Chapter 4: Medical Aspects

This section describes issues related to diagnosis and medical concerns for individuals with Autism Spectrum Disorder (ASD). It includes guidelines for medical assessment and intervention in a wide range of medically related areas. Many of the areas involve daily living skills such as feeding, sleeping, and dental care. Others are psychosocial in nature, and include anxiety, tics, and mood disorder. This section is best used in conjunction with the rest of the document because medical interventions alone are not sufficient to improve behavior or maximize learning (National Institute of Mental Health, 2007). It is, however, important to address potential medical problems because they can significantly impact development of social, cognitive and academic skills (American Academy of Pediatrics, 2007).

Screening and Diagnosis

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. The American Academy of Pediatrics (AAP, 2007), the American Academy of Neurology (2003), and the Child Neurology Society recommend developmental screening for young children at all well-child check-ups with an autism specific screen at 18 months of age. Due to potential regression, an additional autism screen is recommended at 24-30 months of age.

Medical Key Points:

- **Early identification as part of well-child care visits.**
- **Implementation of testing for identifiable etiologies.**
- **Monitoring for co-existing conditions.**
- **Knowledge of pharmacologic and complementary medicine options.**

Screening tools may include the Modified Checklist for Autism in Toddlers (M-CHAT) and are available at **www.aap.org** (see Appendix 11: American Academy of Pediatrics - Clinical Guidelines on Autism). 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.

Ideally, care for the individual would take place in one setting. Within the school-age population, children who are exhibiting a concerning combination of language, social and behavioral difficulties should be referred for a more detailed evaluation. At risk children include those with social-practical language difficulties, restricted and or intense interests, and significant challenges in social initiation and or both.

The evaluation of all children for a possible ASD diagnosis should include consultation with a medical professional experienced with the autism spectrum. These professionals include child neurologists, child and adolescent psychiatrists, and developmental and behavioral pediatricians, as well as general pediatric specialists with expertise in ASD. A complete history and physical examination should be performed, with emphasis on neurodevelopmental and general medical history, family history of individuals with similar difficulties or known medical history of neurological or developmental conditions, relevant documentation

from previous evaluations, and physical or behavioral findings suggestive of specific genetic, metabolic, neurological or other medical conditions.

Since some medical disorders are associated with or appear similar to ASD, the medical evaluation is needed before any definitive diagnostic statement regarding ASD is made. Medical tests can be helpful in defining an underlying etiology (study of causes) for ASD, or indicating the most helpful treatment. An identifiable cause is present in only a small percentage of this population. According to the American Academy of Neurology and the Child Neurology Society (2006), there are other appropriate screening tests the doctor may order when autism is suspected (see Appendix 12 for complete clinician guidelines).

These include:

1. Genetic tests, specifically high resolution chromosome analysis studies (karyotype) and DNA analysis for Fragile X, because some causes of autism may be inherited—or genetic. Genetic testing can provide information about any specific inherited problems, genetic defects, or nervous system abnormalities the child may have.

   Fragile X is caused by an inherited change in a specific gene. A few children with autism test positive for Fragile X. The doctor should order the test if there is a family history of developmental problems, neurological conditions or if the child has certain physical signs.

2. A relatively new technology called array comparative genome hybridization, or CGH, has dramatically increased the number of certain types of identified chromosomal abnormalities (especially micro-deletions and micro-duplications) not identified using the high-resolution karyotype. While not yet standard, it is reasonable to consider a CGH in children with ASD, particularly if karyotype and Fragile X testing are unremarkable/not conclusive.

3. Electroencephalography (EEG) is indicated only in some individuals, such as those with a history of autistic regression (normal developmental progress with loss of functional language and or social skills) and in those with the clinical suspicion for seizures, among other indications. The EEG study should be done in the awake and sleep state, recording at least one complete sleep cycle. Because some medications used for sedation for sleep can transiently suppress epileptiform activity, sleep should be recorded with natural onset (such as naptime or overnight sleep) or with medication that does not affect epilepsy activity. There are some data to suggest that some aspects of ASD improve if a co-occurring seizure disorder is diagnosed and adequately treated.

4. Other selective metabolic tests may be ordered to see if there is a genetic or non-genetic condition that affects the child. A doctor might order metabolic tests if there are other specific symptoms such as lethargy or cyclic vomiting.

