Autistic Spectrum Disorders

Best Practice Guidelines for Screening, Diagnosis and Assessment

California Department of Developmental Services, 2002

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Contents

Acknowledgements

The State of California Department of Developmental Services (DDS) gratefully acknowledges the contributions of nearly one hundred individuals who participated as consensus panel members, reviewers and consultants in developing these *Guidelines*. The broad base of expertise and wisdom offered by these individuals made this document possible. Contributors included highly experienced specialists in autistic spectrum disorders (ASD), parents of individuals with an ASD, DDS and regional center personnel.

The DDS is appreciative of the leadership, dedication and commitment of the Northern California Autism Collaborative (NCAC), the Director's Advisory Committee on ASD and the Association of Regional Center Agencies members. The DDS especially recognizes Howard G. Cohen, Renee C. Wachtel and Catherine Hayer of the NCAC and Department consultants, Ron Huff and Mary Lu Hickman for their vision and months of hard work devoted to this project.

The Department extends its appreciation to the following individuals for their assistance in expediting the development of these *Guidelines*: Gloria Wong, Executive Director, Eastern Los Angeles Regional Center; Raymond Peterson, Executive Director, San Diego Regional Center; Julie Jackson, Deputy Director, Department of Developmental Services; Rick Ingraham, Manager, Department of Developmental Services.

Finally, we are appreciative of the work of the Center for Health Improvement, to Karen Bodenhorn and her staff who coordinated development and production of the document and provided editorial oversight, and to Carolyn Walker who served as editor.

The DDS trusts that these *Guidelines* will serve to strengthen and broaden the screening, diagnostic evaluation and assessment of ASD throughout California, and in doing so, enhance the lives of the families and individuals who live with ASD and its effects every day. We are indebted to all of the individuals who contributed to this effort.

Cliff Allenby

Director
Department of Developmental Services, September 2002

Preface

Based on current research and professional consensus, the goal of these *Guidelines* is to provide a consistent and comprehensive base of information for screening, evaluation and assessment of persons with autistic spectrum disorders (ASD). The core concepts and best practices were developed through panel consensus, supported by evidence-based findings to assist families, service providers and public officials in making informed decisions regarding early identification and intervention for children with autism.

Since 1995, the California Department of Developmental Services (DDS) has documented a steady increase in the number of individuals diagnosed with ASD. Although autism has been recognized for more than fifty years, the recent increase in the number of children diagnosed with this condition has escalated concern among parents and professionals. In response to a growing need for guidance, technical assistance and information, DDS began to address these issues.

In 1997, the California Department of Education (CDE), in collaboration with DDS, the Association of Regional Center Agencies (ARCA) and other public service agencies, developed best practice recommendations for designing and delivering programs for individuals with ASD. In 1999, DDS documented, in a report to the California State Legislature, a 273 percent increase in individuals seeking services for ASD within the regional center system. Once thought to be rare, the occurrence of ASD is now estimated to be one in 250 to one in 500 children.

The continuing increase in the number of persons diagnosed with ASD, along with increasing requests from the professional community for technical assistance, prompted DDS to further escalate its actions. In July 2001, DDS launched an Autistic Spectrum Disorder Initiative with the following goals: to establish policy and best practice in assessment and intervention, and to establish public and private partnerships to address the needs of persons with ASD. Completion of these *Guidelines* represent one of the first steps of the initiative. To assist with the ASD Initiative, a Director's Advisory Committee on ASD was formed (See Appendix M for a full listing of Advisory Committee Members). This committee consists of professionals and parents with recognized commitment to best practices in ASD who advise DDS on program and policy issues pertaining to autism.

At the same time, related events were occurring within DDS and in the professional community at-large. In April 2001, work began on a DDS Wellness grant awarded to Valley Mountain Regional Center and Children's Hospital Oakland to promote clinical excellence

in diagnosis and intervention services for young children with ASD. The goals of the grant were to convene an interdisciplinary panel; draft guidelines for the screening, diagnosis and assessment of ASD in children from birth to 5 years of age; and begin training of regional health care providers. Similarly, the ARCA Eligibility Committee had been meeting to gain consensus on guidelines for diagnosing, assessing and establishing service eligibility for ASD.

The California State Legislature gave direction for developing evaluation guidelines in August 2001. Responding to the 1999 report from DDS and to concerns of parents and the professional community, the Legislature passed Assembly Bill 430, acknowledging the need for "the same diagnostic tools and Öthe same diagnostic methods...to ensure consistency and accuracy of diagnosis of autism disorder and other pervasive developmental disorders throughout California."

Finally, several national consensus panels have published evidenced-based guidelines for screening, diagnosis and assessment of ASD. These *Guidelines* build on the work of the aforementioned groups within California and the best practice foundation laid by other organizations. The *Guidelines* are intended to provide professionals, policymakers, parents and other stakeholders with recommendations based on published research, clinical experience and judgment available about "best practice" for screening, evaluating and assessing persons suspected of having ASD. The DDS expects that the *Guidelines* will increase education and awareness of ASD among the public and policy-makers and provide a basis for training to achieve the high quality clinical screening and diagnostic skills anticipated.

Section I

Introduction

INTRODUCTION

Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment provides recommendations, guidance and information about current "best practice" in the field. These *Guidelines* offer evidence-based recommendations and cannot be interpreted as policy or regulation, but as a tool designed to help health care providers and families make informed decisions regarding identification, diagnosis and assessment of autistic spectrum disorders (ASD). Additionally, these *Guidelines* provide a framework for the development and broad implementation of educational and training programs designed to reach professionals who in their day-to-day practice may encounter individuals suspected of having an ASD.

Consensus was reached among advisory panel members (see Appendices K, L and M for a list of the persons contributing to this document) to employ the term "autistic spectrum disorder" as the most familiar expression and the one most commonly used in the literature and by professionals in practice. Broadly described, ASD refers to a pattern of behaviors involving three central features—impairments in socialization, verbal and nonverbal communication and restricted and stereotyped actions—that can vary widely in terms of symptom expression, degree of impairment and developmental onset through the individual's life span. Use of the term, "autistic spectrum disorder" in these *Guidelines* are meant to be descriptive; the reader should not use the term autistic spectrum disorder as a formal diagnostic classification. (For additional discussion of the term ASD see Appendix A.)

The conditions on the autistic spectrum addressed in these *Guidelines* include: autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS) and Asperger's Disorder. Each disorder is defined in the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revised* (American Psychiatric Association, 1994; 2000). Both Rett's disorder, a genetic disorder with a specific developmental trajectory affecting young girls, and childhood disintegrative disorder (CDD), which is rare and poorly understood, were excluded. While both of these disorders share some features with ASD at earlier points in development, their clinical course deviates somewhat with development. Both Rett's and CDD are characterized by a poorer prognostic outcome and limited response to intervention designed for children with ASD.

Recommendations in these *Guidelines* cover individuals from birth through age 22 and are organized into two major sections: guidelines for children from birth through 5 years of age and guidelines for individuals age 6 through 22. Much of the information appropriate to children birth through 5 years of age is applicable to older children and adolescents. Rather than repeat the information, the chapters concerning individuals age 6 and older builds on practices appropriate to younger children and emphasizes information and practices that are appropriate for and unique to the older group. (For a summary listing of all of the Best Practice Recommendations see Appendix N.)

CORE CONCEPTS THAT GUIDE SCREENING, DIAGNOSIS AND ASSESSMENT

Major advancements in the sciences of early identification and treatment of ASD have increased public awareness and focused more attention on this class of neurodevelopmental disorders. The core concepts that follow provide guidance for all professionals in the state of California who are responsible for the screening, diagnostic evaluation and/or assessment for intervention planning for persons with ASD. These core concepts suggest a common language by which both professionals and parents can communicate with each other. Importantly, they also provide referring parties with information about what they can expect from well-informed diagnostic and treatment planning teams.

These *Guidelines* represent wide collaboration and consensus from expert panels across the state of California regarding screening, evaluation and interdisciplinary assessment for individuals who may meet diagnostic criteria for autistic spectrum disorder. Variables considered by the panels in developing these *Guidelines* included current scientific knowledge, level of expertise needed to execute a particular function, pragmatics of clinical practice and respect for the family ecology.

- **The *DSM-IV* is the current classification standard for establishing a diagnosis of ASD.**

  The *Diagnostic and Statistical Manual, 4th edition* (*DSM-IV*) and the *Diagnostic and Statistical Manual, 4th edition, Text Revision* (*DSM-IV, TR*) published by the American Psychiatric Association (1994 and 2000) are the current standards for the diagnosis and classification of ASD. In clinical practice, the *DSM-IV* is a tool to inform clinical judgment. Its use requires specialized training that provides a body of knowledge and clinical skills (American Psychiatric Association, 1994). Derivation of a differential diagnosis between the ASD and other alternative psychiatric or developmental disorders should employ the *DSM-IV* criteria for analysis and clarification of diagnostic impressions.

