

*Quick Reference Guide*  
*for*  
**AUTISTIC SPECTRUM DISORDERS**



*Best Practice*  
*Guidelines for Screening,*  
*Diagnosis and Assessment*



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## ABOUT THE QUICK REFERENCE GUIDE



The *Quick Reference Guide for Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* is a summary of the key ideas and new concepts presented in *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* (2002; referred to herein as *Best Practice Guidelines*). The *Quick Reference Guide* was developed to facilitate use of the more comprehensive *Best Practice Guidelines*. Both documents offer evidence-based recommendations and are not intended for interpretation as policy or regulation. Rather, they are designed to help health care providers and families make informed decisions regarding identification, diagnosis, and assessment of autistic spectrum disorders (ASD).

Throughout the *Quick Reference Guide* and the more comprehensive *Best Practice Guidelines*, several core concepts guide clinical decision making. These core concepts suggest a common language by which both professionals and parents can communicate with each other. They also provide information about what can be expected from well-informed diagnostic and treatment planning teams.

The core concepts follow: *DSM-IV* is used for diagnostic classification; early identification leads to higher quality of life; informed clinical judgement enhances diagnostic accuracy; ASD present different challenges throughout the life span; confidentiality is balanced with informed exchange; interagency collaboration and problem solving should be promoted at every opportunity; an interdisciplinary process yields a comprehensive profile; evaluations are family-centered and culturally sensitive; timely referral and service coordination improve outcomes; best practices involve constant review and training.

A complete list of best practice recommendations is included at the end of this *Quick Reference Guide*. Details regarding development of the complete *Best Practice Guidelines* are available in the “Acknowledgements” and “Preface” of that document, which is available online at <http://www.ddhealthinfo.org> or by ordering a printed copy from the California Department of Developmental Services, Children and Families Services Branch at (916) 654-1596.

## About Autistic Spectrum Disorders

Broadly described, autistic spectrum disorders (ASD) refer to a pattern of behaviors involving three central features—impairments in socialization, atypical verbal and nonverbal communication, and restricted patterns of interest and stereotyped actions. The features can vary widely in symptom expression, degree of impairment, and onset. The conditions on the autistic spectrum addressed in the *Best Practice Guidelines* and this publication include: autistic disorder, Asperger’s disorder, and pervasive developmental disorder-not otherwise specified. The *Diagnostic and Statistical Manual, 4<sup>th</sup> edition (DSM-IV, 1994)* and the *Diagnostic and Statistical Manual, 4<sup>th</sup> edition, Text Revision (DSM-IV, TR, 2000)* published by the American Psychiatric Association are the current classification standards to establish a diagnosis of autistic spectrum disorders.

It is essential that a diagnosis of autistic spectrum disorders is made by clinicians with sufficient training and experience with persons who have an ASD. This is best done as part of an interdisciplinary team. The *Best Practice Guidelines* includes a comprehensive discussion of the licensing, education, and training requirements and ethical standards for professionals in this field.

The information in this guide is organized into two major sections: recommendations and practices for children from birth through age 5 and for individuals age 6 through 22.

Both the *Quick Reference Guide* and the *Best Practice Guidelines* use clinical terms consistently and with precise meaning. “Screening” refers to the prospective identification of children birth through age 5 most likely to have an ASD and/or developmental delay. “Referral” refers to the process of initiating the diagnostic evaluation of a child. The terms “diagnostic evaluation” and “evaluation” refer to the diagnostic process; whereas, “assessment for intervention planning” and “assessment” are the terms used to describe the intervention planning process. For clarity in discussion, both documents present these functions as distinct processes; however, in practice, the activities and procedures may take place concurrently, within a single session, or across multiple sessions.





## BIRTH THROUGH AGE FIVE



### Screening for Autistic Spectrum Disorders

Historically, detecting autistic spectrum disorders (ASD) before a child was 3 years old was unreliable. However, recent research demonstrates that an ASD is identifiable in very young children and that a significant number of features of ASD are present by 18 months of age. Studies have shown that autism can be reliably diagnosed in children between the ages of 24 and 30 months by an experienced clinician.

### Early Identification Leads to Better Outcomes

In addition, recent studies have demonstrated that early therapeutic intervention is associated with the best developmental, behavioral, and adaptive outcomes. Since ASD-specific early intervention services are dependent upon early detection and formal diagnosis, timely screening for ASD, at-risk identification, and prompt referral for comprehensive evaluation and assessment are paramount.

### Importance of Developmental Surveillance and Screening

Recent research distinguishes between proactive monitoring for developmental indicators and actual screening for specific developmental problems. “Developmental surveillance” is the routine monitoring and tracking of developmental milestones of all children at well-child visits to identify those at risk for any type of atypical development, as well as those at specific risk for autism. Concerns raised by developmental surveillance should lead to screening or

referral for diagnostic evaluation. “Screening” refers to the use of standardized instruments applied to a population to identify those children at risk for a developmental disorder who should be referred for a diagnostic evaluation.

To facilitate early identification and early intervention, best practice for screening for autistic spectrum disorders necessitates three fundamental additions to procedures currently employed by health care practitioners.

- Proactive monitoring, or developmental surveillance, for developmental milestones occurs at all well-child visits.
- Eliciting caregiver concerns about development and behavior occurs at each contact with a health care professional.
- All children are screened specifically for autistic spectrum disorders at ages 18 and/or 24 months.