5. Laboratory investigations include formal hearing (audiological) evaluation for children with developmental delay or autism.

6. Screening for vision issues.

7. Skin Wood's lamp assessment should be performed to assess for a skin-brain (neurocutaneous) disorder, such as tuberous sclerosis.

8. Lead screening may be ordered if there is a risk that the child might have lead poisoning or in the case of developmental delay. Since some children with autism tend to eat non-food items and lead may be found in paint chips, the doctor may order a blood test for lead screening.

9. Evaluation of Gastrointestinal (GI) Dysfunction. Despite second-hand reports, no causal relationship has been established between gastrointestinal dysfunction and ASD. Since individuals with ASD can have GI dysfunction of diverse etiology, such as gastroesophageal reflux, chronic constipation, and disaccharidase deficiency, the evaluation should be based on the clinical presentation and not necessarily on the diagnosis of ASD.

10. Brain imaging, such as MRI, rarely shows any significant abnormality in individuals with ASD unless there is a co-existing condition for which imaging is indicated, such as non-familial microcephaly or macrocephaly, regression, seizures or focal neurologic features.

11. Other tests should be ordered as clinically indicated and not because of the diagnosis of ASD. Children with developmental or cognitive impairment and ASD may be candidates for testing for inborn errors of metabolism, including amino and organic acid assays. Other studies such as allergy testing, immune system workup and heavy metal assays should be done only if there are clinical features of these types of disorders.

12. Psychological tests and speech and language tests are likely to be ordered to help plan for a child's education (Neurology 2000 and National Guidelines Clearinghouse, 2006).

For more information, a parent fact sheet on screening and diagnosing of children with autism and follow up test information is available online from the American Academy of Neurology and Child Neurology Society (2008) at **http://aan.com/professionals/practice/guidelines/guideline_summaries/Autism_Guideline_for_Patients.pdf**.

For general practice providers and pediatricians, see the AAP guidelines in Appendix 11 or online at professional resources **www.aap.org/healthtopics/Autism.cfm**. Additional AAP materials are detailed on page 15 under the AAP toolkit.

School-age Diagnosis

Similar to the preschool age child, the diagnostic assessment of a school-age child should occur through a multidisciplinary approach including assessment of cognitive, language, motor and social skills. In addition to a medical evaluation, school-age children should undergo formal psychological assessment by a child psychologist experienced in evaluating children with ASD. As a component for this assessment, the use of well-recognized diagnostic tools is imperative because of the presence of less obvious symptoms in this age group.

Evaluation by a speech and language pathologist with expertise in assessing children with ASD is useful, even in a child with apparently normal speech, in part to examine social and practical skills.

The diagnostic assessment of a school-age child should occur through a multi-disciplinary approach.

The school has a role in the diagnostic assessment of a school-age child for possible ASD. In addition to being a source of referral for diagnostic evaluation, school personnel can assist by providing accounts of behavioral observations and academic and psychological testing information. For some children, a school visit by a member of the diagnostic team may be valuable. The diagnostic assessment of a school age child should occur through a multidisciplinary approach.

The family is an essential member of the diagnostic team. Family members contribute by providing important historical information. They can optimize their roles by becoming familiar with the features of ASD and helping the diagnostic team recognize the features that may or may not be present in the child.

Diagnostic and Screening Instruments

The following instruments are used to diagnose or assess the clinical course of children with ASD. They measure function and dysfunction across the various areas of ASD. Please note that those using these instruments for screening and diagnostics should have a good knowledge of ASD and training in the use of the different instruments. This is by no means meant to be a complete listing of tools as research continually evolves to develop more effective diagnostic instruments.

Diagnostic Tools

Asperger Syndrome Diagnostic Scale (ASDS)

The ASDS is a quick, easy-to-use rating scale that can help determine whether a child is at-risk for Asperger Disorder. Anyone who knows the child or youth well can complete this scale. Parents, teachers, siblings, paraeducators, speech and language pathologists, psychologists, psychiatrists, and other professionals can answer the 50 yes or no items in 10 to 15 minutes. Designed to identify Asperger Disorder in children ages five through eighteen years, this instrument provides an AS Quotient that tells the likelihood that an individual has Asperger Disorder (Myles, Beck, Simpson, 2001).