- **Early identification is essential for early therapeutic intervention and leads to a higher quality of life for the child and family.**

  Numerous studies on early intervention outcome have delineated the benefits of early identification and intervention for children with developmental disabilities and, particularly, for those with difficulties on the autistic spectrum (Dawson & Osterling, 1997; Harris & Delmolino, 2002; Smith, 1999; Committee on Educational Interventions for Children with Autism, 2001). Strong empirical support exists for the benefits of intensive behavioral programs for young children with autistic spectrum disorders, although the precise teaching strategies and curricula content are often a topic of debate (Dawson & Osterling, 1997; Gresham & MacMillan, 1998; Lovaas, 1987; Ozonoff & Cathcart, 1998; Rogers, 1998; Sheinkopf & Siegel, 1998). While the components of intervention programs are often a source of controversy, it is generally agreed that program intensity combined with early diagnosis and intervention can lead to substantial improvement in child functioning (Harris, 1994b; Sheinkopf & Siegel, 1998). A substantial benefit of early intervention is the positive impact on the family's ability to interact in a developmentally appropriate manner with their child and to have a greater understanding of the disability and how it interacts with family life (Committee on Children with Disabilities, 1994). Early identification and diagnosis enhances the opportunity for effective educational and behavioral intervention; reduction of family stress by giving the family specific techniques and direction; and access to medical and other supports (Cox, Klein & Charman, 1999). In the end, early intervention improves the quality of life for the individual and his/her family, and is cost efficient for the human service delivery system (Jacobson, Mulick & Green, 1998).

- **Informed clinical judgment is a required element of a screening, diagnostic and assessment process that leads to accurate identification of and intervention planning for ASD.**

  In the absence of a single biomedical marker, simple laboratory test or procedure for identifying children who meet the diagnostic criteria for one of the ASD, accurate identification of individuals with ASD is entirely dependent on clinical competencies. For the diagnosis of ASD, the knowledge base must include familiarity and experience with the research literature and with children with ASD. Clinical judgment, based upon knowledge and experience with this population, is critical to the interpretation of *DSM-IV* criteria for ASD. Access to professionals who possess the necessary levels of clinical competency, such as pediatricians and psychologists, can be found in private health systems, state-funded regional centers, and university medical centers.

- **The screening, diagnosis and assessment of ASD presents different challenges through the individual's life span.**

  While the core impairments in individuals with autistic disorder are commonly identified in early childhood, other spectrum disorders (PDD-NOS, Asperger's disorder) may be identified much later. Although identification of an ASD is usually made during childhood, it is important to recognize that ASD is a lifelong disability that compromises the individual's adaptive functioning from childhood through adulthood to variable extents, and requires different forms of intervention throughout the lifespan. Assessment should never be viewed as a discrete process, but rather as ongoing, flexible and responsive to changes in the individual's profile caused by intervention effects, maturation, family dynamics and other factors.

- **Practitioners must be aware of and understand confidentiality issues and honor the need for shared information.**

  These *Guidelines* encourage the use of interdisciplinary teams and interagency collaboration in the screening/early identification, diagnostic evaluation and assessment of individuals suspected of having an ASD. These *Guidelines* also recognize that "open" oral and written exchange of information among clinicians and agencies places a grave ethical and legal responsibility on those professionals to share only personal information that is clinically pertinent to the purposes of the intervention. A fully informed written consent at each step in the process is not only an ethical responsibility but a legal one as well. The scope of information shared should be decided on a "need to know" basis. For example, the education system might need specific information from the diagnostic and assessment team about a child's learning strengths and challenges. However, family history regarding psychiatric or other health illness that may be important to the diagnostic process should be held in confidence and not automatically shared with the educational planning team without specific consent. Such discretion can be difficult to manage when parents, for example, are asked to sign multiple releases of confidential information with many providers.

- **Accurate diagnostic evaluation and assessment requires collaboration and problem solving among professionals, service agencies and families.**

  These *Guidelines* promote interdisciplinary, interagency collaboration and partnership between the referred individual, their family and the service delivery system. It is critical that service providers promote collaboration across disciplines, agencies and programs to resolve conflicts of legal mandates. Collaborative efforts should be made to avoid duplication of effort and maximize efficient use of time in pursuit of the desired outcomes for the individual and his/her family. Respect for divergent perspectives is necesssary to delineate

a comprehensive diagnostic profile of children, adolescents and adults with autistic spectrum disorders. Rather than viewing each component of the process as separate, these *Guidelines* stress establishing linkages among, for example, the primary care provider (PCP), the diagnostic and assessment team and educational planning teams. The diagnostic team, in turn, needs to keep the PCP informed by providing feedback and assisting the PCP in working with the family to ensure appropriate referrals for intervention services, transition planning and family support.

- **An interdisciplinary process is the recommended means for developing a coherent and inclusive profile of the individual with ASD.**

  Autistic spectrum disorders affect multiple developmental domains. Therefore, utilizing an interdisciplinary team constitutes best practice for a diagnosis of ASD and is an essential component of the assessment process. An interdisciplinary team is essential for establishing a developmental and psychosocial profile of the child and family to guide intervention planning. Such an approach promotes seamless communication among team members and leads to a more integrated, cohesive translation of findings. The interdisciplinary team creates a view of the individual that is detailed, concrete, easily understood and offers realistic recommendations (Klin, Sparrow, Marans, et al., 2000). A quality interdisciplinary process involves shared leadership, respect, integration and coordination among professionals. Team members recognize that their individual contributions inform construction of the overall picture of the child and that their individual interpretations enable formulation of conclusions and recommendations based upon the combined efforts of the team.

- **From screening through intervention planning, the evaluation process must be family-centered and culturally sensitive.**

  A family-centered frame of reference reinforces the concept of parents and caregivers as the most knowledgeable source of information about the child, acknowledges that the child is part of a larger family system and sets the stage for ongoing collaboration and communication between professionals and family members. The needs, priorities and resources of the family should be the primary focus and be respectfully considered during each step of screening, diagnostic evaluation and assessment for intervention planning.

  A family-centered frame of reference includes cultural sensitivity and regard for family and community diversity of cultural values, language, religion, education, socio-economic and social-emotional factors that influence coping and conceptualization of the individual with ASD. Maintenance of family involvement should remain at the forefront of interactions in keeping with the concept of family as an equal partner in the diagnostic, assessment and intervention processes.

- **Timely referral and coordination of evaluation and ongoing assessment enhances outcome.**

  The diagnostic and assessment process should proceed in a timely manner to expedite the provision of services to the individual and family. Referring professionals should be familiar with options within the individual's geographic area and serve as the communication bridge with service providers to minimize service delays and duplicative efforts. While a child may receive a diagnosis at a young age, a comprehensive profile of skills and deficits is often not obtained for months (and sometimes years) after diagnosis. This incomplete or absent documentation of skills is problematic for the child, family and community service providers. Parental stress is heightened as parents worry about their child while also spending time and energy trying to arrange for needed intervention services. Timely referral, integration, and coordination of clinical teams and service providers lessens family stress and leads to more streamlined and efficient service delivery.

- **Rapid developments in the field require regular review of current best practice procedures and up-to-date training.**

  Rapid developments in conceptualization, measurement and basic research on ASD require a commitment to periodic review of current best practices. The heterogeneity of behavioral expression in ASD across age and developmental status, combined with rapid increases in clinical research and knowledge about the core features of the disorder, necessitate ongoing education and training opportunities for participating clinicians. Major shifts have occurred in scientific thinking about ASD. The knowledge base in ASD is changing so rapidly that parents and professionals face a daily challenge of keeping abreast of new developments. The challenge is to stay current with new methods of evaluation and treatment, learn about and obtain the latest screening tools, and maintain an awareness of local and regional community resources.

PROFESSIONAL QUALIFICATIONS FOR SCREENING, DIAGNOSING AND ASSESSING ASD

It is essential that clinicians with sufficient training and experience with this population make diagnoses of ASD. Disorders along the autistic spectrum are characterized by an extremely heterogeneous syndrome of behaviors that can diverge widely in terms of symptom expression and degree of impairment. Furthermore, the knowledge base regarding the core features of an ASD and its presenting characteristics continues to develop and expand rapidly. (Lord, 2000; Mundy & Stella, 2000; Waterhouse, Wing & Fein, 1989). Given the impact of a diagnosis in terms of appropriate service eligibility and intervention, clinician expertise is paramount.

Licensing, Education and Training Requirements

Currently, state licensure in a medical or mental health field is required to render a diagnosis of autism. Ethical standards put forth in graduate and residency training programs strongly suggest that professionals should not render diagnostic conclusions regarding disorders in clinical populations with whom they have had limited or no experience. This ethical standard recognizes that developmental and psychiatric disabilities are vast fields within which no single clinician can be completely versed in all disorders and impairments.

The minimal professional requirements needed to make a diagnosis of ASD include the following:

1. Qualification to render a diagnosis of ASD under the provision of California state licensure.

2. Documented appropriate and specific supervision and training in ASD as well as experience in the diagnosis of ASD. This would include the following:

   - Graduate and/or postgraduate studies in a psychology, education and/or child development program with particular emphasis in developmental disabilities, including autism and related neurodevelopmental disorders

   AND

   - Supervised experience in a graduate training program (e. g. predoctoral, postdoctoral) in a clinic and/or treatment setting serving children with ASD. Specific residency or fellowship training should have specific didactic training and clinical experience in the diagnosis and treatment of ASD. This would necessarily include training in the diagnosis of ASD as well as the administration of measurement tools specific to ASD

OR

- Documented fellowship in a credentialed medical training program in pediatrics, child neurology or child psychiatry. This would extend beyond the typical four-week rotation through developmental/pediatrics in general pediatric training, which encompasses a broad range of developmental difficulties in addition to autism. Specific residency or fellowship training should have specific didactic training and clinical experience in the diagnosis and treatment of ASD.

