Special Considerations for Diagnostic Evaluation

The lead diagnostic clinician is knowledgeable about the variability in presentation of ASD symptoms that can occur based on the individual's gender, age, or developmental level. When selecting diagnostic procedures and formulating conclusions, the individual's specific presentation is taken into consideration.

DIAGNOSING ASDs IN YOUNG GIRLS AND YOUNG WOMEN

Females with ASDs tend to be identified later than males (Shattuck et al.,2009) despite the fact that females with ASDs often exhibit a greater degree of cognitive impairment than males and that, in general, children with more severe impairment have been found to be identified as having ASDs at younger ages (Mandell, Novak, & Zubritsky, 2005). Increasing clinical and research evidence supports the idea that this delayed diagnosis of females with ASDs may be due to differences in their symptom presentation when compared to males with ASDs. For example, McLennan, Lord, and Schopler (1993) found that boys with ASDs may exhibit more social and communication impairments in early childhood, whereas girls' social difficulties may become more apparent in adolescence. Nichols, Moravcik, and Tetenbaum (2009) noted that females with ASDs also have been found to differ from males with ASDs in terms of lower IQ scores, fewer restrictive and repetitive behaviors, better imaginative play, better attention and concentration, and lower parent ratings of social skills that may reflect higher social expectations for girls.

Because of the higher prevalence of ASDs in males, diagnostic criteria and instruments tend to reflect the presentation of ASDs in males and may not account for possible variations in symptom presentation based on gender. Therefore, when a diagnostic evaluation is conducted to determine whether an ASD diagnosis is warranted for an individual who is female, the lead clinician considers the individual's presentation in comparison to other females of the same age and cognitive ability and uses clinical judgment in evaluating scores from diagnostic instruments that fall just below diagnostic cut-offs (Koenig & Tsatsanis, 2005).

DIAGNOSIS OF VERY YOUNG CHILDREN

Clinical judgment must supersede and inform data gained by instruments, observations, and interviews, particularly for children younger than 3. For example, it has been demonstrated that young children under 3 years of age who are diagnosed with ASDs often do not meet all formal diagnostic criteria at age 2 (Lord, 1995; Zwaigenbaum et al., 2009). Specifically, these children often do not display clear repetitive interests or stereotypic motor movements. At age 2, these children often demonstrate more impairment in social-communicative and joint attention behaviors. In essence, the clinician should be highly cognizant of the limitations of formal diagnostic criteria in young children and familiar with research regarding their developmental expression. The only interview format instrument with adequate psychometric properties for children under the age of 5 years is the *Autism Diagnostic Interview-Revised (ADI-R;* Lord, Rutter, & LeCouteur, 1994).

In very young children, behavioral observation should include the child's interactions with both the clinician and the parent/caregiver.

The lead clinician makes recommendations regarding the need for re-evaluation of preschool-aged children on a case-by-case basis. Although clinicians with expertise in ASDs have the capacity to make a definitive ASD diagnosis, presentation of ASD symptoms may fluctuate in preschool-aged children particularly if an initial diagnosis is made at age 2 years or younger or if initial symptoms are described as very severe or very mild. Subsequent to intervention, it is not uncommon for a child who was diagnosed with Autistic Disorder at 2 or 3 years of age to be described as PDD-NOS at age 4 or 5 years. At the same time, certain ASD symptoms such as circumscribed interests and lack of peer relationships may become more pronounced at age 4 or 5 years, so that a child described as PDD-NOS at age 3 years may receive a diagnosis of Autistic Disorder at age 4 or 5 years.

DIAGNOSTIC EVALUATION FOR INDIVIDUALS AGE 6 YEARS AND OLDER

Diagnosing older children or individuals may differ from evaluation of young children in a number of important ways:

- Differential diagnosis can be more challenging because of the increasing possibilities for alternative diagnoses and the long-term effects of environmental interactions on behavior. The clinician must be familiar with ASDs, as well as the range of psychiatric, neurodevelopmental, and behavioral disorders that are either primary or coexisting conditions. Although little is known about the developmental expression of major psychiatric disorders in very young children, the clinical picture becomes more differentiated as children mature.

- Asperger's Disorder will emerge more frequently as a potential diagnosis because the features of this disorder are generally more salient or more apparent in contrast to same-age peers as the child gets older.