Other screening instruments for Aspergers may include the Social Communication Questionnaire, Social Responsiveness Scale, Asperger Syndrome School Questionnaire and the Children's Communication Checklist.

Autism Diagnostic Interview—Revised (ADI-R)

The ADI-R is a standardized semi-structured investigator-based interview of individuals with ASD. It can be used for children with mental age at or above eighteen months. There is good supporting research to confirm its reliability and validity. The short form of the ADI-R takes approximately one hour to complete. The long form is more lengthy and is primarily used in research studies (Lord, Rutter, Le Couteur, 1994).

Autism Diagnostic Observation Scale (ADOS)

The ADOS is a structured observation schedule for the diagnosis of ASD. It focuses on qualitative features of socialization and communication and has an interactive component. Several versions are available, including one for children who are not yet using phrased speech. Since it is used in a highly structured environment, it may not reflect the more subtle features of ASD. Therefore, observations in non-structured settings and parent interview may be necessary (Lord et. al., 2000).

Gilliam Autism Rating Scale (GARS)

The GARS is based on the DSM-IV definitions of ASD and has four sub-tests: stereotyped behaviors, communication, social interactions, and developmental disturbances. This rating scale has good reliability and validity when used for the identification and diagnosis of individuals at or above age three. This scale can be easily and quickly completed by individuals who best know the child (Gilliam, 1995).

Screening Tools

Autism Behavior Checklist (ABC)

The ABC is a 57-item checklist that can be used as a screening instrument. It is used to estimate the severity of autistic features in an individual and to follow these features over time. It is not as reliable as the ADI-R (Krug, Arick, Almond, 1980).

Autism Screening Instrument of Educational Planning (ASIEP-2)

The ASIEP-2 rates individuals at or above eighteen months of age in five areas (sensory, relating, body concept, language, and social self-help.) It is used for evaluations and monitoring of individuals with ASD features (Krug, Arick, Almond, 1993).

Checklist for Autism in Toddlers (CHAT)

The CHAT is a brief checklist to screen for ASD/PDD in children aged 16-30 months. It has two components (Baron-Cohen, Wheelwright, Cox, et al., 2000):

1. A short list of questions for the primary caregiver .
2. Observations in an office setting of behavioral features of ASD.

Two studies have validated its usefulness as a screening tool for children with full features of ASD and, to a lesser degree, for children with high-functioning autism or Asperger Disorder. Those are *The Checklist for Autism in Toddlers*, adapted from Baron-Cohen and Gillberg's *Can Autism Be Detected at Eighteen Months? The Needle, the Haystack, and the CHAT* (1992).

Modified Checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is an expanded American version of the original CHAT from the U.K. The M-CHAT has 23 questions using the original nine from the CHAT as its basis. Its goal is to improve the sensitivity of the CHAT and position it better for an American audience (Robins, Fein, Barton, Green, 2001).

Pervasive Developmental Disorder Screening Test (PDDST)

The PDDST is a screening tool that can be used in multiple settings. Stage 1 is to be used in a primary care setting, Stage 2 for developmental disorders, and Stage 3 in a specialty clinic for children with ASD. It consists of a checklist of core areas of dysfunction and ASD based on parental report. The PDDST is designed as a screening test and is a parent-report measure. As such, it does not constitute a full clinical description of early signs of autism but does reflect those early signs that have been reported by parents and correlated with later clinical diagnosis (Siegel, 2001).

Psychoeducational Profile—Revised (PEP-R)

The PEP-R offers a developmental approach to the assessment of children with autism or related developmental disorders. It is an inventory of behaviors and skills designed to identify uneven and idiosyncratic learning patterns. The test is most appropriately used with children functioning at or below the preschool range and within the chronological age range of six months to seven years.

The PEP-R provides information on developmental functioning in imitation, perception, fine motor, gross motor, eye-hand integration, cognitive performance, and cognitive verbal areas. The PEP-R also identifies degrees of behavioral abnormality in relating and affect (cooperation and human interest), play and interest in materials, sensory responses, and language (Schopler, Reichler, Bashford, Lansing, Marcus, 1990).