3. Clinical experience with the variability within the ASD population as well as extensive knowledge of typical child development.

TERMINOLOGY

"Screening," "Diagnosis" and "Assessment"

Throughout the *Guidelines*, "screening" refers to the prospective identification of children birth through age 5 most likely to have an ASD and/or developmental delay. "Referral," as it applies to children ages 6 through 22, refers to the process of initiating the evaluation of a child in this age group. 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. Although these *Guidelines* discuss these functions and recommended procedures separately, the authors recognize that in practice, these activities and procedures may take place concurrently, within a single session or across multiple sessions.

"Interdisciplinary" and "Multidisciplinary"

Both interdisciplinary and multidisciplinary processes stress the importance of gathering information from a variety of disciplines that have unique knowledge of a particular aspect of the child and family. Professionals most often involved with persons with ASD include psychologists, psychiatrists, neurologists, pediatricians, other physicians, speech pathologists, audiologists, occupational therapists, social workers and behavioral and educational specialists. Input from all involved professionals may be necessary to obtain a complete picture of the child and family for effective service planning. A quality interdisciplinary assessment requires respect, integration and coordination among professionals with diverse backgrounds. The interdisciplinary team model is the preferred model in the evaluation and assessment of ASD. The interdisciplinary process involves professionals from various disciplines providing their unique contributions regarding aspects of the child's development and family functioning. The defining

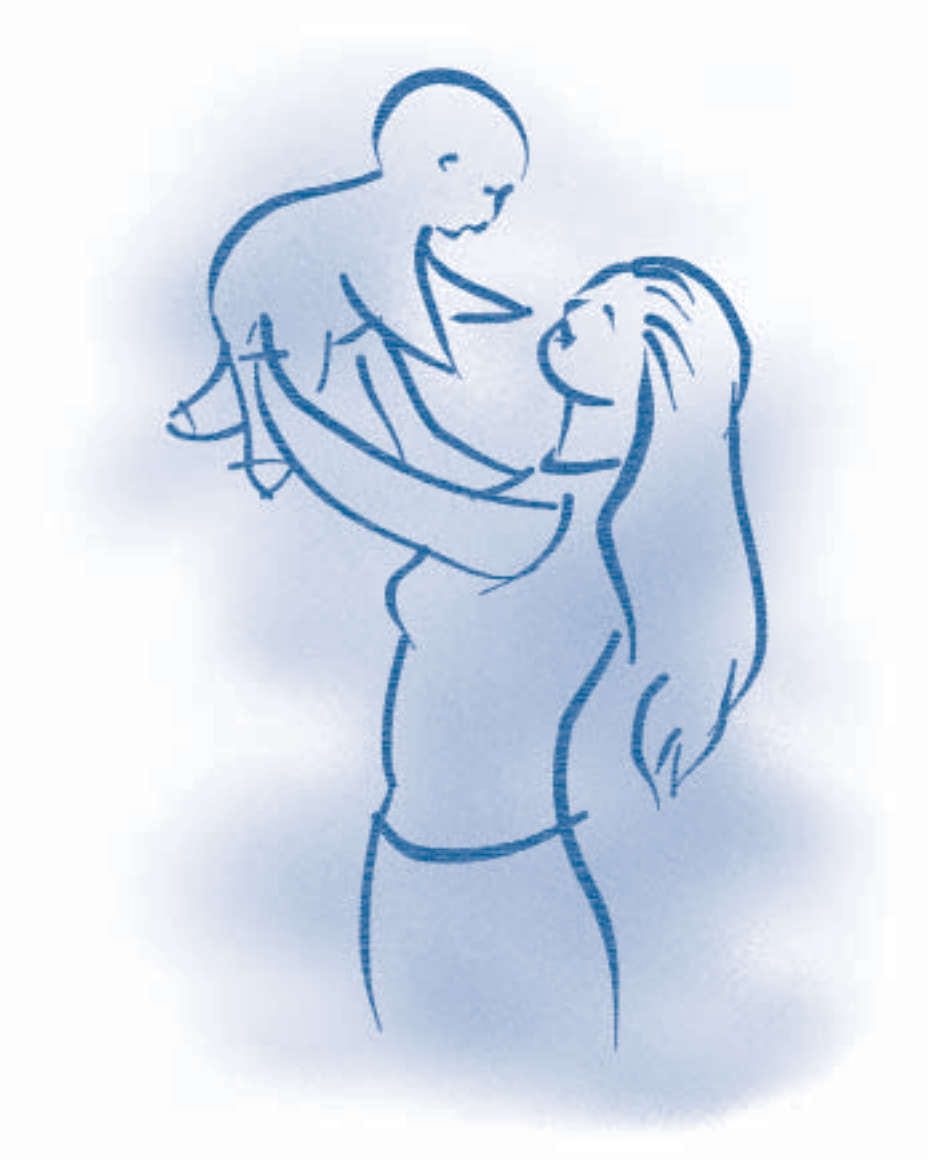
feature of this approach is the ability to integrate and synthesize information through an interactive group process (Rokusek, 1995). Members are aware that their interpretation informs the whole and are able to formulate conclusions and recommendations based upon the combined efforts of all.

Furthermore, the interdisciplinary approach eliminates some of the difficulties encountered in more traditional multidisciplinary approaches, such as redundancy, time required to complete the evaluation and conflicting recommendations. Interdisciplinary team members are located within the same entity and, as a team, assess the child and family. Time and effort required to collect redundant information is reduced, and individual members are able to adjust their procedures based upon information readily available from other members. Often, professionals can merge several assessment procedures into one experience for the child and family. Finally, a well-coordinated interdisciplinary process incorporates child, family and community resource factors into a complete profile, which leads to increased benefits and savings over time.

In contrast to an interdisciplinary process, a multidisciplinary process typically progresses as a series of separate evaluations, each conducted by different professionals with little ongoing contact or coordination. Professionals often are affiliated with different entities (i.e., a university or hospital) and are rarely in close proximity. A multidisciplinary process can take one to two days, with the child and family participating in numerous sessions, or it can take place over the course of several months. The latter is common, allowing for differences in waiting lists, financial considerations, time and distance. Professionals in a multidisciplinary process often operate without benefit of collaboration with other team members and often draw separate conclusions based upon their particular experience. This is a highly stressful process for children and families. Information gathered using the multidisciplinary model is often redundant, and the results from other multidisciplinary team member evaluations may not be available at the time they are needed by another team member. At times, professionals may repeat portions of previous assessments, regardless of the information available, due to lack of a relationship with the other professional and/or concerns regarding knowledge or conclusions drawn.

Section II

Birth Through Age Five



Chapter 1
Screening for Autistic Spectrum Disorders

Initial detection of autistic spectrum disorders (ASD) is a two-step process: developmental surveillance and screening that begins in infancy with the child's primary care provider (PCP).

Best Practice:
All professionals responsible for the care of children perform routine developmental surveillance to identify children with atypical development.

Developmental Surveillance

Developmental surveillance is the routine monitoring and tracking of specific developmental milestones at well-child visits. This includes the gathering of information through reliable standardized instruments combined with parent and professional observations and judgment and tracking developmental progress as compared with children of similar age. Concerns raised by developmental surveillance should lead to screening or referral for diagnostic evaluation.

Screening

Screening refers to the identification of risk factors for a disorder using specific tests. Screening the population of children from birth through age 5 for ASD seeks to identify those children in the population most at risk of developing an ASD and/or developmental delay. The application of specific screening instruments for a particular disorder may occur at a specific age for the general population or when concerns and/or results of routine developmental surveillance indicate that a child is at risk for developmental difficulties. Screening instruments are not intended to provide diagnoses, but rather to suggest a need for further diagnostic evaluation and intervention planning assessment. For an evidenced-based analysis of screening instruments see the American Academy of Neurology and Child Neurology and Child Neurology Society Multidisciplinary panel review (Filipek, et al, 2000) and the Screening Tools Comparison Report prepared by First Signs, Inc. (First Signs, 2000).

Rationale for Screening for ASD

Three concepts guide the process for early identification and screening of young children for ASD.

ASD Can be Identified in Very Young Children.

It has been clearly demonstrated that ASD are identifiable and relatively stable in very young children. A proactive policy of appropriate screening would lead to referrals to specialists capable of clarifying the child's difficulties and beginning early intervention.

Historically, it has been difficult to reliably detect ASD before the age of 3. In part, this is due to lack of awareness of health care providers about the presentation of ASD in young children (including their relatively more limited skill development, particularly in language and social behaviors). Formal diagnostic criteria are based upon deviations in language, cognitive, social and behavioral skills that may not be apparent in very young children, who are below the age at which these skills would be expected in typical development. For example, it would be difficult to judge developmental deviation in peer relationships in children of 18 months, an age at which these skills would not be expected to have developed.

Advances have been made in identifying behavioral indicators as well as atypical development in children less than 2 years of age who are later diagnosed with ASD. Furthermore, it has been demonstrated that autism can be reliably diagnosed by an experienced clinician in children between the ages of 24 and 30 months (Gillberg et al., 1990; Lord, 1995; Stone & Hogan, 1993; Stone, Hoffman, Lewis & Ousley, 1994). Since ASD-specific early intervention services are dependent upon early detection and formal diagnosis, it is imperative that young children be screened for ASD, identified as being at risk and referred for comprehensive evaluation and assessment in an efficient and timely manner.

