, the child may qualify for Medicaid through a state Medicaid Waiver Program, described in the following paragraphs.

**Medicaid Waivers for Autism**

Several states have attempted to alleviate institutionalization of children with ASDs by filing for Medicaid waivers with CMS. The 1915(c) authority—or the Home and Community Based Service (HCBS) Waiver allows states to target eligibility for the program and provide home and community-based services to children and adults with disabilities, including ASDs.

Although multiple states have 1915(c) waivers for community based services to individuals with mental retardation and/or developmental disabilities and for which individuals with ASDs may qualify, a number of states have received waivers specifically targeted for children and adults with ASDs.
APPENDIX C

AUTISTIC SPECTRUM DISORDERS GUIDELINES – REFERENCES

Practice Guidelines; Professional Societies

http://www.aacap.org/clinical/parameters/


http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/5/1221

Practice Guidelines; States

NYS Department of Health, Early Intervention Program
Corning Tower Building, Room 208
Empire State Plaza, Albany, New York 12237-0618
(518) 473-7016 www.health.state.ny.us/community/infants_children/early_intervention/autism/index.htm


Connecticut State Department of Education's Division of Teaching and Learning Programs and Services Bureau of Special Education(2005) Guidelines for the Identification and Education of Children and Youth with Autism-July 128 pages

[www.state.ct.us/sde/deps/special/Guidelines_Autism.pdf](http://www.state.ct.us/sde/deps/special/Guidelines_Autism.pdf)

**Diagnostic Scales and Instruments**


General Reference

Summary of best practices and policy recommendations from NIMH Subcommittee

Autism and Hope, Symposium at the Brookings Institute, December 14, 2005
http://www.brookings.edu/comm/events/20051216autism.htm#TRANSCRIPT


Eligibility

Overview of EPSDT
http://cms.hhs.gov/MedicaidEarlyPeriodicScrn/

Individuals with Disabilities Education Act
http://www.usdoj.gov/crt/ada/cguide.htm#anchor65310

Autism waiver Fact Sheet
http://www.dhmh.state.md.us/mma/waiver
Internet Resources for Professionals

www.nas.org.uk/nas/jsp/polopoly.jsp?d=306&a=3280

Asperger’s Disorder links  http://www.disabilityresources.org/ASPERGERS.html

Internet Resources for Parents/Family Members


National Institutes of Mental Health  

Reaching for a Brighter Future: Service Guidelines for Individuals with Autism Spectrum Disorders/Pervasive Developmental Disorders (ASD/PDD)  
http://www.psychmed.osu.edu/AutismBook_1.pdf

Autism Society  
http://www.autism-society.org

Learn the Signs – developmental milestones  
http://www.cdc.gov/ncbddd/autism/actearly/default.htm

Autism Research Institute  
http://www.autismwebsite.com/ARI/index.htm

Autism Network Resources for Physicians  
http://home.san.rr.com/autismnet/research.html