In addition, *all* professional encounters with young children, including contacts with daycare providers and preschool teachers, should be viewed as opportunities to elicit developmental information and concerns.

## **Primary Care Providers Are Central to Early Identification**

Successful identification of ASD in young children and the effectiveness of intervention programs are dependent upon the ability of primary care providers (PCPs) to monitor children’s development and initiate referrals in a timely manner. Consequently, the importance of the PCP cannot be overemphasized. Such monitoring necessitates modifications or changes in the way many PCPs currently address developmental surveillance and screening.

Monitoring child development for early identification of children at risk demands that PCPs are thoroughly versed in normal child development and aware of developmental indicators of ASD.

## **Eliciting, Valuing, and Addressing Parental Concerns**

Parents of children with autism often note features that were markedly deficient in their children during the child's first two years of life. Because parents are experts about their children, eliciting and valuing parental concerns is imperative. Studies have shown that when parents raise developmental concerns, some PCPs respond by waiting to see if the delays will resolve spontaneously or by discounting parental observations. While a small number of children do “catch up” without formal intervention, this approach will delay identification and treatment of children with autistic spectrum disorders who could substantially benefit from earlier identification and treatment. *All* parental inquiries regarding developmental concerns about their child must be taken seriously and addressed appropriately.

## **Assuring Appropriate Referral of a Child with a Possible ASD**

A major obstacle to screening and identification of children with ASD is the confusion surrounding the referral process. Health care providers need to know referral resources for evaluation of children with suspected ASD.

Important referral sources include California's state-funded, nonprofit regional centers; specialized medical centers; Early Start programs; and local school districts. Referral initiated directly by the PCP or the PCP's staff facilitates efficient coordination of information and services. Referrals should be accompanied by sufficient information to enable understanding of the basis for concern and provide as much background information about the child and family as possible.

## Screening Instruments for General Development and ASD

Screening instruments are not intended to provide diagnoses, but rather to suggest a need for further diagnostic evaluation and intervention planning. Most measurement tools and tests fall into one of four broad categories, and all are appropriate and important to the identification process. These include general development tools, screening tools specific for ASD, parent interview measures, and direct child observation/interaction instruments. Providers may use different tools based upon their training, expertise, and scope of practice. A list and discussion of appropriate screening instruments are available in the *Best Practice Guidelines*.

## Diagnostic Evaluation

A diagnosis of an autistic spectrum disorder provides guidance for intervention and paves the way for prompt access to services. A diagnostic evaluation is a complex, multifaceted process involving assessments, interviews, observations, and examinations which may happen concurrently or sequentially by a team of skilled health care practitioners. Consequently, best practice for a diagnostic evaluation of ASD includes several important new elements.

- The primary care provider holds a central role in screening and coordination of health care.
- The complexity of the diagnostic evaluation makes an interdisciplinary team the preferred vehicle for achieving appropriate diagnosis and recommendations for intervention.
- The variability and evolution of symptoms over time require regular, periodic reevaluation to confirm the diagnosis and plan treatment.
- A comprehensive diagnostic evaluation for autistic spectrum disorders includes specific activities and examination of multiple domains of function to differentiate autistic spectrum disorders from other conditions and to provide a complete profile of the individual.

### Increased Emphasis on Role of Primary Care Providers

The primary care provider (PCP) often is the central point of contact for a child and his or her family. As such, the PCP plays an essential role in providing the initial evaluation and coordinating care. PCPs make appropriate referrals to initiate diagnostic evaluation; arrange for

specialty care; provide information and support; serve as liaisons and advocates for the child and the family; and obtain authorization from insurance providers.

## **An Interdisciplinary Team Is Preferred for Conducting a Comprehensive Diagnostic Evaluation**

Because a diagnostic evaluation for autistic spectrum disorders involves multiple activities and multiple areas of expertise, professionals from numerous disciplines and organizations are invariably part of the process. Primary care providers, medical specialists, psychologists and psychiatrists, regional center professional staff, and other health care providers are among those professionals who comprise the interdisciplinary team. Ideally, one member of the team is designated as the primary coordinator for the child's care. In the absence of the interdisciplinary team, a single clinician with experience evaluating ASD in young children can make a diagnosis.

## **Variations in Symptoms Over Time Necessitate Reevaluation**

The variations in symptoms that a child may manifest and the evolution of specific symptoms over time require periodic reevaluation to reaffirm or alter a diagnosis. Although many trained professionals are able to make a definitive diagnosis when a child is very young, the stability of diagnosis within the spectrum may fluctuate. This is often the case with children who are 2 years old or younger and for those at the extreme ends of the spectrum. In addition, symptoms and behaviors may change considerably with intervention, particularly as language and social skills progress. Follow-up in the early childhood years enables clinicians to track developmental changes in

symptomatology and behaviors, alter interventions as necessary, and better predict outcomes.

## **A Comprehensive Diagnostic Evaluation Involves Multiple Components**

To properly differentiate autistic spectrum disorders from other conditions and to provide an appropriate plan for intervention, a diagnostic evaluation necessarily includes several distinct components.

### ***Review of Relevant Background Information***

The essential purpose of background information review is twofold: to guide the diagnostic evaluation related to the specific parental concerns and questions, and to inform the selection of appropriate assessment measures. This includes documentation of previous tests (medical or other) and information about the child's developmental history.