Adolescent and Adult Psychoeducational Profile (AAPEP)

The AAPEP extends the PEP-R (see description above) to meet the needs of adolescents and adults. (Mesibov, Schopler, 1988).

Functional Assessments

Real Life Rating Scale

The Real Life Rating Scale (RLRS) assesses function of 47 behaviors. It can be used to monitor the effects of treatment in multiple environments and can be repeatedly used without affecting intra-observer reliability (Ritvo, Freeman, Yokota, Ritvo. 1986).

Promotional Training Programs

Several initiatives concerned with autism awareness for health care providers, parents, and early learning educators are now available. These education programs will increase the concept of early identification by health care providers and early learning specialists. Additionally, the materials teach parents how to

recognize developmental issues and advocate on behalf of their children in the process of searching for a diagnosis.

First Signs Program

The First Signs educational and training program incorporates an integrated mix of mailings, public service announcements, press activities, training, research, and web site materials at www.firstsigns.org. These provide essential developmental information, an explanation of the screening process, a systematic guide to each stage of the process, listings of available local and national resources, and links to research, books, articles and programs nationwide.

The program features the First Signs Screening Kit, which includes an educational video ("On the Spectrum: Children and Autism"), screening guidelines based on the practice parameter and endorsed by the AAP, highly validated developmental and autism screening tools, a pediatric practitioner's referral guide to early intervention, and a developmental milestones wall chart.

Currently, First Signs uses the M-CHAT in screening for autism. The following general developmental screening tools are among those used in the First Signs program, although new tools, both for general development and autism, continue to be evaluated.

- **Parents Evaluation of Developmental Status (PEDS)** is a parent questionnaire which is 70 to 80 percent accurate in identifying children with disabilities from birth through eight years. It can be administered by a wide range of health care professionals or office staff (Glascoe, Robertshaw, 2000).
- **Ages and Stages Questionnaire (ASQ)**, developed by Diane Bricker, Ph.D., and Jane Squires, Ph.D., identifies children ranging in age four months through five years experiencing developmental delays. It is a series of questionnaires that works well when used to stimulate conversations with parents or caregivers about a child's development and any concerns they may have (1999).
- **Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler Checklist (CSBS DP)**, developed by Amy M. Wetherby, Ph.D., CCC-SLP, and Barry M. Prizant, Ph.D., CCC-SLP has 24 multiple choice questions to be completed by a parent or caregiver. It is used to identify developmental delays in children ranging from age six through twenty four months (2001).

Learn the Signs. Act Early.

The Centers for Disease Control and Prevention (CDC) under the federal agency of the Department of Health and Human Services collaborated with many partners to develop a promotional campaign to increase national autism awareness and benefit children. The campaign, called "Learn the Signs. Act Early: It's time to change how we view a child's growth" targets health care providers, parents, and early educators. The partners coming together in this effort include the American Academy of Pediatrics, the Autism Society of America, Autism Speaks, First Signs, the Organization for Autism Research, the CDC, and many community champions.

The following are objectives of the campaign:

- Increase awareness of developmental milestones and early warning signs.
- Increase knowledge in the benefits of early action and early intervention.
- Increase parent-provider dialogue on the topic of developmental milestones and disorders.
- Increase early action on childhood developmental disorders.

The promotional materials consist of distinct resource kits for health care professionals, parents, and early educators. The supplies include posters, fact sheets, informational cards, CD-ROMs, flyers, and growth charts. The resources are free and downloadable from the web site or can be obtained through the mail or by phone. More information can be found at the CDC web site: **www.cdc.gov/ncbddd/autism/actearly/**.

American Academy of Pediatrics (AAP) Toolkit

This toolkit was developed to support health care professionals in the identification and ongoing management of children with ASD in the medical home. The AAP released its pediatric toolkit with an extensive array of resources for caring for children with autism. The information can be accessed on the web or through a CD-ROM, "Autism - Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians."

A multifaceted clinical resource, the toolkit has the following practice tools and resources: (1) identification, (2) referrals, (3) physician fact sheets, and (4) family handouts. To view a detailed product profile with sample tools and resources, go to: **www.aap.org/publiced/autismtoolkit.cfm**.