Recently, researchers have begun to focus on the developmental precursors of communication, language and social development in the first two years of life. Children with disorders on the autistic spectrum consistently seem to demonstrate deficits in social-cognitive and social-communicative behaviors early in life (Baron-Cohen, 1987; Wing & Gould, 1979). These include failures of joint attention, nonverbal and preverbal communication, social reciprocity, affective understanding and imitation.

Wimpory, Hobson, Williams and Nash (2000) elicited parental reports of behaviors of their young children with autism during the first two years of life. This research was noteworthy in that it is one of the few to incorporate into its methodology a comparison group of typically developing children. In addition, the research featured data collection from parents while children were less than four years of age, thus eliminating the effects of prolonged recall. Parents of children with autism noted several features that were markedly deficient in their children during the first two years of life. These included: poor eye contact and poor coordination of eye gaze with vocalization or gesture, no pointing to or showing of objects and an inability to follow another's focus of attention through eye gaze or gesture. Children with autism also displayed less preverbal babbling and no reciprocity in vocalizing or imitation.

These findings are similar to those found through home videotape studies. Osterling and Dawson (1994) reviewed first birthday videotapes of children later diagnosed with autism. Developmental pediatricians, blind to the diagnosis, were able to classify correctly 82 percent of children based on four variables. Babies later

diagnosed with autism displayed fewer joint attention and social behaviors such as pointing, orienting to name, showing of objects and looking at the face of another.

Lord (1995) investigated the stability of the diagnosis of autism in 2-year-olds at age 3. Again, distinct social and communicative behaviors distinguished children with autism at age 2 from those referred for possible autism that did not meet diagnostic criteria. Children with autism at age 2 displayed deficits in joint attention, social referencing and interest in other children. They also attended less to voice and had difficulty understanding and using nonverbal gestures.

Best Practice:
All professionals involved in the care of young children are aware of developmental indicators of ASD.

The detection of young children with developmental and behavioral problems can be difficult due to the variety of disorders and their manifestations at different ages. This is particularly apparent in young children with ASD whose communicative and social difficulties are often poorly understood and are therefore frequently attributed to normal variations in typical development. Many studies have demonstrated, however, that early detection and early therapeutic intervention are associated with the best developmental, behavioral and adaptive outcomes.

Screening for ASD Should be Conducted in Conjunction with Routine Developmental Surveillance.

Best practice procedures recommend that all children be screened specifically for ASD at ages 18 and 24 months. Screening at these two periods is recommended because most children who are later diagnosed with an ASD display symptomatology (excesses/ atypical behaviors) and/or lack achievement of core developmental milestones (absence of functional communication and/or symbolic play skills) by the second year of life. Current research literature suggests that a significant number of features of ASD are present by 18 months of age (Cox et al., 1999; Lord, 1995; Lord et al., 1997; Osterling & Dawson, 1994; Stone et al., 1999), specifically, verbal and nonverbal communication deficits. In addition, since some children with ASD evidence regression in skills between 15 and 24 months (and rarely after two years), screening at age 2 years facilitates identifying these children as well. *This is not to suggest that concerns noted earlier by parents or other professionals should be dismissed until this time.* Age of onset can vary and is often related to severity of impairment. Optimally, developmental screening specific to ASD would occur at any point at which routine surveillance and/or child observations indicate it is warranted.

Best Practice:
Specific screening for ASD occurs for all children at 18 and/or 24 months of age.

Because Parents are the Experts Regarding Their Children, Eliciting and Valuing Parental Concerns is Imperative.

Most parents of children with autism expressed concerns regarding their child's development before 18 months of age. Until recently, a considerable gap existed between the time parents first reported concerns and subsequent referral and definitive diagnosis. Siegel, Pliner, Eschler and Elliott (1988) reported an average two-year delay between first concerns addressed to the pediatrician and definitive

diagnosis for the child. Recently, Howlin and Moore (1998) reported eighteen-month to two-year delays from recognition to diagnosis in the United Kingdom. A lengthy and cumbersome referral and diagnostic process contributes to considerable parental anxiety, places unneeded stress on parents and families and squanders valuable intervention time. In the absence of information and with disregard for their concerns, parents will seek information from other, often questionable sources of information (e.g., the Internet). This can lead to earlier diagnosis and intervention for some children, but is equally likely to lead to misdiagnosis and inappropriate treatment for others. Research has supported the notion of parental accuracy with regard to developmental concerns in their child (Glascoe, 1989; Glascoe, 1999). With the documented efficacy of early intervention in achieving optimal outcomes for young children and their families, it is imperative that *all* concerns be taken seriously and addressed appropriately.

All professional encounters with young children should be viewed as an opportunity to elicit developmental information. This would include visits with PCPs, daycare providers, school officials and teachers, to name a few. Inquiries of parents regarding developmental concerns should be responded to at every well-child visit. Daycare providers and school staff should make it a practice to ask parents and caregivers periodically about issues regarding their child's development.

Best Practice:
Parents' concerns about their child's development and behaviors are elicited at every health care provider contact, including well- and ill-child visits.

Glascoe (1999) suggests a rather simple approach for screening that involves eliciting developmental concerns from parents—for example, asking "Do you have any concerns about your child?" The question can be further clarified into more observable domains—language, behavior, etc. Glascoe describes the advantages of this approach as follows:

1. Concerns are easy to elicit.
2. Inquiry is brief.
3. The procedure does not involve the challenge of eliciting skills from young children who may be less than cooperative.
4. It provides a family-centered approach to addressing problems.
5. Unlike more singularly focused screening instruments, it can facilitate a wider range of options for the PCP, including parenting education, reassurance and referral for more formal diagnostic testing or further screening or developmental testing.

Elicitation of parental concerns could occur at any appropriate family encounter—well-child visits, sick-child visits, or other therapy appointments. Expression of any concern by the parent is grounds for follow-up procedures. The advantage to this approach is simplicity in that no materials are required. Furthermore, eliciting concerns initiates a dialogue with the parent who may not otherwise feel comfortable or be able to discuss concerns.

If warranted, follow-up could be pursued at that time or at a subsequent appointment with further parent discussion, more standardized paper and pencil tools and/or direct child observation. The choice of follow-up methodology is at the discretion of the professional.

While the importance of follow-up to parental concerns should not be understated, screening should not be done *only* in response to a parental concern. While many parents do voice concerns regarding their children to health care professionals, this is not always the case. Some parents may not be able to articulate their observations. This is especially true with ASD where early social signs are subtle. Other parents may simply not notice developmental problems or may not view them as cause for concern due to other environmental and cultural factors.

The Key Role of the PCP in Early Identification and Screening

The importance of the PCP in developmental surveillance and screening cannot be overemphasized. The successful identification of ASD in young children and the effectiveness of intervention programs are dependent upon the ability of PCPs to monitor children's development and initiate referrals in a timely manner.

Developmental Surveillance within the Primary Care Practice

Some noteworthy clinical signs, or "red flags," exist that can help identify children at risk for developmental delay and/or ASD within a routine office or other health facility visit. These indicators typically are tracked through routine developmental surveillance procedures, which should occur at all well-child visits. The most powerful indicator is degree of language development. Any child not using single words by 16 months of age or some two-word phrases by 2 years of age should be further evaluated. Children who do not use gesture (i.e., pointing, waving, etc.) or who cannot follow nonverbal communication by 12 months should also be referred. Finally, any loss of skills at any age is a serious red flag and warrants immediate referral to an appropriate diagnostic team (Filipek et al., 1999; Filipek et al., 2000). (Appendix B includes a list of red flag indicators.)

Screening for ASD within the Primary Care Practice

Primary care providers are generally the first point of contact for parents with concerns and questions regarding their child's development. Parents expect their pediatricians and family physicians to offer guidance regarding developmental issues; if no help is forthcoming, these parents may turn to other sources. Well-child visits are the logical time and place for developmental surveillance and screening for specific disorders to occur. Although the American Academy of Pediatrics Practice Guidelines (2001) and the federal and state Early and Periodic Screening, Diagnosis and Treatment (EPSDT) schedules require routine developmental surveillance at each well-child visit, numerous studies have shown that this

does not occur in most health care practices (Belcher, 1996). In practice, time constraints often hinder routine developmental surveillance, and parents often do not voice developmental concerns unless specifically elicited by the PCP (Glascoe, 1991b). In addition, some children are seen only in the emergency room or urgent care clinic for health care, particularly after the age of 2 when the immunization schedule is diminished. When screening does occur, measures used are at times insensitive to communication and social milestones in young children and may miss children with less obvious developmental delays (Greer, Bauchner & Zuckerman, 1989).

Studies have shown that even when parents bring up developmental concerns, some PCPs respond by waiting to see if the delays will resolve spontaneously or by discounting parental observations. They may be unaware of the high degree of accuracy often associated with parental concerns regarding their child's development (Glascoe, 1991b). While a small number of children do "catch up" without formal intervention and achieve developmental milestones somewhat later than same-age peers, this is the exception. A significant number of youngsters require early intervention either on a transient or ongoing basis to function within their family and community environment. Furthermore, those children who turn out to be "false-positives" (parental concerns are expressed, but the child has no clinically significant delays) tend to score somewhat lower on developmental domains than those children who are true "negatives" (parents have no concerns, and the child demonstrates typical development) (Glascoe, 2001).