### ***Parent/Caregiver Interview***

A parent/caregiver interview provides additional information that may not be available in background information about the child or through any other means. Components of a parent/caregiver interview include the following:

**CHILD HEALTH HISTORY**—prenatal and perinatal histories, past medical history, and review of systems (such as hearing, vision, and gastrointestinal function).

**DEVELOPMENTAL AND BEHAVIORAL HISTORY OF THE CHILD**—a wide-ranging list of relevant content to be explored either through formal diagnostic interview tools or by direct interview of the parents or caregiver. In practice, a combination of both methods improves diagnostic accuracy.

**FAMILY MEDICAL AND MENTAL HEALTH HISTORY**—presence or absence of any medical, developmental, or psychiatric disorders in the family history that may relate to the current concerns or that may assist in differential diagnosis, diagnostic clarity, and/or treatment planning. Current research clearly indicates a genetic component associated with ASD.

### ***Medical Evaluation***

The purpose of the medical evaluation is to assist with determining the etiology of the disorder, associated medical conditions, and any other health conditions that may also be present. Such a medical evaluation includes

- general physical and neurodevelopmental examination
- developmental neurological examination
- laboratory tests
- genetic testing and consultation
- neurological laboratory evaluation
- other laboratory investigations
- sensory evaluation (vision and hearing)

### ***Direct Behavior Observation***

Direct observation of the child's behavior is essential to a diagnostic evaluation. This allows the clinician opportunities to directly observe the child in structured and unstructured situations, clarify issues that arise during the parent interview, and observe patterns of interaction with family and unfamiliar adults.

Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of an ASD. The degree of structure, the specific toys in the environment, and the allotted space are all critical elements in establishing an optimal



environment for observation. All behavior must be interpreted within the context of the age and developmental level of the child.

The *Best Practice Guidelines* discusses appropriate procedures and tools to facilitate observation.

### ***Cognitive Assessment***

Research has repeatedly established that children with ASD vary widely in their cognitive potential. In addition, experts recognize that assessment of cognitive functioning is crucial to the differentiation of ASD from other disabilities and to the identification of concomitant impairment in a child with an ASD. Cognitive ability also has an important role in prognosis and intervention planning. Consequently, evaluation of cognitive functioning in both verbal and nonverbal domains is a necessary component of the complete diagnostic profile of a child.

The use of both standard and informal assessment procedures is recommended. The goal of standardized assessment is to ascertain where the child is functioning relative to his/her same-age peers. Formal cognitive/intelligence testing should include an assessment of both verbal and nonverbal functions.

Criticisms linger regarding the use of standardized, formal testing procedures with children with autistic spectrum disorders. While some concerns are valid, the goal of cognitive evaluation is to ascertain the current ability of the child. This information can be reasonably obtained by clinicians experienced in working with children with autistic spectrum disorders. The *Best Practice Guidelines* includes a comprehensive discussion of standardized instruments.

### ***Adaptive Functioning***

Children with autism often demonstrate large discrepancies between their nonverbal cognitive potential and their ability to function

successfully in their families and communities. An evaluation of adaptive functioning offers the clinician indications of the child's capacities for personal and social self-sufficiency and problem solving in real life situations. Ideally, a representative assessment of typical adaptive function would include information from as many sources as possible. Appropriate domains of adaptive function for evaluation include

- communication—receptive/expressive and pragmatic language
- socialization
- fine and gross motor development
- self-help/daily living skills—eating, dressing, hygiene
- social-emotional functioning

Procedures and tools for evaluating adaptive function are discussed in the *Best Practice Guidelines*.

## Assessment for Intervention Planning

Whereas “diagnostic evaluation” refers to the process of gathering information to arrive at a diagnosis, “assessment for intervention planning,” or assessment, expands upon diagnostic evaluation with the objective of directing treatment planning and intervention based upon the child’s individual profile. A comprehensive assessment should

- detail the child’s individual strengths and areas of need
- establish the child’s health and developmental patterns, and profile family resources and needs within the community context
- determine areas in which additional information is needed
- set the stage for development of an intervention plan that meets the needs of the child and family within their community

Assessment is an ongoing and flexible process, and recommendations may be revised as the child develops, responds to the intervention, and adapts to family and community factors. As in both screening and diagnostic evaluation, an interdisciplinary team is important to gain insight into the variety of components of a child’s functioning and interventions needed to maximize functioning.

### Concepts Central to Assessment for Intervention Planning

Current best practice for assessment of autistic spectrum disorders (ASD) focuses on three key concepts: the significance of the family; the importance of the setting, or environment, in which the child is evaluated; and the need for a comprehensive assessment.

### *The Significance of the Family in the Assessment Process*

Assessment recognizes the family as an integral part of the clinical team. Parents' values, needs, beliefs, and fears, as well as their expectations for their child, profoundly influence the implementation of recommendations and intervention plans. Cultural and family values, socioeconomic factors, and other philosophical and belief systems have equally significant effects on the realization of recommendations and intervention plans.

### *The Assessment Environment Affects Observation*

Because the setting in which the child is evaluated—home, office, or child care facility—affects the observation of the child, it must be chosen carefully to obtain representative information regarding development and behavior.