- Establishing an early developmental history is more challenging as the age of the individual increases. As a result, records and multiple sources of data become more important.

- The clinician may have opportunities for direct interview of a child with adequate language skills in addition to observation and interviewing the parents or caregivers. Thus, the clinical team should have experience conducting assessments, forming relationships, and interviewing children in this age group.

- Collaboration with service providers, schools, and other healthcare entities will often be a necessary component of the diagnostic process.

Record Review – 6 Years and Older

When a child is older at the time of first presentation for diagnostic evaluation, there will likely be more information for review. Sources of information may include previous medical, school, and psychological records. Data from other evaluations or intervention reports (e.g., behavioral, speech) are also valuable sources of information. The child will also have had more contact with the community outside the family (e.g., school, neighborhood), which provides the opportunity for more collateral information.

To a larger degree than when working with younger children, the clinician must juxtapose descriptions of current behaviors with those previously reported to corroborate those behaviors or define new ones. This information aids in planning the evaluation and is helpful in differential diagnosis. In addition, a review of the records will direct the clinician's approach to evaluation as well as establish developmental trends and identify salient avenues of investigation during observations and interviews. The developmental course of ASDs varies considerably with respect to child and environmental factors.

Previous records can supplement and assist parent recall. For example, although a parent may not remember whether a child began talking at a developmentally appropriate age, medical and school records may indicate that speech and language services were provided. When there are other children in the family, developmental milestones may begin to "merge" as children get older. Current videotapes and those of early childhood can be helpful for review.

Previous records also allow clinicians to review issues of concern to the family as well as descriptions of behavior that may have led clinicians to earlier conclusions. The focus of record review is more to examine past descriptions of behavior rather than to reach diagnostic conclusions. Finally, the review of records and clarification of definitions in the parental narrative can lead to a more concise conceptualization of the current concerns.

Parent/Caregiver Interview – 6 Years and Older

Initially, the clinician should clarify the nature of the evaluation and its consistency with parental expectations. Many times, older children present for evaluation because of conflict with service providers as to the nature of the child's difficulties and the most appropriate course of intervention.

Interviews of parents of older children pose additional challenges to the clinician. The tremendous range of syndrome expression in general and the mild and atypical nature of symptoms of "higher functioning" individuals in particular are further complicated by the fact that the older the individual, the more difficult it may be for family members and other caregivers to recall specifics about developmental milestones and other aspects of early childhood. Similarly, parents of children with significant cognitive impairment are often not aware of or unclear about the extent of their child's disability and expectations for remediation. Earlier history may be described and interpreted in light of current challenges. It is not unusual for parents and caregivers to suspect their child has an ASD because of either a suggestion by the referring party or a recent diagnosis from someone less familiar with the disorders. In these instances, current information can influence recall. One method for increasing reliability of parent report is the presence of both parents and/or another significant caregiver, such as a teacher or close family friend. It is also helpful to frame questions within descriptions of current events. This may entail having the parent describe a familiar routine and/or activity.

Direct Observation and Interaction – 6 Years and Older

With verbal children and adolescents, information may be gathered through direct interview. The specific format can be either formal or informal and is dependent upon the specific referral questions. Before discussing the content of the interview, several factors should be assessed regarding the communication skills and style of the verbally fluent individual. These factors are particularly enlightening regarding differential diagnosis and exploration of pragmatic deficits. They include:

- the ability to manage conversational interchange—topic management, initiation, response ratios, shifting, maintenance, and extension;
- the ability to recognize and respond to clarification or requests or to request clarification;
- the ability to interpret non-literal language accurately such as humor, sarcasm, irony, etc.;
- the ability to recognize indirect and polite forms;
- the awareness of a need for shifts in register—i.e., teacher/student, peer/peer (this may be observed in other contexts);
- the capacity to modulate tone and volume and other prosodic features;
- the flexibility to deal with a range of situations and the ability to modulate responses; and
- nonverbal communication, which includes shifts in eye gaze, body positioning, etc.

These factors are often helpful in establishing differential diagnostic features of communication style, regardless of language content. For example, with minimal prompting, persons with Asperger's Disorder are eager to discuss their area of interest. They are also not usually prone to allow the interviewer to expand or add information or share his or her own interests. The taping of interviews is often helpful in that features can be reviewed in more detail later and/or with parents when appropriate. It is extremely important to retain the utmost respect for the child's (more typically the adolescent's) wishes for confidentiality of shared information and comfort with taping and observation.