Research efforts have demonstrated that screening is manageable within current primary care practice parameters in terms of time and cost (Sasso, 2001). Most screening instruments appropriate for ASD are brief and can be completed in the waiting room. For example, the Modified Checklist for Autism in Toddlers (M-CHAT) and the Pervasive Developmental Disorders Screening Test (PDDST-II) are available free of charge (the M-CHAT appears in Appendices C and D for English and Spanish versions, respectively, and the PDDST-II appears in Appendix E).

Best Practice:
A regional interagency training and information sharing process is in place to assure early identification of persons with ASD.

The Role of California's Regional Centers and Public Schools in the Early Identification of Children with ASD

California Early Start is a program for infants and toddlers from birth to age 36 months. Children may receive services if they meet at least one of the following criteria:

- A developmental delay in either cognitive, communication, social or emotional, adaptive or physical and motor development, including vision and hearing; **OR**
- Established risk conditions of known etiology, with a high probability of resulting in delayed development; **OR**

- At risk of having a substantial developmental disability due to a combination of risk factors (California Government Code, Section 95014).

Early Start services (including evaluation, assessment, early intervention and service coordination) are provided to eligible infants and toddlers and their families at no cost to the family. Early Start is funded by federal funds (IDEA, Part C) and California state general funds.

Services are based upon an evaluation of the child's developmental needs as determined through the Individualized Family Service Plan (IFSP) and may include:

1. Assistive technology
2. Audiology
3. Family training, counseling and home visits
4. Health services
5. Medical services for diagnostic/evaluation services only
6. Nursing services
7. Nutrition services
8. Occupational therapy
9. Physical therapy
10. Psychological services
11. Respite
12. Service coordination (case management)
13. Social work services
14. Special instruction
15. Speech and language services
16. Transportation and related costs
17. Vision services

The Early Start program mandates that regional centers and the public schools' local education agencies work together to conduct "child-find" activities to locate all infants and toddlers who may be eligible for early intervention services. Such child-find activities may include establishing liaisons at local hospitals, distributing materials to agencies and local physicians, giving presentations to local groups and other similar activities. The regional centers and Local Education Agencies (LEAs)

are charged with informing the primary referral source of the eligibility criteria for Early Start and the types of services that are available.

Regional centers offer screening services to the public or to select populations to find children who qualify. Intake and service coordinators in the Early Start programs at many of the regional centers are trained to utilize screening instruments designed for detecting symptoms of an ASD. They use these tools during interactions with Early Start families to identify children who are showing "red flags" of a possible ASD. The children can then be referred for further diagnostic work-up to confirm or rule out the presence of an ASD. Services are provided through a local regional center and/or education agency. Local education agencies are primarily responsible for infants and toddlers with solely low-incidence disabilities (vision, hearing and severe orthopedic impairments, including any combination of these low-incidence disabilities). Family resource centers/networks provide parent-to-parent support, information and referral for all families.

The Role of Other Professionals in the Early Identification of Children with ASD

Professionals other than PCPs are frequently the first individuals to identify young children with developmental difficulties, which may be due to ASD. In particular, speech pathologists and occupational therapists often work with youngsters identified as having language, sensory and motor challenges. Often, these difficulties are related to an unidentified ASD. It is important that training programs for these professionals include information and workshops regarding ASD.

Other health professionals (e.g., licensed marriage and family therapists and licensed clinical social workers) may also encounter a child with an ASD. These professionals should be aware of the common "red flag" indicators of ASD, and should know appropriate referral sources.

Professionals in fields that frequently interact with young children with ASD should be targeted for education and outreach and made aware of indicators of ASD through their respective training programs. Such professionals include:

1. Child Protective Services social workers
2. Audiologists
3. Speech and language pathologists
4. Occupational therapists
5. Physical therapists
6. Nurses and other public health providers
7. Hospitals/attending physicians
8. Early intervention specialists

Best Practice:
Healthcare professionals stay up-to-date on best practice guidelines and related research.

Screening Instruments for General Development and ASD

General developmental tools, as well as screening tools specific for ASD, should be used. Providers may use different tools based upon their training, expertise and scope of practice (i.e., primary care, child development center, regional center).

Several general developmental screening tools are designed to identify and track developmental progress in young children. Instruments can vary considerably in terms of administration, ease of use, time and amount of information provided. Developmental measures also vary with respect to their reliability, validity and ability to accurately reflect developmental progress and deviations.

Measurement Format

Paper and pencil screening tests are a quick and efficient method of gathering developmental information from parents. Measures can either assess for the presence of any developmental anomaly or be specific to the identification of a disorder. Other measures are a combination of parent response and clinician-elicited information. Paper measures have several advantages over informal questioning. Most paper measures are validated against age-appropriate behaviors and are reliable in differentiating the target group from a control population. They are also time efficient, and can be administered to parents while they wait for an appointment with the PCP. More importantly, paper measures complement any developmental concerns obtained from the PCP's query of the parent.

Available Tools

Most measurement tools and tests fall into one of four broad categories as follows.

General Developmental Measures

Several general developmental screening tools are designed to gather and track developmental progress in young children. Instruments vary considerably in terms of administration and ease of use, time and wealth of information provided. Developmental measures also vary with respect to their reliability, validity and ability to accurately reflect developmental progress and deviations.

- Developmental Profile II (DP II)
- Ages and Stages Questionnaire (ASQ), 2nd Edition
- Brigance Screens Infant and Toddler; Early Preschool Screen
- Brigance Inventory of Early Development, Revised
- Child Development Inventory (Ireton)

Screening Tools Specific to ASD

Within the past few years, a variety of screening tools specific to ASD have been developed. The following instruments were selected based upon ease of use, time

efficiency and acceptable psychometric properties and are recommended for use in primary care practice. Relevance of the instrument and demonstrated utility with very young children were also factors of primary importance in their inclusion. Those recommended for use in primary care practice include:

- The Stage 2—Pervasive Developmental Disorders Screening Test (PDDST-II)
- The Modified Checklist for Autism in Toddlers (M-CHAT)
- The Checklist for Autism in Toddlers (CHAT),
- The Screening Tool for Autism in Two-Year-Olds (STAT)

Parent Report Measures

The following measures are completed by parents and they require little time to complete. The staff training required for scoring is minimal.

One of these instruments should be used at the 24-month screening.

- **Modified Checklist for Autism in Toddlers (M-CHAT)**. The M-CHAT (Robins et al., 2001) is a 23-item checklist designed as a screen for ASD at 24 months of age. The form consists of items in yes/no format that parents can easily fill out in the waiting room. A Spanish translation is also available (see Appendix D). Unlike its predecessor, the CHAT (Baron-Cohen, Allen & Gillberg, 1992), it does not require health care staff observation or extensive time to complete. The instrument has demonstrated validity in identifying the majority of children with ASD and developmental delay at 24 months of age. (Appendices C and D have the complete instrument in English and in Spanish with scoring information.)
- **Stage 2—Pervasive Developmental Disorders Screening Test (PDDST-II).** The Pervasive Developmental Disorders Screening Test-II (Siegel, 2001) is a parent report measure designed to indicate the likelihood of global and pervasive developmental disorders in children from birth through 3 years of age. The scale consists of seventy-one true/false items, presented in six-month age intervals. Cutoff algorithms have been established for differentiating children with the likelihood of an ASD from children with other developmental challenges.

  Parents are asked to rate items as "usually true" for their child or "usually false." The instrument can take from fifteen to thirty minutes to complete, depending on the age of the child. Scoring instructions are provided to clinicians. (Appendix E contains the PDDST-II.)

Best Practice:
Specific screening between 18 and 24 months for ASD includes the Modified Autism in Toddlers (M-CHAT) or the Pervasive Developmental Disorder Screening Test-II (PDDST II) or other approved instrument.

Best Practice:
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.

Parent Report and Direct Child Observation/Interaction
These instruments require clinical observation of behaviors in addition to parent report. Training in eliciting and rating behaviors in question is necessary for administration. The instruments may be used as a supplement to the parent report measures.

- **Checklist for Autism in Toddlers (CHAT)**
- **Screening Tool for Autism in Two-Year-Olds (STAT)**

Referral of a Child with Possible ASD

A major hindrance to screening and identification of children with ASD is the confusion surrounding the referral process. Many service providers do not know where children with developmental problems should be seen or how to initiate the referral. The PCP needs a resource directory that lists: geographic location served; contact individual within the team; an explanation of the referral process; insurance plans accepted; and services rendered.

Where to Refer Children with Possible ASD

When concerns arise that a child may have an ASD, a referral should be made to an interdisciplinary team for a comprehensive diagnostic evaluation. It is important that these teams and/or individuals demonstrate expertise in evaluating children with ASD as outlined in chapter one of this document.

California Medical Centers That Have Demonstrated Expertise
The state of California is home to several medical centers that have demonstrated expertise in the diagnosis of ASD. Clinic teams were selected based on clinical knowledge in terms of experience, training and empirically-based research and publication within the field. [Appendix I includes a listing of these facilities and their predominant specialty (diagnostic or intervention, for example)].