Rarely do young children, regardless of disability status, perform optimally in an unfamiliar environment with an unfamiliar adult. While home assessments may not always be possible, the assessment should strive to gather as much information as possible from informal observation, parental and other service provider interviews, and videotapes, if available. Suggestions for maximizing the assessment environment include

- allowing a parent or familiar caregiver to remain with the child
- giving instruction in language familiar to the child
- encouraging the child with favorite toys or food treats as appropriate
- clearing the assessment room from distractions and irrelevant materials

### *Factors to Consider in a Comprehensive Assessment*

Assessment for intervention planning includes comprehensive exploration in five specific domains: communication (speech and language); motor skills and sensory processing; behavioral functioning; adaptive functioning; and family functioning and coping resources.

#### **COMMUNICATION: SPEECH AND LANGUAGE**

Impairment in multiple aspects of communication, including nonverbal and verbal communication, is central to ASD. Four broad areas of communication warrant particular attention:

- expressive language
- receptive language
- sociocommunicative and socioemotional
- language-related cognitive domains

A sampling of instruments for parent interview/observation and direct child assessment of speech, language, and communication is available in the *Best Practice Guidelines*.

#### **MOTOR SKILLS AND SENSORY PROCESSING**

Although for most children with ASD motor skills are a relative strength, motor challenges are often present at the ends of the spectrum. Difficulties in motor functioning lead to difficulty processing and obtaining information from the environment. Particular attention to functional motor skills is necessary.

Many children with ASD appear to have difficulty modulating and processing sensory and environmental input. Sensory challenges can be a limiting factor for a child's current functioning and ability to benefit from intervention. A comprehensive assessment must include a description of the child's sensory profile and the interrelationship between current functioning and intervention strategies.

Tools for assessing motor skills and sensory processing are discussed in the *Best Practice Guidelines*.

### **BEHAVIORAL FUNCTIONING**

Children with ASD often display serious behavioral difficulties that impact the child's safety, interfere with family functioning, and limit participation with the extended family and the community-at-large. Contrary to the viewpoint that difficult behavior is solely maladaptive or self-stimulatory, a large body of research supports the frequently purposeful and functional nature of challenging behavior to gain a desired object or outcome.

Behavioral problems may develop for many reasons, including communication failures, environmental stressors, the need for routine and structure, or to gain attention, escape undesirable situations, or gain access to objects or activities. Two methods of understanding behavior include "positive behavioral support" and "functional analysis of behavior." Both are explained, along with tools to guide behavioral assessment and the data gathering process, in the *Best Practice Guidelines*.

### **ADAPTIVE FUNCTIONING**

Adaptive functioning encompasses self-care and daily living skills. The procedures and tools indicated in the *Best Practice Guidelines* section on diagnostic evaluation are appropriate to assess adaptive functioning.

### **FAMILY FUNCTIONING AND COPING RESOURCES**

Adaptation to a child with a disability manifests differently from family to family and among members within a family. Consequently, an assessment of the family environment and the family's capacity to assist their child with disabilities is an important part of any comprehensive assessment. Family assessment with the goal of providing family-centered intervention strengthens the family's ability to influence its child's development and well-being. The *Best Practice Guidelines* presents tools that can help assess family functioning and coping.

## Formulation, Presentation, and Documentation of Findings

Findings and determinations from the diagnostic evaluation and assessment for intervention planning are formulated into a comprehensive report, and presented to the family in person and through a timely written report.

### Diagnosis Integrates Clinical Judgment with Formal Diagnostic Criteria

Diagnostic formulation refers to the process through which evaluation and assessment data are collated and integrated into a cohesive, clinical description of findings. The diagnostic formulation must be based on a review of all relevant data as it applies to the diagnostic criteria for autistic spectrum disorders (ASD). Further, *DSM-IV* criteria must be interpreted with respect to clinical judgment and integration of data. Research suggests that diagnostic conclusions rendered by professionals with considerable expertise in ASD have a high degree of reliability and validity as children develop and, in some studies of young children, were more predictive of diagnostic stability than formal diagnostic instruments.

In instances where a definitive diagnostic presentation is not readily apparent, particularly with very low and very high functioning children, the clinical team should formulate a plan of action for gaining further information. At no time should the team diagnose a child without confidence in the diagnosis. The team should be prepared to discuss with parents the reasons underlying ambiguity and the provisions for clarification.

## Presentation of Findings Deserves a Family-Centered Focus

Once a diagnostic conclusion is formulated, it is presented to the family. Team members should consider

- the team's ability to explain rationale for diagnostic conclusions and intervention recommendations in comprehensible language, within the context of the child's history
- sensitivity to parents' concerns, as well as to their educational and cultural background, language, and coping styles

The clinician must be able to guide parents honestly and accurately in realistic expectations for their child based upon the findings, empirical literature, and clinical experience. Clinicians should also convey their confidence or reservations about the findings, along with supporting documentation and implications for intervention planning. In addition, clinicians must be able to discuss treatment options, including questionable alternative treatments or theories parents may suggest, without alienating the family.

## Documentation: Elements of the Written Report

While documentation must be cited and correspond to *DSM-IV* criteria for ASD (the equivalent *DSM-IV* term is “pervasive developmental disorder”), it must also be comprehensible to parents and those responsible for implementation. Appropriate elements for inclusion in a comprehensive report are discussed in the *Best Practice Guidelines*.



## AGE SIX AND OLDER



### Issues Precipitating Referral in School-Age and Older Children

Children who first present for evaluation at school age or older generally do so as a result of parental and/or school concerns regarding social functioning. Behaviors that were acceptable or less noticeable in a familial or cultural context may emerge once the child enters school and demands for behavioral conformity and competence increase.