Interviews with children of this age can take many forms and are dependent on the referral question, the child's ability level, and the interviewer's own experience. Clinical expertise in interviewing children is crucial. This includes an understanding of the response style of children at various ages and developmental levels, children with ASDs, and children with non-autistic disorders. Regardless of the referral question or diagnostic considerations, children presenting for an evaluation are not without some significant concern regarding behavior, development, and/or social emotional functioning. It is important to distinguish between the hesitations presented in an initial interview with an unfamiliar adult and the specific deficits found in ASDs. Reluctance to participate may be marked in children with significant anxiety and those whose oppositional or conduct disorders are prominent. Play interviews are entirely appropriate with children in the 6–10 age range and may be particularly revealing. Internal concerns of children are often more amendable to play assessment than to direct questioning.

Differential Diagnosis – 6 Years and Older

Considerable experience and knowledge in working with ASDs are critical clinical issues with older children and adolescents to differentiate ASDs from other diagnostic alternatives. It is important to examine possible factors that have prompted suspicions of an ASD and ask why this child has either (a) presented at this age or (b) not been identified earlier. The clinician must have knowledge of the qualitative and quantitative indicators of ASDs, as well as the developmental expression of behaviors in both typical and atypical development in childhood and adolescence. Because differentiation of psychiatric and co-occurring diagnoses is so vital in this age group, knowledge and/or consultation with specialists are of great benefit.

Diagnosing ASDs in Adolescents and Adults

Occasionally, individuals can remain undiagnosed until adolescence or adulthood, particularly when symptoms are relatively mild (such as with Asperger's Disorder) or when access to heath care is limited. Also, some persons may have reached adulthood prior to more widespread awareness of ASDs and remain undiagnosed despite fairly significant symptomatology and otherwise adequate healthcare access. Many of the same issues pertinent to individuals age 6 years or older also pertain to adolescents and adults. However, with increasing age, the record review and the critical elements of early development in the parent/caregiver interview become increasingly challenging. In some cases, this information may be unavailable. Furthermore, the diagnosis can significantly evolve with age in response to therapies and as a result of coping mechanisms to the point of differing significantly from the initial diagnosis (Seltzer et al., 2003). Early developmental history can be critical for establishing a diagnosis, but current behaviors are critical for treatment. Later onset disorders, such as schizophrenia, can share common features with ASDs, but will not be associated with the characteristic early developmental history of ASDs. Therefore, often input from a variety of specialists is critical in the accurate diagnosis of older persons with ASDs. Employment history, capacity for functional independence, and history of social interactions including any potential romantic relationships are additional issues that are important in the histories of older persons.

BENEFITS OF COLLABORATION BETWEEN LEAD CLINICIAN AND EDUCATORS

The diagnostic evaluation for ASDs considers data from multiple sources about the individual's functioning across multiple domains. Best practice recommends that lead clinicians attempt to obtain and allocate adequate time to review relevant records. For many individuals, school records provide valuable information such as a description of strengths and concerns in the school setting, assessment data, and response to attempted interventions. Interviewing a teacher or another educational service provider can offer additional detail regarding specific issues or clarification of information contained in school records. Evaluation of an individual's functioning across settings can be enhanced when parents and teachers complete the same standardized ratings scales, interviews, or other data collection procedures. Some degree of variation between parent and teacher reports is common and can facilitate consideration of variables that influence the individual's functioning.

Parental consent is required for the lead clinician to obtain school records or have educators complete rating scales or interviews. Therefore, at the outset of the evaluation process, the lead clinician discusses the benefits of shared information and encourages parents to provide consent to obtain relevant information and share results of the diagnostic evaluation with appropriate professionals, agencies, and organizations, including schools. In the course of discussing the benefits of sharing information across medical, educational, and other services providers, the lead clinician discusses the overlaps and distinctions between these systems with the family, as appropriate. For example, obtaining parental consent to request school records may provide an appropriate context for clarifying the differences between medical diagnosis and educational eligibility for special education services.