Medical Intervention for Individuals with ASD

Autistic Spectrum Disorders (ASDs) are now recognized as neurobiologically based conditions. ASDs, similar to other neurodevelopmental disabilities, are generally not "curable," and individuals with ASD require ongoing medical monitoring and care, as would any person with a chronic medical condition. This care should occur under the supervision of a medical professional, such as a child psychiatrist, general or developmental pediatrician, or pediatric neurologist. For an adult individual, the medical professional could be a psychiatrist, a primary provider, or a neurologist. In all instances it should be a medical professional with expertise in working with individuals with ASD.

The role of the medical practitioner starts with appropriate identification and continues with medical testing and monitoring for co-occuring conditions and their treatments.

The AAP calls for comprehensive care and care coordination to take place in a medical home setting. This model of care recognizes the need for primary care doctors to treat the whole patient by coordinating care among specialists, and involving and supporting the family in care decisions. Due to the variety of medical monitoring and chronic medical conditions that can surround an individual with autism, the medical home model provides an appropriate context for health care.

What is a medical home?

Every individual deserves a medical home. In 2002, the American Academy of Pediatrics released a statement calling for a medical home for all children and youth with special health care needs. The AAP describes a medical home as a "model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."

In Washington State, medical home has evolved into the Patient-Centered Medical Home (PC-MH), providing comprehensive primary care for children, youth, and adults. The collaborative effort of the American Academy of Family Physicians, the AAP, the American College of Physicians, and the American Osteopathic Association established a set of principles to enhance patient-centered care (2007).

The groups recognized the value to all of a health care setting that facilitates partnerships between individual patients, families, personal physicians, and specialists for children and adults through the lifespan. To learn more about the Washington State Patient-Centered Medical Home, go to **www.medicalhome.org**.

Treatment Goals

The primary goals of treatment are to maximize an individual's ultimate functional independence and quality of life by minimizing the core autism spectrum disorder features, facilitating development and learning, promoting socialization, reducing maladaptive behaviors, and educating and supporting families (AAP, Clinical Report, Management of Children with Autism Spectrum Disorders, 2007) (see Appendix 11: American Academy of Pediatrics - Clinical Guidelines on Autism).

All treatments - medical and non-medical - should be reviewed at every visit. The frequency of this monitoring should be individualized to a person's specific needs. It includes monitoring an individual's progress, treating associated medical conditions, assisting the family in investigating and accessing appropriate medical and other interventions, and keeping the family informed about new medical tests and interventions. Adequate time should be allotted to address these issues.

Medical Areas to be Addressed

Accidental Injury

Increased rates of accidental injury can result from many of the more specific behavioral abnormalities. Social avoidance can cause excessive running. Sensory issues can cause ingestion of nonfood items or accidental burns and cuts. Absence of a sense of danger can place the individual in potentially harmful environments. Monitoring and preventive anticipation are important.

Aggression

While some degree of aggressive behavior is common in all children at various ages, children with ASD tend to express these behaviors more frequently and with greater intensity. Tantrums are common in young children with ASD. Oppositional Behavior is common in older children and adults. Tantrums can persist and elaborate into dangerous self-injury, aggression, and property destruction. Reasons for aggression are varied. Intervention is dependent on the suspected underlying triggers or causes (see Appendix 6: Functional Behavioral Assessment).

Anxiety

In addition to the impaired social interaction characteristic of ASD, some children will avoid social contact that results in high levels of anxiety (social anxiety). Generalized anxiety and anxiety secondary to interference with rituals or routine can also be problematic. Specific aversions (fears/phobias) can grow to debilitating proportions and prevent participation in formerly preferred activities. These anxiety disorders can respond to behavioral and/or pharmacologic treatment.

Attention Deficit/Hyperactivity Signs and Symptoms

Attention challenges in children with ASD can be manifested in poor discrimination learning, focusing on unusual or partial cues needed for an adaptive response, and rapidly shifting attention, which may be associated with increased general activity. Some children with ASD manifest more of these hyperactive and inattentive symptoms than others. Although attention-deficit hyperactivity disorder (ADHD) diagnostic criteria exclude the presence of autism, the target symptoms may sometimes respond to the same treatments as ADHD in the general population.