Other children may present at a later age for additional evaluation, having been identified earlier as exhibiting unusual behavioral and/or communication patterns.

### Common Indicators Prompting Initial Referral

Four factors commonly prompt initial referral at an age beyond preschool:

- symptom changes and diagnostic dilemmas
- social deficits
- difficulty in meeting academic expectations
- considerations such as family, cultural, community, or other demographic factors that mediate the dysfunctional quality of behaviors

*Screening tests appropriate for younger children are not particularly useful in the older age group.* The symptoms at initial presentation drive the selection of a referral resource. The referral should lead to a timely and comprehensive evaluation that meets the child's and family's needs relative to cost and initiation of services.

## Diagnostic Evaluation of Older Children

Best practice for conducting a diagnostic evaluation of autistic spectrum disorders (ASD) in individuals age 6 and older incorporates all components of the process for age birth to 5 and also requires consideration of numerous important factors unique to older children.

- Symptoms of autistic spectrum disorders have a wide range of expression and change over the course of development and intervention and in relation to the degree of any associated mental handicap.
- Differential diagnosis is more challenging due to the increasing possibilities for alternative diagnoses, the long-term effects of environmental interactions on behavior, and the possibility of coexisting conditions.
- The success of the diagnostic and assessment processes depends on collaboration among all service agencies, disciplines, programs, professionals, and caregivers responsible for providing services to the individual.
- Establishing an early developmental history is more challenging as the age of the individual increases.

## Components of a Diagnostic Evaluation/ Assessment Process

In addition to those areas included in a diagnostic evaluation of children birth through age 5, a diagnostic evaluation/assessment for autistic spectrum disorders (ASD) in a child of school age or older involves new and expanded areas for investigation. These include the opportunity to interview the child directly and the need for a detailed psychological evaluation, a communication assessment, and evaluations of social competence and functioning. A complete diagnostic evaluation of older children and adolescents includes the following areas:

- record review
- medical evaluation
- parent/caregiver interview
- direct child evaluation
  - interview
  - observation in different environments
- psychological evaluation
  - cognitive assessment
  - adaptive functioning assessment
  - mental health assessment/psychiatric functioning
- communication assessment
- evaluation of social competence and functioning
- evaluation of behavior, interests, and activities
- assessment of family resources and needs

## Record Review

The focus of record review is to examine and compare descriptions of past development and behavior with current concerns. The older a child at the time of first presentation, the more information he or she will have amassed, potentially including medical, school, and psychological records and data from other evaluations or intervention reports such as speech therapy progress reports.

## Medical Evaluation

As in the evaluation of younger children, the medical evaluation of children age 6 and older involves four major components: a comprehensive medical history, the family medical and mental health history, the physical and developmental neurological examination, and laboratory testing.

Areas of investigation of special interest among children age 6 and older include

- medical records for evidence of neurologic or systemic disease, particularly disorders that may be episodic or insidious in their onset
- results of previous physical, neurological, and cognitive examinations for evidence of abnormalities and consideration of whether to repeat tests in light of newer tests or inconsistent results
- coordination difficulties (in handwriting, sports activities, and bike riding, for example) and the timing of their onset
- changes in the child's personality, mood, or temperament
- the presence of problems with attention span, distractibility, or impulsivity and when and under what conditions they occur

- several years of normal development followed by a marked developmental regression (with adolescents in particular, one should evaluate the possibility of a seizure disorder, particularly in the face of behavioral deterioration and lower cognitive functioning)

A thorough review of the medical history also takes into consideration any medications currently or previously prescribed and their benefits and side effects.

## **Parent/Caregiver Interview**

Parent interviews of older children are potentially complicated by the fact that the older the individual, the more challenged is the memory of a parent, sibling, family member, or other caregiver providing historic detail. In addition, the possibility exists that earlier history may be inadvertently described and interpreted in the context of current behavioral or communication challenges.

A combination of approaches, however, can help the clinician gather information with a relatively high degree of accuracy. Probing a single, specific event; employing formal instruments; and obtaining objective rather than subjective descriptions of behavior through means such as family videotapes are examples of such approaches.

## **Direct Child Evaluation**

The most significant difference between direct child evaluation of children birth through age 5 and those age 6 and older is the opportunity to gather information through a face-to-face interview of those older children with adequate language skills. Observation of the

child's communication skills and style are helpful with differential diagnosis and with the exploration of pragmatic deficits. A child's ability to manage conversational interchange; ability to accurately interpret nonliteral language such as humor and irony; capacity to modulate tone, volume, and other stylistic features of speech; and nonverbal communication skills, such as shifts in eye gaze and body positioning, are just a few examples of observations helpful to clinicians.

Play interviews are entirely appropriate with children in the 6 to 10 age range, as internal concerns of children are often more amenable to play assessment rather than direct questioning.

Respecting the child's wish for confidentiality is important and a factor unique to the older age group.

## **Psychological Evaluation**

Three broad areas of psychological evaluation help to establish a framework against which to evaluate specific diagnostic criteria and to establish a differential diagnosis: measures of overall intellectual level (cognitive assessment), measures of adaptive functioning, and an assessment of mental health and psychological functioning.

For those older children and adolescents who function academically at grade level, cognitive performance may not be a source of concern. Referral questions in this group typically center on significant behavioral and/or social concerns best addressed through an adaptive assessment and/or child interview.