Key Considerations Related to Differential Diagnosis

Throughout the diagnostic evaluation process, the lead diagnostic clinician collects and integrates data to determine whether an ASD diagnosis is warranted. This requires both collection of sufficient data and clinical skill to differentiate ASDs from other disorders with similar or overlapping presentations, identify which specific ASD diagnosis is most appropriate, and identify difficulties that may coexist with ASDs.

COMMON DIFFERENTIAL DILEMMAS

Diagnosis of ASDs is based on presentation of specific behaviors and deficits in the domains of communication, reciprocal social interaction, and restricted interests and repetitive behaviors as specified by *DSM-IV-TR* diagnostic criteria. There are several non-autism spectrum disorders that may be associated with difficulties in one or more of these behavioral domains. Symptoms often associated with ASDs may not be specific to ASDs. For example, hand flapping or other repetitive movements may occur in the context of global developmental delay, a stereotypic movement disorder, or intense anxiety. The lead diagnostic clinician is able to differentiate between ASDs and other developmental or psychiatric disorders with overlapping symptoms including:

- disorders associated with multiple areas of difficulty,
- disorders associated with deficits in language and/or communication,
- disorders associated with social interaction problems,
- disorders associated with restricted interests or repetitive behaviors, and
- other disorders associated with ASDs.

Disorders Associated with Multiple Areas of Difficulty

- Mental Retardation
- Reactive Attachment Disorder
- Traumatic Brain Injury
- Schizophrenia
- Early Onset Psychosis
- Childhood Onset Dementia

The lead diagnostic clinician is able to differentiate ASDs from cognitive impairment and identify their co-occurrence. Cognitive impairment often co-occurs with ASDs. Therefore, it is important to describe the cognitive abilities of individuals diagnosed with ASDs and determine whether an additional diagnosis of Mental Retardation is warranted. However, individuals with significant cognitive impairment who do not have ASDs may exhibit ASD-like behaviors including social communication deficits and/or motor stereotypies, such as hand-flapping (Bradley, Summers, Wood, & Bryson, 2004; Wing, 1981). Because of this overlap in symptoms, it is difficult to differentiate ASDs from Mental Retardation in children with mental ages below 2 years (Lord, 1995; Rutter & Schopler, 1992). Differential diagnosis requires consideration of how an individual's behaviors relate to his or her overall developmental profile, as well as use of evaluation procedures that identify any behaviors strongly indicative of ASDs (e.g., using another person's hand as a tool). When diagnosis is complicated by possible cognitive impairment, use of standardized instruments to assess cognitive and adaptive functioning, as well as ASD symptoms, is indicated.

BEST PRACTICE

The lead clinician is able to differentiate ASDs from other developmental or psychiatric disorders with overlapping symptoms.

Diagnostic evaluation may require differentiation from Reactive Attachment Disorder or Traumatic Brain Injury. In rare cases, evaluation may require differentiation from conditions such as schizophrenia, early onset psychosis, or childhood onset dementia.

Disorders Associated With Deficits in Language and/or Communication

- Expressive Language Disorder
- Receptive Language Disorder
- Mixed Receptive-Expressive Language Disorder
- Selective Mutism

The lead diagnostic clinician is able to differentiate ASDs from other developmental and psychiatric disorders that also are associated with deficits in language and/or communication. Developmental Language Disorders such as Expressive Language Disorder, Receptive Language Disorder, or Mixed Receptive-Expressive Language Disorder are marked by deficits in the individual's ability to understand or use language or both. Such language deficits may result in social interaction problems because of the individual's frustration with understanding or expressing himself or herself to others. However, language disorders are not associated with idiosyncratic language usage, deficits in social reciprocity, or restricted interests and repetitive behaviors. In addition, individuals with language impairments typically can be distinguished from individuals with ASDs based on intact nonverbal communication. In Selective Mutism, the individual does not speak or communicate in certain settings, but exhibits intact communication in some environments and does not exhibit the marked social impairments and restricted and repetitive behaviors associated with ASDs.

Disorders Associated with Social Interaction Problems

- Attention Deficit Hyperactivity Disorder
- Social Phobia
- Depression
- Reactive Attachment Disorder
- Personality Disorders

Social interaction and peer relationship problems are a prominent feature of multiple developmental and psychiatric disorders. The lead diagnostic clinician is able to differentiate the impairments in social-emotional reciprocity and social communication that are core features of ASDs from the social difficulties associated with Attention Deficit Hyperactivity Disorder (ADHD), Social Phobia or another anxiety disorder, Depression, Reactive Attachment Disorder (RAD), and Personality Disorders.