Regional Centers
Regional centers are state-funded, nonprofit agencies that serve Californians with developmental disabilities residing in every geographic area of the state. As articulated in the California Lanterman Developmental Disabilities Act and Title 17 of the California Administrative Code, a developmental disability is defined as one of five conditions (mental retardation, autism, epilepsy, cerebral palsy or a condition that is similar to mental retardation or requires similar treatment). Onset of the eligible condition must occur before age 18, be substantially handicapping and be expected to continue indefinitely. Each of the twenty-one regional centers maintains clinic staff that provides specialist diagnostic evaluations for ASD and the other disabili-

ties. Other regional center services include case management, advocacy and specialized clinical and resource development services for persons who meet eligibility criteria throughout their life span. In addition, regional centers administer comprehensive services, including early intervention, through their birth through age 3 Early Start programs. Many children with suspected ASD likely will qualify for these Early Start programs. Primary health care providers should be made aware of the regional center that serves children in their area.

Once a positive screen for ASD is obtained, the PCP or other referring professionals should routinely make a referral to the local regional center even if it is concurrent with a referral to a medical center and/or school district (California Department of Education, 1997). This will ensure a timely, more fluid, family-centered diagnostic and assessment process.

To evaluate children with ASD, regional centers either maintain diagnostic clinic teams with expertise in diagnosing ASD in-house or offer diagnostic services through vendor contracts with outside qualified professionals or agencies, including, but not limited to, medical centers. Each regional center maintains a list of providers that specialize in ASD, which the referring party can request. Providers should call the regional center in their area to inquire about the availability of interdisciplinary teams that specialize in diagnosing ASD. For eligible children, regional centers will provide a coordinated plan for intervention and support services. Regional centers are responsible for providing services and developing coordinated plans for eligible individuals with ASD throughout their life span. (Appendix J lists each regional center and the area it serves.)

School Districts

Local school districts provide educational services to children with special needs from birth through age 22. In terms of the diagnostic evaluation process, the districts' primary role is to assess the child's strengths and needs for appropriate educational and intervention planning. School districts perform psycho-educational evaluations with the purpose of qualifying young children to receive special education services within a diagnostic category as designated by the California Department of Education. These educational categories differ from and do not capture the level of detail found in standard diagnostic classification systems such as the *DSM-IV* and the *International Classification of Diseases, 10th edition* (World Health Organization, 1993). The educational system is not responsible for providing concomitant medical or other diagnostic evaluation services that may be necessary for a comprehensive interdisciplinary evaluation. Thus, while it is necessary to refer families of children with ASD and other developmental disabilities to the school district for special education services, referral to a comprehensive diagnostic team is usually necessary for a full diagnostic evaluation.

Conveying Information to Parents

Early identification of children with developmental challenges, and particularly ASD, is delayed by a reluctance to transmit to parents concerns about delays or the need for a referral that may stem from screening test results. The suggestion of a serious developmental disorder is highly stressful and frightening for parents of extremely young children and must be approached in a very sensitive, family-centered manner. Literature supports the notion that most parents desire clarity regarding the nature of their child's difficulties. Parents report that stress is at its peak before and while struggling to secure a diagnosis for their child (Konstantareas, 1989). PCPs should be prepared to offer parents appropriate referral resources and assist them in contacting other providers and securing future assessments. PCPs should be aware of parent support networks, family support services and other appropriate sources of information, such as the Autism Society of America website. All families should receive a follow-up call after referral to be sure that the referral is progressing and that services have been initiated.

Referring sources must be highly sensitive to the fact that parents often do not discern the differentiation between screening and diagnostic measures and must repeatedly stress that referral for an ASD evaluation does not mean that the child has ASD.

Best Practice:
Within the constraints of confidentiality, efficient sharing of information among clinicians assures timely referral and more complete evaluation of children for concerns regarding ASD.

Supporting Documentation for Referral

Referrals should be accompanied by sufficient information for the interdisciplinary team to understand the basis for the concern and provide as much background information about the child and the family as possible. Preferably, the PCP or staff from the PCP's office, rather than the parent, initiates the contact so that coordination of information and services can occur.

CHAPTER 2
DIAGNOSTIC EVALUATION

The Diagnostic Evaluation Process: Applied Principles

Early and Accurate Diagnosis of ASD Leads to More Positive Outcomes

Many clinicians hesitate to diagnose a young child suspected of ASD because they are unaware of the indicators of ASD, foresee the emotional impact on the family, lack confidence in the accuracy and stability of the diagnosis, or they lack knowledge of the availability of early intervention and preschool services. However, there are a number of important benefits for the child and family in receiving an accurate diagnosis as soon as possible.

- Diagnostic classifications assist in earlier access to needed services through state and federally funded programs and are critical to treatment and intervention planning.
- While children vary considerably within the rubric of ASD, there are common social and communication deficits that must be recognized for learning and progress to occur.
- Diagnosis provides a common language across providers and paves the way for future medical and research endeavors. This is particularly pertinent to an expanding knowledge base for ASD. Standard diagnoses are often needed for comparison with children of similar profile and are useful for tracking changes in behavior and symptom presentation over time.
- Important information is provided concerning developmental course and response to treatment.
- Most importantly, parents and caregivers often feel a sense of relief and comfort when they have a framework within which to understand their child's difficulties. However stressful and devastating it is to realize that a child has a significant disability, parents generally prefer knowledge to ambiguity.
- The primary purpose of a diagnosis is to provide guidance for intervention. Accurate, early diagnoses lead to earlier appropriate treatment, which leads to enhanced outcome.
- An early and accurate diagnosis of ASD assists families in planning for future children.

BEST PRACTICE:
The diagnosis of ASD should be made as soon as possible to facilitate intervention and initiate family counseling.

Best Practice:
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.

Diagnostic Criteria Must be Interpreted within a Developmental Framework

Diagnostic criteria for pervasive developmental disorders (American Psychiatric Association, 1994) specify that impairment must be interpreted relative to the child's developmental level. Thus, children with ASD evidence significant differences between nonverbal cognitive ability and social/communicative functioning. This disparity can be difficult to detect in toddlers and older preschool-age children with developmental ages below 12–18 months. Lord et al. (1997) indicate that discrepancies between areas of development in young children make it difficult to identify specific social deficits as opposed to more generalized developmental delay, particularly when nonverbal skills are below a year. When skills and behaviors are consistent with the child's mental age, other diagnoses may be more accurate than ASD.

The Reevaluation of Diagnostic Conclusions for Very Young Children is Essential for Monitoring Progress and Intervention Objectives

Young children with ASD should receive follow-up diagnostic evaluations on a periodic basis. Experienced clinicians and researchers typically provide follow-up on an annual basis for children under 5. The rationale for follow-up is the following:

Stability of Diagnosis

Presently, children are being referred for evaluation regarding suspicion of ASD at earlier ages. Although many trained professionals are able to make a definitive diagnosis at a young age, the stability of diagnosis within the spectrum may fluctuate. This is often the case with children who are very young (2 years and under) and for those at the extreme ends of the spectrum. It is not uncommon for a child to meet diagnostic criteria for autistic disorder at age 2 and then be described at age 3 or 4 as PDD-NOS. Symptoms and behaviors may change considerably with intervention, particularly as language and social skills progress.

Accurate Estimation of Cognitive Functioning

Considerable challenges are inherent in assessing cognitive functioning in very young children with ASD using standardized measures. In general, cognitive performance is less stable in children under 3 years of age. An accurate assessment of cognitive functioning is crucial for prognosis and intervention planning (Vig & Jedrysek, 1999). Thus, a focus of re-evaluation should be to obtain closer approximations to an accurate description of potential in the child. This can be achieved as the child gains experience with more structured learning situations through appropriate intervention.

Best Practice:
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.

Tracking Outcome

Follow-up in the early childhood years allows clinicians to track developmental changes in symptomatology and behaviors. This allows an enhanced ability to predict outcome (prognosis) and response to intervention.

Diagnostic Evaluation is a Concurrent, Multilinear Process

While many activities are needed to complete an accurate depiction of symptoms, the evaluation by the team or clinician needed to initiate intervention should not be delayed until other testing is completed. Children are often referred to several specialists (audiologist, neurologist, etc.) before referral to the clinician who will provide the diagnostic evaluation. While evaluations from other specialists are important for a comprehensive diagnostic picture, they may not have direct impact on intervention planning. For example, while hearing results would have an obvious impact on treatment options, a later finding of fragile X syndrome would not alter intervention plans as significantly. Clinical judgment and knowledge determines the optimal order and timing of the various diagnostic components.

A Comprehensive Diagnostic Evaluation for ASD Encompasses a Thorough Assessment of Multiple Domains

The diagnostic evaluation for ASD necessarily includes six specific components:

- Review of Relevant Background Information
- Parent/Caregiver Interview
- Comprehensive Medical Evaluation
- Direct Observation
- Cognitive Assessment
- Measures of Adaptive Functionin

Each component is a necessary part of the diagnostic evaluation to ensure that the child and family presentation is consistent with those commonly found in ASD and to identify factors that are a focus of clinical attention. Ensuring accurate diagnosis enables appropriate early intervention services for children and families.