### ***Cognitive Assessment***

The goal of cognitive assessment with the school-age child is to gain insight into a child's ability to solve problems, apply and process information, and tolerate structured learning demands. In addition, cognitive assessments identify the child's strengths, weaknesses, and processing preferences, whether visual or auditory.

With older children, issues of diagnosis are particularly more complex for those with a significantly greater or lesser intellectual ability. Care should be taken to refrain from assuming that children with higher intellectual ability are equally competent in all other areas of cognitive and adaptive functioning.

Measures of cognitive function should include standardized instruments. Findings at this age are more valid and stable than with younger children. In addition, the clinician has a wider array of choices of instruments for older children. Tests are chosen in accordance with the child's estimated level of cognitive development and language ability. Tests that minimize verbal comprehension and expression are indicated for children with minimal language. The *Best Practice Guidelines* offers a comprehensive list of instruments for cognitive assessment.

Regardless of the instrument chosen, awareness of the "floor" effect—the insensitivity of an instrument at lower levels of function—inherent in many standardized IQ tests is particularly relevant for children and adolescents who function at lower developmental levels.

### ***Assessment of Adaptive Functioning***

Many higher functioning children with autism, while scoring in the normal range on IQ tests, are functionally impaired in that they are unable to demonstrate their abilities in daily situations. Such

information is relevant for diagnosis and intervention planning and for differentiating ASD from other conditions, such as mental retardation.

### ***Assessment of Mental Health, Behavior, and Psychological Functioning***

An assessment of mental health, behavior, and psychological functioning specifically helps differentiate ASD from other psychiatric disorders and/or determine the presence of coexisting psychiatric conditions. Depression, anxiety disorders, attention-deficit/hyperactivity disorder, Tourette's disorder, bipolar disorder, psychotic disorders, oppositional and mood disorders, and motor and vocal tics are among the conditions to be differentiated.

Clinical diagnostic interviews supplemented by structured interview tools and play- or activity-based assessments, projective tests, and other instruments such as self-report measures are appropriate avenues for assessing behavioral and psychological functioning. The *Best Practice Guidelines* presents assessment instruments for psychological functioning.

## **Communication Assessment**

Children of school age and older suspected of having an ASD may present with widely varying verbal skills. In addition to the more formal, structural aspects of language, such as articulation and receptive/expressive vocabulary, a communication assessment should pay particular attention to language and communication abilities in social situations—the “social-pragmatic” functions of language—as well as to nonverbal skills used to communicate and regulate interaction.



### ***Verbal Children and Adolescents***

For children with language skills, a communication assessment should differentiate patterns consistent with ASD from those seen in children with other disorders that share some of the same unusual language features common to autism. Generally, ASD must be differentiated from developmental language disorders, as well as language disorders that are concomitant with other disorders such as schizophrenia spectrum disorders. In addition, language features can help distinguish among the autistic spectrum disorders, particularly Asperger's disorder.

Because social-pragmatic abilities are specific and are not assessed by some traditional measures of language competence, these measures may result in incomplete or misleading findings. Therefore, direct assessment, naturalistic observation, and interviews with significant others, including parents and educators, are all appropriate and reliable strategies to assess social-pragmatic skills.

### ***Nonverbal/Minimal Language Children and Adolescents***

Children with limited or no functional language presenting after age 6 may have an unidentified autistic spectrum disorder or a nonautistic developmental disorder. For a child age 6 or older with limited or no functional language, several areas of examination are important: the child's preferred mode of communication—augmentative or gestural, for example; the child's level of language skill relative to overall developmental level; his or her communication intent and comprehension skills; and his or her nonverbal communication.

An understanding of the child's capacity for social communication with or without language is obtained through structured and unstructured observations in a variety of settings. Assessment of nonverbal communicative behaviors consists of analysis of sociocommunicative and socioaffective behaviors, including for example, eye contact and the use of gaze to communicate intent and

share attention. The *Best Practice Guidelines* includes a list of appropriate communication assessment tools.

## Evaluation of Social Competence and Functioning

Difficulties with peer relationships are a common basis for referral of school-age children and adolescents. Children with ASD vary widely in their capacity for social comprehension and successful interaction. Differentiating children with ASD from those with, for example, attention-deficit/hyperactivity disorder, oppositional defiant disorder, anxiety, depression, psychotic features, or mental retardation requires evaluation of social function and deficits in peer relationships collected from multiple sources. The *Best Practice Guidelines* indicates instruments helpful in evaluating social competence and functioning.

## Patterns of Behavior, Interests, and Activities

Careful documentation and observation of the child's behaviors, interests, and activities, including the presence of restricted and repetitive behaviors and interests, which are common in children with ASD, is an essential component of the diagnostic evaluation. Some of these behaviors may be seen in children with other disorders as well, such as children with mental retardation, Tourette's syndrome or other movement disorders, attention impairment, obsessive-compulsive disorder, social anxiety and phobia, bipolar disorder, schizophrenia, and certain psychotic disorders. Systematic evaluation can help clinicians diagnose ASD and distinguish ASD from these other disorders. Such evaluation requires

- assessment of the functional nature of routines, such as distinguishing a bedtime routine from the need to tap the wall before going through a door

- establishment of the developmental appropriateness of interest and activities, such as a preoccupation with and considerable knowledge of dinosaurs typical of young children versus an atypical preoccupation of a younger child with, for example, bus schedules, calendars, or the solar system

## **Family Resources and Needs**

For a child whose diagnosis is uncertain, assessment of the family can distinguish between environmental and biological factors known to contribute not only to ASD, but also to other childhood disorders. Further, a family assessment identifies the family's ability to foster their child's development, their service needs, and opportunities for parent training and support. This also enables parents and families to become effective partners in the child's development.