While 50 percent of children with ASD are reported to respond to medication management of "ADHD" symptoms, 20 percent could not tolerate methyphenidate. This rate is two times greater than typical peers (Reiersen, Todd, 2008).

Dental Care

According to American Academy of Pediatric Dentistry "Dental Home" guidelines, all children should be seen by a dentist for routine cleaning and evaluation by age one or within six months of the first tooth eruption. The same guideline holds true for children with ASD. Children with ASD are at increased risk for dental and gum disease due to damaging oral habits (such as the chewing of gravel or other hard material in pica; or tooth-grinding (bruxism); behavioral or seizure medications that reduce saliva flow or cause gum overgrowth; mouth breathing due to low oro-motor tone; trauma due to self-injuring behaviors, seizures or motor disorders; and physical abuse, to which children with disability are unfortunately at increased risk.

Children with autism often need general anesthesia to tolerate dental procedures. The treating dentist should have experience working with children with special needs, particularly if sedation is to be used.

Parents should strive to teach good dental hygiene at an early age since the sensory aversion associated with tooth brushing may make it difficult, if not impossible, to teach and implement brushing skills at an older age (see Appendix 13: Tips for Making an Oral Care Visit Successful for the Client with Autism).

Elopement (Wandering)

According to the Autism Society of America:

> It is important that your child has proper identification in the event that he or she runs away or gets lost and is unable to communicate effectively. Once a child with ASD becomes mobile, he or she may decide to walk out of the home without supervision. Children on the autism spectrum often like to be outside and in motion, so leaving the home to play outside is common. Once outside of the home, the child is then vulnerable and may be unable to get home or communicate where they live. If the child will tolerate wearing a medical ID bracelet or necklace, get one (they can be found at your local drug store).
>
> However, many children with autism do not like to wear jewelry, so the next best option is to place iron-on labels into each garment. Some children can be taught to carry and provide an identification card from a wallet or fanny pack and can learn to show their identification cards if they are not able to verbalize the information to another person. Some parents have also used specially designed tracking devises, perimeter systems, or service dogs for children on the spectrum who are known to elope.

Project Lifesaver is a reliable rapid-response active locating system relying on state of the art technology and a specially trained search and rescue team working in partnership with law enforcement to find individuals. People may enroll in the Project Lifesaver Program and wear a personalized bracelet that emits a tracking signal. When caregivers notify the local Project Lifesaver agency that the person is missing, a search and rescue team responds to the wanderer's area and starts a search with the mobile locators tracking system. Search times have been reduced from hours and days to minutes. In over 1,500 searches, there were no reports of serious injuries or deaths. Recovery times have averaged less than 30 minutes.

This program is active and administered in many counties in Washington through the local sheriff's office. Contact your county sheriff's headquarters for more information or visit the national Project Lifesaver web site at **www.projectlifesaver.org**.

Feeding/Nutrition

Individuals with ASD often display a limited variety of food preferences. This may be due to refusal to transition between textures, unwillingness to try foods of a particular color or texture, or difficulties related to mealtime. These food preferences may be a reflection of the rigidity with which many of the individuals function. Their parents perceive their food choices as unhealthy or too limited. With slow introduction of healthier food choices, the individuals can generally be encouraged to try new foods. Under-nutrition and overt malnutrition are rarely seen. A wide variety of dietary supplements and elimination diets are informally reported to improve or reduce many of the unfavorable behaviors seen in these individuals.

At this time, there are no conclusive scientific studies to support the use of these dietary interventions. Individuals with pica (eating non-edibles like rocks), coprophagia (feeding on feces) or obsessive-compulsive symptomatology manifesting as food or eating rituals should be referred for evaluation. Parents of children who experience these difficulties should consult with a professional (speech language pathologist, occupational therapist, psychologist, registered dietitian, nutritionist, behavior analyst etc.) who have experience working with feeding issues (e.g., skill deficits, behavioral feeding disorders etc.) in these children. For more information on feeding teams, go to: **http://depts.washington.edu/cshcnnut/** and learn more about the Western Maternal Child Health Nutrition Partners at: **www.mchnutritionpartners.ucla.edu**.