Disorders Associated with Restricted Interests or Repetitive Behaviors

- Stereotypic Movement Disorder
- Tourette's Disorder
- Obsessive Compulsive Disorder

The lead diagnostic clinician is able to determine whether restricted interests or motor stereotypies occur in combination with the deficits in social reciprocity and communication required for an ASD diagnosis or present as a Stereotypic Movement Disorder or in the context of another disorder such as Tourette's or Obsessive Compulsive Disorder (OCD).

Other Disorders Associated with ASDs

The lead diagnostic clinician is aware of other conditions associated with ASDs (e.g., Nonverbal Learning Disorder, Semantic-Pragmatic Disorder) that are not included in the *DSM-IV-TR* and is able to explain the difference between these labels and medically accepted categories.

DIFFERENTIATING AMONG ASDs

At the most basic level, differential diagnosis requires a determination of whether the individual's presentation warrants an ASD diagnosis. If an ASD diagnosis is warranted, the lead diagnostic clinician then delineates which *DSM-IV-TR* diagnosis is most appropriate. This requires differentiation among Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). While differentiating among these diagnoses is complicated by the varying interpretations and ongoing revision of diagnostic criteria, determination of a specific *DSM-IV-TR* diagnosis often is essential for accessing services. The lead diagnostic clinician is able to explain the specific diagnosis given and the current debate surrounding distinctions among the three diagnoses within the category of Pervasive Developmental Disorders.

COMMON COEXISTING DIFFICULTIES

Other psychiatric disorders that require clinical attention can coexist with ASDs. This complicates the clinical picture and requires careful evaluation to identify additional challenges that should be a focus of intervention. These coexisting symptoms may be secondary to the experience of having ASDs such as an individual who develops symptoms of anxiety or depression secondary to social stress. In other cases, psychiatric symptoms may coexist with ASDs as a result of conditions that are interactive rather than sequelae of the disorder. For example, significant cognitive impairment may be a rate-limiting factor in terms of skill acquisition and rate of learning. Other times, coexisting anxiety, depression, obsessive compulsive disorders, and other difficulties reach clinical proportions and themselves become the focus of intervention.

Disorders that Commonly Coexist with ASDs

- Mental Retardation
- Attention Deficit Hyperactivity Disorder
- Affective Disorders
- Obsessive Compulsive Disorder
- Medical Problems
- Atypical Response to Environment

MENTAL RETARDATION

ASDs often are associated with some degree of cognitive impairment resulting in a diagnosis of Mental Retardation. Although estimates of the co-occurrence of Autism and Mental Retardation were once as high as 70% to 80% (Bryson & Smith, 1998), current estimates range from 30% to 60% (Chakrabarti & Fombonne, 2005; Shea & Mesibov, 2005). Higher rates of diagnosis of Mental Retardation typically are found among individuals diagnosed with Autistic Disorder, with lower rates among individuals diagnosed with another ASD.

In very young children, the primary challenge related to the overlap and co-occurrence of ASDs and Mental Retardation often is to differentiate among ASDs alone, Mental Retardation alone, and an ASD combined with Mental Retardation. For individuals diagnosed with ASDs who have mild global impairments, the possibility of a diagnosis of Mental Retardation may not emerge until the child enters or progresses through elementary school and differences from same-age peers become more pronounced. In cases where the possibility of Mental Retardation complicates diagnosis, use of standardized instruments to assess cognitive and adaptive functioning as well as ASD symptoms is indicated.

ATTENTION DEFICIT HYPERACTIVITY DISORDER

It is not uncommon for an individual diagnosed with an ASD to exhibit significant difficulties with symptoms associated with Attention Deficit Hyperactivity Disorder (ADHD) including poor attention regulation, hyperactivity, and impulse control (Gadow, DeVincent, & Pomeroy, 2006; Reiersen, Constantino, Grimmer, Martin, & Todd, 2008). ADHD symptoms or executive functioning deficits often are conceptualized as part of ASDs

although not all individuals with ASDs exhibit significant impairments in these areas. Current *DSM-IV-TR* diagnostic criteria disallow a diagnosis of ADHD in individuals with an ASD diagnosis; however, recognition that ADHD symptoms can create additional impairments or heighten existing impairments in individuals with ASDs has influenced many professionals to treat dual diagnosis of ASDs and ADHD as an acceptable clinical practice.