## Differential Diagnosis

In establishing an accurate and reliable diagnosis, autistic spectrum disorders (ASD) must be differentiated from each other and from other developmental, psychiatric, and behavioral disorders. In addition to differentiating among possible diagnoses, clinicians must consider the possibility of coexisting behavioral, cognitive, or psychiatric conditions.

The increased possibilities for alternative diagnoses demand considerable expertise, and consultation with specialists is often required.

### Ruling Out Alternative Diagnoses

The possibilities for alternative diagnoses increase among children age 6 and older. As children mature, language acquisition and cognitive experience grow and vary widely. As a result, ruling out alternative diagnoses is important. See the *Best Practice Guidelines* for a complete discussion of how to conduct a differential diagnosis.

Some children present with impaired reciprocal social interactions, which may seem “autistic-like” but neither meet criteria for ASD nor are adequately described by current diagnostic categories.

### Common Coexisting Disorders

Broadly speaking, coexisting symptoms fall into two categories: differentiated disorders that co-exist simultaneously with an autistic

spectrum disorder; and secondary disorders which are symptoms that result from an autistic spectrum disorder. “Higher-functioning” children and adolescents seem especially vulnerable to coexisting conditions of a secondary nature, particularly affective, or mood, disorders. For example, a child functioning well academically may experience social rejection from his or her peers and consequently suffer anxiety and stress.

## Elements of Diagnostic Formulation, Presentation, and Documentation

The considerations for diagnostic formulation, presentation, and documentation pertinent to children birth through age 5 pertain to children age 6 and older. There are also additional concerns for the older child or adolescent.

### Diagnostic Formulation

Formulation is invariably more complex with older children and adolescents. The clinical team often is faced with identifying an autistic spectrum disorder that was overlooked or misclassified, delineating concomitant disorders, or identifying an alternative diagnostic classification. When arriving at a diagnostic conclusion is particularly difficult, the task of the clinical team is not only to formulate a plan to gain further information, but also to integrate the data as well as possible to begin intervention.

### Presentation of Findings

Parents of children age 6 and older may be especially frustrated and confused by previous unsatisfactory or ambiguous clinical encounters. Parents and caregivers need clarity and concrete information regarding findings and recommendations for future assessments and/or intervention. The parents should understand that evaluation is an ongoing process and that their child's progress will be reassessed at appropriate times.





# BEST PRACTICE RECOMMENDATIONS

Chapter headings for Best Practice Recommendations refer to *Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment* (2002)

Age	BEST PRACTICE RECOMMENDATION
<b>Screening for Autistic Spectrum Disorders</b>	
<b>0 to 5</b>	All professionals responsible for the care of children perform routine developmental surveillance to identify children with atypical development.
<b>0 to 5</b>	All professionals involved in the care of young children are aware of developmental indicators of ASD.
<b>0 to 5</b>	Specific screening for ASD occurs for all children at 18 and/or 24 months of age.
<b>0 to 5</b>	Parents' concerns about their child's development and behaviors are elicited at every health care provider contact, including well- and ill-child visits.
<b>0 to 5</b>	A regional interagency training and information sharing process is in place to assure early identification of persons with ASD.
<b>0 to 5</b>	Healthcare professionals stay up-to-date on best practice guidelines and related research.
<b>0 to 5</b>	Specific screening between 18 and 24 months for ASD includes the Modified Checklist for Autism in Toddlers (M-CHAT) or the Pervasive Developmental Disorder Screening Test-II (PDDST II) or other approved instrument.
<b>0 to 5</b>	Primary care providers have access to an up-to-date resource directory that facilitates the referral process of children and adolescents to a clinical team that specializes in diagnosing ASD.
<b>0 to 5</b>	Within the constraints of confidentiality, efficient sharing of information among clinicians assures timely referral and more complete evaluation of children for concerns regarding ASD.

Age	BEST PRACTICE RECOMMENDATION
<b>Diagnostic Evaluation</b>	
<b>0 to 5</b>	The diagnosis of ASD should be made as soon as possible to facilitate intervention and initiate family counseling.
<b>0 to 5</b>	All clinical team members are familiar with and are able to recognize the child's developmental level and behaviors that correspond to the diagnostic criteria for ASD in young children.
<b>0 to 5</b>	Because symptoms change over time, a young child with an early diagnosis of ASD should be reexamined at least annually to confirm the diagnosis and plan treatment.
<b>0 to 5</b>	To enable intervention as soon as possible, the diagnostic evaluation is efficiently organized and coordinated.
<b>0 to 5</b>	The diagnostic evaluation includes examination of multiple domains of functioning to differentiate ASD from other conditions and provides a complete profile of the individual to allow for comprehensive intervention planning and service initiation.
<b>0 to 5</b>	Planning for diagnostic evaluation before meeting with the child and family includes identifying and reviewing all sources of relevant background information, selection of tests including alternative test procedures, and identifying opportunities for informal observation that can supplement formal assessment procedures.
<b>0 to 5</b>	An interdisciplinary team is the preferred method for conducting a comprehensive diagnostic evaluation. In the absence of the interdisciplinary team, a single clinician with specialist training and experience in evaluating ASD in young children can make a diagnosis.
<b>0 to 5</b>	The primary health care provider is involved with other professionals in the diagnosis and treatment of a child with ASD, and assists and coordinates specialty care and referrals.
<b>0 to 5</b>	Informed clinical judgment is maintained through periodic training that includes case review, peer review of individual cases, and discussion of published literature.
<b>0 to 5</b>	When clinically indicated, observations of a child in various settings and at different times increases the validity of information obtained and assists in diagnosis, case management, and intervention.