Both Standardized and Informal Assessment Procedures are Necessary to Obtain an Accurate Estimate of Functioning in Persons with ASD

The use of both standard and informal assessment procedures addresses the challenges that children with ASD present. The goal of standardized assessment is to ascertain where the child is truly functioning relative to his age-related peers. Formal cognitive/intelligence testing should be conducted, assessing both verbal and nonverbal functions. Informal measures would include modifications to usual procedures as well as careful observation of behavior in low demand situations. The use of both procedures allows for an estimation of child functioning relative to peers, learning readiness skills, communicative abilities and needs and typical skills presented in daily life situations.

Best Practice:
To enable intervention as soon as possible, the diagnostic evaluation is efficiently organized and coordinated.

Best Practice:
The diagnostic evaluation includes examination of multiple domains of functioning to: differentiate ASD from other conditions, and provide a complete profile of the individual to allow for comprehensive intervention planning and service initiation.

Best Practice:
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.

Best Practice:
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.

The Role of Clinicians and Agencies in the Diagnostic Evaluation Process

Input from all disciplines is an essential component of an optimal diagnostic process. A diagnostic categorization alone is insufficient to guide intervention as children with ASD may vary widely in terms of skills and levels of impairment both across the spectrum and within a specific diagnostic category. Thus, the interdisciplinary team is a critical component of the larger system of services and supports for children and families and is ideal for establishing a comprehensive developmental and psychosocial profile of the child and family to guide intervention planning.

Financial and time constraints may preclude the use of such teams for the initial diagnostic evaluation. A high quality, diagnostic evaluation can occur with a single, appropriate clinician, as stipulated in the Introduction, "Professional Qualifications for Screening, Diagnosing and Assessing Autistic Spectrum Disorders." Guidelines for using evaluation information are included in the next section.

Specialists in ASD

The role of the skilled diagnostician includes the following:

- Integrate findings from prior evaluations and assessments as well as documented observations by persons in other settings (i.e., school, daycare, etc.) who are familiar with the child.
- Utilize evaluation tools based on clinical knowledge. While measurement tools can assist treatment planning, research and child components across settings and informants, such tools do not replace clinical judgment. Lord, Rutter, and DiLavore (1996) found that experienced clinicians were able to accurately diagnose autism at age 2, with 72 percent stability at age 3. Expert evaluators are aware of the psychometric properties and utility of checklist instruments (i.e., Childhood Autism Rating Scale, Gilliam Autism Rating Scale, M-CHAT, PDDST-II, etc.) and interview/observation tools (Autism Diagnostic Observation Scale—Generic; Autism Diagnostic Interview, Revised). Knowledge of ASD is a prerequisite to the appropriate use of such instruments. (See Appendix F for a listing of diagnostic instruments.)
- Interpret treatment options, prognosis, and referral for further assessment within the parameters of empirical research findings. While more detailed and specific intervention plans are the desired outcome of the assessment process, the diagnostic evaluation should address issues that affect parents directly. Oftentimes, parents report dissatisfaction with the diagnostic process with regard to feedback and debriefing. Parents have questions regarding the meaning of the diagnosis for their child and family and how intervention approaches can remedy deficits in *their particular child*.

Primary Care Providers

The primary care provider (PCP) is essential to the diagnostic process with regard to appropriate referral and as a liaison and advocate for the child and family. This would include initiating the diagnostic evaluation and ensuring appropriate documentation is available. PCP staff will typically be responsible for obtaining authorization through insurance providers for appropriate services. Therefore, it is essential that PCPs and their staff be aware of the procedures that will occur during the diagnostic evaluation to minimize parental stress regarding managed care and finances and possible rejection of the referral by the ASD clinic.

Best Practice:
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.

Regional Centers and School Districts

Regional centers may be directly involved in the diagnostic process with regard to referral, intake assessment, evaluation, family support and coordination of services. Regional centers provide either in-house expertise in diagnostic services or they contract with local health care providers who specialize in ASD diagnosis (please refer to the discussion about regional centers in Chapter 1). A strong policy of interagency collaboration and referral exits between school districts and regional centers (California Department of Education, 1997). In their *Best Practices for Designing and Delivering Effective Programs for Individuals with ASD*, the Department of Education and Department of Developmental Services (DDS) affirmed timely referrals between regional centers and schools and interagency coordination for families in accessing services from the appropriate agency. School districts comply with the Individuals with Disabilities Education Act (IDEA) and applicable state regulations regarding the presence of autistic-like characteristics. School districts may refer children for diagnosis at diagnostic centers operated by the California Department of Education. Local school districts primarily focus on intervention planning assessment and educational service implementation. Both the regional center and school district personnel often accompany families to the evaluation appointment and/or maintain close contact with diagnostic teams regarding their conclusions and recommendations for further assessment and intervention.

Other Providers

Depending upon the age of the child, other service providers may be involved in the diagnostic process with regard to referral, family support and coordination of services. In some instances, regional centers conduct the diagnostic evaluation. Sometimes, regional centers and school districts contract with specialist evaluation teams to obtain diagnostic conclusions for children suspected of having ASD. These agencies typically are directly involved in service delivery and thus assume a greater role in the diagnostic process. This often includes accompanying families to the evaluation appointment and/or maintaining close contact with diagnostic teams regarding conclusions and recommendations for further assessment and intervention.

Best Practice:
Informed clinical judgment is maintained through periodic training that includes case review, peer review of individual cases, and discussion of published literature.

Diagnostic Environment

The setting or "environment" in which the diagnostic evaluation occurs has a significant impact on the skills and behaviors demonstrated by the child. Very young children often have fewer experiences with school, daycare or directives from unfamiliar adults. The formal evaluation setting is also very different from preschool or daycare environments. Thus, the choice of setting for diagnostic evaluations must be made within the parameters of generalizability of findings.

Debate often occurs regarding the choice of a clinic or more naturalistic setting for the evaluation of young children. Both options offer advantages and weaknesses. The clinic setting offers the team ease of communication among members, access to needed materials, cost efficiency and environmental control. Formal clinic settings, however, can have a significant impact on child behavior, which directly influences diagnostic conclusions and external validity of findings. Children with ASD may be particularly uncomfortable in novel surroundings and display behaviors that are not typical of functioning in familiar environments.

Naturalistic settings offer the advantage of observing the child in a familiar environment. In the home or daycare setting, the clinician is afforded the opportunity to observe typical child behaviors and interactions with other family members and familiar adults. The family may also feel more comfortable in the home, which eliminates the necessity of traveling or the difficulty in readying a child who is likely resistant to change and has difficulty with transition to a novel situation.

A diagnostic evaluation in a naturalistic setting presents significant pragmatic challenges. Cost effectiveness in terms of clinician time and compensation is often the greatest impediment. Furthermore, communicative ease among team members is often difficult. This often leads to redundancy concerning procedures and poor integration of findings. The challenge of coordinating team members to perform an evaluation together at non-clinic locations can be extremely difficult and lead to lengthy waiting lists. Finally, clinicians have little control over environmental variables. This is particularly pertinent to standardized testing and observation procedures that often require relatively distraction-free environments and materials that are often not easily transported. It also requires clinicians to be highly specific, a priori, regarding necessary materials. While record reviews and discussions with caregivers before the evaluation offer valuable insight into the child's current functioning level and temperament, it is not uncommon for children to present quite differently in person. This often necessitates changes to the evaluation plan, which may be impossible to accommodate without access to clinic resources.

In the interests of cost effectiveness and maximum utility of the diagnostic evaluation, best practice would indicate a combination of these options with the core evaluative session occurring in a clinic setting over more than one contact when indicated.

Observations at multiple sites are not required in all cases for diagnostic clarity; however, they are often helpful in terms of assessment and reconciling conflicting information. As part of a diagnostic evaluation, record reviews could include relevant videotape at home or school that the parent may have available. With the parents' consent, it is also helpful to gather information from teachers and daycare providers before the evaluation if such information is available.

Best Practice:
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.

Components of a Best Practice Diagnostic Process

Autistic spectrum disorders are defined behaviorally with respect to three key areas of child functioning: 1) social behavior, 2) communication and 3) activities and interests. The diagnostic evaluation process requires thorough examination of these components as well as their relationships with family functioning and medical and health history.

The family of a child suspected of having ASD should be referred to a regional center or specialty clinic that has the capacity to conduct a comprehensive diagnostic evaluation. Continuous referrals to varied professionals to complete the diagnostic process results in a disjointed and often confusing process. The diagnosis of a developmental disability in a young child is highly stressful and disconcerting for parents. The extension of the process, over weeks, or sometimes months, prolongs anxiety and delays intervention and needed services. The diagnostic center must have the resources to complete the process as expeditiously as possible. While some centers may not have the facilities or staff flexibility to accommodate this, providing conclusions as rapidly as possible can reduce parent stress. This can be accomplished through 1) sufficient time allotted for the evaluation, 2) an appropriate setting and 3) sufficient staff to perform medical and psychological evaluations. Thus, the clinician is not providing a family-centered service when he/she is qualified to diagnose a child but can allot only one hour and then refers out for cognitive and adaptive testing. A family-centered evaluation service entails spending sufficient time with parents to provide detailed feedback and answer all questions.

A complete diagnostic evaluation should include a minimum of the six components described in detail in the following pages.

1. Review of Relevant Background Information

Rationale

The essential purpose of background information review is twofold:

- To guide the diagnostic evaluation to the specific parental concerns and questions, and
- To inform the selection of appropriate assessment measures.