AFFECTIVE DISORDERS

Affective disorders including depression and anxiety are among the most common coexisting disorders found in individuals with ASDs. The etiology of risk in individuals with an ASD for coexisting affective disorders is unclear (Volkmar & Klin, 2000). Individuals at higher levels of cognitive functioning often are included academically with more socially adept, typical peers. In the absence of supports, these individuals are at increased risk for social rejection, which can cause substantial frustration, anxiety, and stress. Such difficulties will increase in later childhood, adolescence, and young adulthood when social competence is more critical to successful adaptation. In these instances, increased rates of affective disorders may be seen as secondary to significant social disability.

There may be a link between some affective disorders and ASDs. This has been most commonly reported in Asperger's Disorder and PDD-NOS. For example, Kim et al. (2000) identified higher rates of mood and anxiety problems among higher functioning children with autism and Asperger's Disorder. A significant proportion of these children presented with difficulties in the clinical range. Enhanced well being and functioning of the child or adolescent is incumbent upon the accurate identification and treatment of these coexisting challenges.

OBSESSIVE COMPULSIVE DISORDER

Although features of Obsessive Compulsive Disorder (OCD) may be mistaken for restricted interests and repetitive behaviors associated with ASDs, it is possible for an individual with an ASD to present with additional symptoms consistent with a diagnosis of OCD.

MEDICAL PROBLEMS

Medical issues associated with ASDs include consideration of both general health issues and the possible cause or etiology of the ASD itself. Associated health problems include pica with possible lead ingestion, poor nutritional status secondary to restricted food preferences, obesity, gastrointestinal complaints such as chronic constipation or diarrhea, sleep difficulties, and seizures. The possibility of an identifiable biological cause of the ASD also requires careful consideration and an individualized assessment for possible neurological, genetic, and metabolic etiologies. These topics are considered in greater detail in Chapter Four in the section on the Comprehensive Medical Examination.

ATYPICAL RESPONSE TO ENVIRONMENT

Individuals with ASDs often exhibit atypical responses to their environments such as unusual sensory preferences or aversions. Atypical responses to the environment often may be conceptualized as part of the diagnostic criteria related to restricted interests or repetitive behaviors. Atypical sensory responses are discussed in greater detail in Chapter Four in the section on Assessment of Motor and Sensory Functioning.

Formulating Conclusions and Presenting Information

The second half of the diagnostic process involves formulating conclusions and presenting information to the family and other service providers.

After reaching a diagnostic conclusion, the lead diagnostic clinician should discuss evaluation results with the individual's family. A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions.

BEST PRACTICE

A family-centered evaluation entails spending sufficient time with parents to provide detailed feedback and answer all questions.

In order to provide thorough feedback, the lead diagnostic clinician must be able to:

- clarify the distinction between diagnostic evaluation and assessment for intervention planning;
- explain the diagnostic conclusion and the procedures used to arrive at that conclusion;
- interpret treatment options and prognosis, and make referrals for further assessment for intervention planning within the parameters of empirical research findings;
- inform the family of the differences between the medical diagnosis and educational and community-based program eligibility processes;
- communicate findings across disciplines;
- address issues that affect parents directly; and
- provide diagnostic conclusions and recommendations related to available supports and resources, further assessment, and intervention as soon after the evaluation is completed as possible.

DISTINCTION BETWEEN MEDICAL DIAGNOSIS AND EDUCATIONAL ELIGIBILITY

Diagnostic evaluation is conducted to determine if an individual meets medical criteria for an ASD in order to inform treatment recommendations, whereas school-based evaluations are conducted to determine if a child requires special education services in order to make acceptable academic progress based on educational eligibility criteria.