<b>Age</b>	<b>BEST PRACTICE RECOMMENDATION</b>
<b>0 to 5</b>	The evaluative process begins with a review of all sources of relevant background information. Attempts should be made to gather as much of this information as possible before the meeting with the child and family.
<b>0 to 5</b>	Diagnostic accuracy improves when the diagnostic team uses formal diagnostic tools, clinical experience, and clinical judgment in diagnosing children suspected of ASD.
<b>0 to 5</b>	A comprehensive medical assessment including health history, physical examination, and developmental/neurological examination is performed as part of the diagnostic evaluation.
<b>0 to 5</b>	All children as part of their developmental assessment are screened for vision and hearing with referral to specialists as appropriate.
<b>0 to 5</b>	Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of ASD.
<b>0 to 5</b>	Evaluation of cognitive functioning in both verbal and nonverbal domains is a necessary component of the complete diagnostic profile of the child. Developmental levels and/or informal measures are used when formal measures are inappropriate.
<b>0 to 5</b>	Domains of adaptive function are evaluated for all children, as they are pivotal in diagnosing ASD and/or coexisting mental retardation.
<b>Assessment for Intervention Planning</b>	
<b>0 to 5</b>	Ongoing assessment of a child's behavior and developmental profile is maintained in order to reformulate assessment conclusions and plan appropriate intervention.
<b>0 to 5</b>	The involvement of parents is essential in the assessment process as they are most knowledgeable regarding the child.
<b>0 to 5</b>	Cultural and family values are considered throughout the assessment process, as they will guide team recommendations and intervention planning.
<b>0 to 5</b>	The setting in which the child is evaluated, i.e., office, home or childcare facility, is carefully chosen to obtain representative information regarding development and behavior.
<b>0 to 5</b>	Although all domains must be explored for each child, the interdisciplinary team tailors in-depth assessments to the unique needs of each child and his or her family.

Age	BEST PRACTICE RECOMMENDATION
<b>Formulation, Presentation, and Documentation of Findings</b>	
<b>0 to 5</b>	The final diagnostic formulation derives from using clinical judgment to integrate clinical data with <i>DSM-IV/ICD-9</i> diagnostic criteria.
<b>0 to 5</b>	Presentation of the diagnosis to family members is accomplished by those clinicians or team members best able to communicate a comprehensive understanding of the child and support parents during the discussion.
<b>0 to 5</b>	Written reports document diagnostic conclusions keyed to specific <i>DSM-IV</i> criteria. Evaluation and assessment reports are comprehensible to parents and providers and contain practical recommendations for the next phase in the process.
<b>Issues and Concepts in Referral, Diagnostic Evaluation, and Assessment</b>	
<b>6+</b>	Referring parties are provided with detailed information regarding evaluation resources in order to streamline the referral process and minimize delays and stress for children, families, and providers alike.
<b>6+</b>	The interdisciplinary team is preferred for diagnostic evaluation and intervention planning for older children and adolescents, as they may require a broad range of assessment procedures.
<b>6+</b>	Differential diagnosis necessitates careful attention to clinical features consistent with both ASD as well as other disorders of childhood that have overlapping and coexisting symptoms.
<b>6+</b>	Accurate identification and description of coexisting psychiatric conditions and consequent symptoms establishes the basis for quality intervention planning.
<b>6+</b>	An accurate and detailed family medical/psychiatric history and review of psychosocial factors, which may play a role in clinical symptom expression, is essential in the diagnostic process for the older child and adolescent.
<b>6+</b>	The collation and integration of multiple sources of information strengthens the reliability of the diagnosis; conclusions are weighted with respect to all evidence.
<b>6+</b>	The developmental disability and mental health service systems collaborate and cooperate to be effective in addressing the unique service needs of children with ASD.

Age	BEST PRACTICE RECOMMENDATION
6+	An assessment for intervention planning in older children includes an evaluation of skills and competencies required for transitions, such as the transition from elementary to middle school or from home to residential living.
6+	Assessment protocols should be designed to assist in development of functional curricular goals and intervention strategies that take advantage of the child's demonstrated skills and learning style.
<b>Referral Process</b>	
6+	Referring parties clearly identify the reason for referral, select the most appropriate evaluation resource, and share relevant information in a timely manner.
<b>Components of a Diagnostic Evaluation/Assessment Process</b>	
6+	Accuracy of assessment of older children and adolescents with adequate language skills requires a face-to-face interview.
6+	When the evaluation and assessment requires differential diagnosis of psychiatric disorders, the clinician seeks further referral and/or consultation when indicated.
6+	Because of wide variability in the expression of language ability among children and adolescents, a thorough communication assessment is a necessary component of the diagnostic evaluation.
6+	Evaluation of academic achievement is included in intervention planning when learning, behavioral, or psychiatric disorders are suspected of playing a role in the older child's or adolescent's symptom presentation.