Mood Disorder

Loss of interest in usual activities, unexplained fatigue, change in sleep habits (increase or decrease), change in appetite (increase or decrease), change in concentration or cognition, and signs of distress, such as moaning or crying for no apparent reason may reflect clinical depression. A person need not show all possible signs of depression to qualify for the diagnosis, but should have more than one.

The diagnosis should be especially suspected when a recent loss was sustained; although, because of their core deficits, persons with ASD may not appear as bereaved by death of a family member as would be expected and might be more affected by loss of an object. Decrease in sleep time, increase of activity level, unprovoked aggression, loss of inhibition (e.g., sexual), increased appetite, irritability, and giddiness or elation, especially if cyclical, may suggest bipolar disorder.

Again, a person need not show all signs and symptoms. Sometimes the main clue is a cycle of behavior of any kind (such as aggression, running away, self-injurious behavior), often preceded by a few nights of unaccustomed sleeplessness. All individuals with suspected mood disorders should be referred for further evaluation and treatment.

Obsessive/Compulsive and Severe Ritualistic Patterned Behavior

Compulsive behaviors and rituals are frequently seen in individuals with ASD. They can develop from narrow preferences or simple stereotypies (persistent repetition or sameness of acts, ideas or words). Excitement often accompanies ritualistic behavior. Attempts to obstruct or distract a person with ASD from pursuing patterned behavior may easily elicit explosive reactions or aggression, possibly anxiety-driven. When OCD (obsessive/compulsive disorder) features are present, they may respond favorably to appropriate behavioral or pharmacologic interventions or a combination of both. Atypical antipsychotics, such as Risperadone, are most typically used for this group of symptoms as well as for self-injurious behavior (ARP, 2007).

Puberty

Several issues occur during adolescence that may require assessment and monitoring. These include an increased incidence of epilepsy, especially complex partial seizures, mood disorders (depression and bipolar disorder), aggression, masturbation and increased interest in sexuality issues. Interventions are dependent on the underlying condition and include behavioral and pharmacologic treatment. Developmentally appropriate instruction about sexuality and issues such as menstruation and understanding of choices in areas such as birth control are important (see Chapter 6: Component 15 - Sexuality).

Psychiatric Disorders

The core diagnostic component of stereotyped, repetitive behavior and preoccupations, which can have obsessive-compulsive features, may be affected by drug intervention. In addition, individuals with ASD often develop associated or secondary psychopathology (emotional, mental, or behavioral) that may be responsive to treatment. The first line of treatment for most of these problems is behavioral; however in some cases, supplementation with medication is indicated (AAP, 2007).

Co-occurring psychiatric disorders are other medical conditions that are associated with and occur in this population at a higher rate than the general population. Estimates range from 28-78 percent, with approximately 45-55 percent of children with an autism spectrum disorder receiving psychotropic medication management (Ming, Brimacombe, Chaaban, Zimmerman-Bier, Wagner, 2008). Associated symptoms that are most typically targeted include irritability, lethargy, stereotypic behaviors, hyperactivity and atypical speech. While many children with ASD are responsive to medication management, careful monitoring is indicated due to intolerance.

Seizures

Children with ASD are at increased risk for the development of seizure disorders, with 20-30 percent or higher prevalence of epilepsy by adulthood among affected children with severe intellectual or motor disability (Persad, Thompson, Percy, 2005). The seizure prevalence is less than 10 percent among children with ASD who have less severe intellectual or motor impairments (Rapin, 1995). The types of seizures vary considerably, as is also seen in the non-autistic pediatric population. If children are exhibiting activity suggestive of seizures, they should have an EEG (Eltroencephalography measures brain electrical activity) (American Academy of Neurology, 2004).

There should be a low threshold for obtaining an EEG on children who are exhibiting activity suggestive of seizures. Importantly, non-specific EEG changes are quite common in children with ASD across the range of intellectual or motor impairment, and often cannot be clearly interpreted. Treatment with anticonvulsant medication depends on the seizure type and frequency, with close monitoring by a pediatric neurologist during medication initiation, titration and switches.

Self-Injurious Behavior

Self-injurious behavior (SIB), such as head banging, picking, biting, and self-hitting, occur in individuals with ASD, especially those with mental retardation and impaired communication ability. Investigation of potential triggers or causation is mandatory. Intervention may be behavioral and or pharmacologic, depending on the suspected underlying reason.