KEY ELEMENTS OF PROVIDING FEEDBACK TO FAMILIES

The lead clinician discusses evaluation results with families in a manner that is honest and compassionate. During feedback, the lead clinician attends to the following key elements:

- providing specific information about the individual characteristics and behaviors that warrant a diagnosis along with examples of how these concerns interfere with the individual's functioning;
- emphasizing individual assets and areas of typical development;
- answering questions about prognosis based on available research, professional experience, and the individual's unique profile;
- highlighting the significant role of parent involvement and advocacy in determining prognosis; and
- collaborating with families to determine next steps including:
  - beginning to identify a team of professionals with whom they will work on an ongoing basis,
  - developing a plan for follow-up,
  - providing referrals for assessment for intervention planning or intervention services as needed,
  - providing recommendations of a few basic resources, and
  - offering suggestions for addressing any pressing concerns such as specific behavioral challenges.

DOCUMENTATION: FORMULATE A WRITTEN REPORT

A written report should be provided to the individual's family and the initial referral source. Written documentation serves as an essential means of communication between the clinician and the family and between the diagnosing clinician and other professionals who are involved with assessing the child for intervention planning and providing intervention services or future follow-up evaluation. In addition, written documentation often is essential for accessing services such as special education or state-funded programs.

COMPONENTS OF THE WRITTEN REPORT

Clinical Data

- A description of the diagnostic process, any diagnostic instruments used, diagnostic conclusions, and the data obtained via record review, parent interview, and direct behavioral observation and interaction that support making or ruling out the diagnosis
- Description of individual strengths or areas of typical development noted in the diagnostic evaluation process
- Specific descriptors related to the triad of impairments specified in diagnostic criteria for ASDs, as well as information about the child's developmental level, adaptive functioning, and presentation of any maladaptive behaviors
- Diagnostic conclusions that are supported with sufficient detail so that they can be readily understood by another professional
- Quantitative and qualitative evaluation data that would allow an experienced reviewer to readily verify the diagnosis or the reasons it was ruled out

Next Steps

- Appropriate referrals for services and additional assessment needed for intervention planning
- Basic resources on ASDs for family reference
- Follow-up plan

Community Collaboration

- Clear explanation that the evaluation provides a medical diagnosis and that eligibility for social or educational services may have different or additional criteria that require further evaluation
- Whenever possible, partnership of the lead diagnostic clinician with schools and other service providers to document information obtained during the diagnostic evaluation process that may be relevant to eligibility decisions
- Diagnostic conclusions formulated to facilitate translation into educational or other agency terminology
- Overall evaluation report that is comprehensible to parents and social, habilitative, or educational staff to facilitate enrollment in educational or service programs for eligible individuals

BEST PRACTICE

Evaluation reports are written in a manner that is accessible and understandable to parents and the other service providers who may be involved in providing therapeutic, educational, social, or habilitative services.

BEST PRACTICE

Parents are encouraged to share the written evaluation report with other professionals who are providing ASD-related services, as appropriate.

FORMAL DIAGNOSTIC CODES PROVIDE A COMMON LANGUAGE AND ACCESS TO SERVICES

The use of formal diagnostic codes provides a common language for other professionals who may become involved with the child or young adult and his or her family and assists in access to service delivery systems. Third-party payers typically require use of formal diagnostic codes for approval, documentation, and reimbursement of services. In addition to providing diagnostic criteria, as previously discussed, the *DSM-IV-TR* also is one of the primary classification systems used for assigning a specific diagnosis and an accompanying diagnostic code. In addition, many healthcare settings use diagnostic codes derived from another diagnostic manual, the *International Classification of Diseases, Ninth Revision (ICD-9)* published by the World Health Organization. Because of collaboration between the developers, the same codes are used for diagnoses contained in both the *DSM-IV-TR* and the current *ICD* codes used in the United States (*ICD-9-CM*). Diagnostic impressions should not be limited to provision of a diagnosis and its accompanying code but also may include further qualifying information or nonstandard diagnostic nomenclature.

These *Guidelines* acknowledge the controversy and dissatisfaction with the adequacy of *DSM-IV-TR* diagnostic categories and their ability to capture variability among individuals with ASDs. Work on the next edition of the *DSM* is currently underway and substantial revisions related to ASDs are expected. At present, some alternate classification systems are available, such as the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (*DC 0-3R)*, which describes additional diagnostic categories that are particularly relevant to children under 3 years of age (Zero to Three, 2005). However, the *DC 0-3R* diagnostic codes are not widely accepted, and many of the categories are descriptive in nature and limited to describing difficulties in specific developmental domains.