Sensory Issues

Many children with ASD show differences in their responses to various sensory stimuli. They may have increased or decreased awareness to a particular stimulus. Sensory issues may contribute to problematic behavior. At times, stimulus sensitivity may be a manifestation of an underlying condition such as anxiety mood disorder and will improve with treatment of the condition. While anecdotal reports of benefit from specific interventions such as sensory integration therapy or a "sensory diet" are widespread, available study results are limited by the small sample size and further research is warranted (see Chapter 5: Essential Components of Instruction and Chapter 6: Essential Component 9 - Sensory Motor Processing).

Sleep

Sleep difficulties are quite common in individuals with ASD, occurring in 75-95 percent of diagnosed cases (Ming, Brimacombe, Chaaban, Zimmerman-Bier, Wagner, 2008). Problems in sleep onset, night waking, and early waking are particularly frequent, and may reflect behavioral and or underlying "organic" origins. Consequences of sleep problems can include a disrupted family life, poorer learning and memory for the child, and making aggression and other undesired behaviors worse. Therefore, sleep disturbance should be addressed firmly.

Behavioral strategies to ensure good sleep hygiene should be established. A medical workup might be indicated. Consult with the individual's health care provider about the use of medications, including complementary medication such as melatonin. Since seizures can disrupt sleep and insufficient sleep can trigger seizures in pre-disposed children, an EEG should be considered in the appropriate context.

Stereotypies

Defined as persistent repetition or sameness of acts, ideas or words, stereotypie behavior characterizes much of the play of young children with ASD. This can consist of looking at bright objects, listening to repeated sounds and vocalizations or repetitive motor mannerisms. High rates of stereotypies can interfere with adaptive learning in school and in the community. Stereotypies may persist into adulthood. They are more common and refractory in people with ASD and multiple, often undiagnosed, sensory deficits, and in those with greater degrees of intellectual disability. The behaviors are often unresponsive to medication.

Tics

Tics are irregular, stereotyped, repetitive muscular contractions which may mimic apparently meaningful behavior. Tics vary greatly in frequency, intensity, complexity of expression, and body location. Some clinicians report a greater-than-chance co-occurrence of tics and Asperger Disorder or PDD-NOS. Mild non-impairing tics need not be treated. Tics are seldom so severe as to cause functional impairment or physical damage, for which medication is usually indicated. In higher cognitively functioning children, behavioral interventions specifically designed to reduce tics may be effective.

Medications

Like any treatment, medications should be reviewed at every follow-up visit. A variety of medications have been described for individuals with ASD and several have been researched. However, there is no one medication that works for every person with ASD. The medication treatment of an individual with ASD needs to be symptom specific. Hyperactivity, sleep problems, obsessive tendencies, anxiety, aggression, and self-injury are some of the symptoms that may be targeted with specific medications. Often, a single medication will target several symptoms, which can be desirable when working to minimize the number of medications a child is prescribed.

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. The observations of parents and caregivers should be systematically collected by logs, charts, scales, or other accepted behavioral documentation. A trial of medication tapering and discontinuation should be undertaken periodically, under close professional guidance, to determine its efficacy and whether it is still needed.

Alternative and Complementary Intervention

Interventions have been proposed based on theories of autism causation such as heavy metal poisoning, dietary factors, and auditory hypersensitivity. A growing range of insufficiently assessed interventions challenge families and providers to find a meaningful and appropriate balance in management that considers safety and efficacy while respecting parents' rights to pursue help for their affected children in a manner consistent with their values and imperatives. Broadly, complementary or alternative (CAM) approaches may be divided into "biomedical" and "non-biomedical" groupings, the latter of which include educational, behavioral and other therapeutic strategies.

While anecdotal reports of intervention efficacy exist for most popular CAM modalities explored in the treatment of ASD, by definition CAMs have inadequate reproducible scientific research to support confident statements of efficacy or safety; however, the potential benefit for any approach, including but not limited to "placebo effect," may be very real. If a CAM trial is undertaken for a child, one should consider all available information regarding safety and efficacy to ensure that the chosen intervention will not impede the implementation, safety or efficacy of other tested treatments (see Appendix 10: Choosing Treatment Options).