The clinician leading the diagnostic team is responsible for reviewing and integrating available information to guide the focus of the evaluation. The amount of prior information is dependent on the age of the child, with younger children typically having had fewer encounters with professionals. An extensive set of records from the first years of life is more likely to follow children who have significant impairments (i.e., motor, sensory, etc.), including those with risk factors for a developmental disability (i.e., premature birth, birth complications, substance exposure). Older preschoolers may have school, psychological or speech and language reports. Other background information includes parent reports, observations and videotapes.

Best Practice:
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.

Review of background information guides the clinician in the selection of appropriate assessment measures. This reduces the need for redundant testing which is often stressful for a young child and prevents invalidation of results caused by repeated cognitive testing. The results of prior assessments guide the clinician in evaluating how previous examiners came to their diagnostic conclusions. Finally, review of relevant background information helps guide discussion with parents.

2. Parent/Caregiver Interview

Rationale

Parents are experts on their particular child and, as a result, are the primary source of information about their child. With very young children, the parent interview is as critical as direct child observation to the diagnostic evaluation. The lead clinician must possess exceptional skills in interviewing and regard parents and caregivers with the respect they deserve as essential partners in the diagnostic process. At a minimum, the parent interview should include birth, health and developmental history of their child, descriptions of current functioning and family somatic and mental health history. Semi-structured or structured interview measures may be used to guide the interview and will be discussed in more detail in following chapters. Regardless of the selected format, parent questions and concerns should be addressed at the outset and provide the focus for the interview. To inspire greater confidence in the diagnosis and recommendations, the diagnostician should be able to assure the parent that a thorough and comprehensive evaluation will be conducted. Explanations should be provided for all child procedures and parent interview questions.

Components of the Parent/Caregiver Interview

Child Health History

A detailed child health history would include prenatal and perinatal history, a complete health history of the child (including review of pertinent medical records) and family health history. This information can be obtained by the physician or another health care professional (e.g., pediatric nurse, medical social worker) with adequate training and experience in conducting health history interviews. Health care professionals often are able to obtain this information with the provision of basic guidelines, but the information obtained should be reviewed by a physician.

Use of a health history questionnaire is acceptable practice with the provision that relevant issues are clarified by an in-person interview. Whether obtained by interview or questionnaire, essential elements of the health history should include the following.

Prenatal History:

1. Obtain information about previous pregnancies, since previous miscarriages may be a clue to the presence of genetic disorders.
2. Document medical illnesses, which occurred during the pregnancy, since prenatal infections (such as cytomegalovirus and toxoplasmosis) can affect fetal development.
3. Determine medications taken during pregnancy, as they may affect the development of the fetus or predispose the newborn to medical conditions, such as neonatal hypoglycemia in an infant born to a mother with gestational diabetes. Anticonvulsants, for example, are frequently given to mothers with epilepsy and have been shown to cause teratogenic effects on the fetus.

Perinatal History:

1. Obtain information about the length of gestation, onset of labor, and any complications that occurred during labor and delivery. If, for example, a Caesarian section had been performed, determining whether an indication of fetal distress would suggest that further information might be helpful, such as exploring for signs of fetal hypoxia.
2. Establish the infant's birth weight, length and head circumference, which are helpful in determining whether intra-uterine growth retardation was present and evaluating gestational age.
3. Determine any need for post-delivery resuscitation, including Apgar scores, if available, in order to gain further information about the status of the newborn.

4. Document the neonatal course, as it can be quite useful in evaluating the onset of subsequent developmental issues. Early feeding difficulties, for example, can be due to neurological abnormalities of coordination of suck and swallow. Neonatal hypotonia is frequently seen in various genetic conditions, such as Prader-Willi syndrome and Angleman's syndrome. Neonatal seizures may be due to a metabolic disorder or associated with other genetic disorders.

Past Medical History:

1. Obtain information about all hospitalization, surgeries and significant injuries, especially those with head injuries associated with loss of consciousness.
2. Document and explore previous medical illnesses, as they may provide information about the need for specific medical diagnostic testing or treatment. Examples of this would be recurrent episodes of vomiting and dehydration, which could be caused by a deficiency in amino acid metabolism.
3. Specifically question the possibility of clinical seizure activity, as a significant number of children with ASD (approximately 30 percent) develop seizure disorders over time.
4. Obtain specific documentation of infectious diseases and immunization status. This information may be helpful in determining whether any immunological deficiencies might be present and warrant further evaluation.
5. Determine dietary information, which is extremely relevant, since many children with ASD are on restricted diets, either by self-selection or as part of various treatment methodologies. This information should be specific enough to determine if the child is at nutritional risk due to inadequate intake of various essential nutrients or calories.
6. Explore the presence of any known allergies, including the way the allergy was determined and its manifestations in the child. This information should be utilized to determine whether any further evaluation or treatment is indicated.
7. Explore previous medications that had been administered, including prescribed medications and non-prescription medications. Document any behavioral effects of the medications, in addition to the medical effects. This would be helpful to determine whether paradoxical effects on behavior have been observed, for example, behavioral activation by anti-histamines.

8. Thoroughly explore the possibility of developmental regression. Many children with ASD have a period of apparently normal development, although with further detailed questioning, it may be clear that signs or symptoms of developmental abnormalities were previously present. It is important to specifically document which developmental skills were previously present and at what ages and to compare those skills to current function.

Review of Systems:

1. Explore all relevant medical organ systems to determine whether signs or symptoms of underlying medical disorders may be present.
2. Direct special attention to sleep, since many children with ASD have sleep disorders, which can interfere with child and family function. Obtain information about difficulties with falling asleep, night awakening and parasomnias.
3. Specifically elicit signs of problems with hearing and vision. Many children with developmental disorders have impairments in hearing and vision; therefore, obtaining information about parent concerns, past evaluation of vision and hearing acuity (including the methods of testing, child compliance and testing results) and sensory hypersensitivities is important.
4. Obtain information about the possible presence of diarrhea or constipation, since some children with ASD may have gastrointestinal problems.

Developmental and Behavioral History of the Child

The parent interview should include the developmental and behavioral histories and current functioning of the child. This information is gathered using either questionnaires or direct interviewing. In practice, a combination of both components is best. Questionnaires can be sent to the parent before the appointment. Questionnaires include objective, easily identifiable developmental information such as developmental milestones, motor skills, eating and sleeping patterns, etc. Other information provided through this format could include history of evaluations, past treatments and interventions, if appropriate. The clinician uses this information to supplement the parent interview . Collection of easily identifiable and verifiable information before the interview allows more time for the clinician to pursue current concerns and obtain detailed information pertaining to specific diagnostic criteria.

The clinical content of the parent interview should document the following domains:

1. First concerns about the child's development. This includes the parents' first concerns as well as concerns of others (relatives, PCP) that may have preceded parental concerns. It also important to ascertain their interpretation of the events at that time (i.e., family move, illness, daycare experience, etc.).
2. Characteristics of the infant's temperament.
3. Social-emotional milestones. This includes engagement in typical baby games (pat-a-cake, peek-a-boo), eye contact during feeding and games, shared attention, greetings and similar significant events. It is sometimes helpful to provide a reference point (i.e., first birthday) to aid with recall.
4. Sensory abnormalities. It is important for the clinician to provide examples to help discriminate atypical patterns from typical developmental patterns. For example, arm flapping and jumping are common in many preverbal children. For example, children respond to exciting stimuli such as the currently popular children's characters, Barney and Elmo.
5. Feeding and sleep problems or patterns.
6. Fine and gross motor development and milestones.
7. Atypical interests and activities.
8. Interest in other children and/or siblings.
9. Patterns of attachment to caregivers.
10. Ability to use nonverbal communicative means such as gesture and facial expression.
11. Communication, including both verbal and nonverbal intent.
12. Preferred activities and play.
13. Other notable characteristics such as loss of skills or deterioration of behavior.

The above list is a guideline for relevant content to include in the parent interview. The sampling of relevant content areas includes dimensions that tend to highlight behaviors within the ASD range and, therefore, reflect atypical development. Consequently, it is important that the clinician be able to interpret responses and ask questions within the framework of typical child development and knowledge of individual family characteristics as well as cultural norms and values.

The parent interview can be either a standardized interview or a more informal gathering of information. Clinicians experienced in the diagnosis of ASD tend to rely more on informal interview questions that are specific to the diagnostic criteria for ASD and are relevant to the child's age and developmental level in establishing a diagnosis. Again, this emphasizes the need for clinical and professional expertise in ASD. Standardized interviews, such as the Autism Diagnostic Interview, Revised (ADI-R; Lord, Rutter, et al., 1994), are semi-formal and constrained by administration protocol in gathering information. Such formalities and protocols can provoke anxiety for the parent who is undoubtedly already apprehensive for their young child. Informal procedures often allow the clinician more flexibility in providing examples of specific behaviors for the parents. An informal approach allows for reframing the wording of questions to increase comprehension. Parents and caregivers should feel comfortable and relaxed during the interview and confident providing information.

Formal Diagnostic Interview Tools

Formal questionnaires and interviews can be used as a guide in obtaining this information but must be interpreted with regard to their reliability and validity in diagnostic accuracy with respect to the age of the child. Briefly, the only interview format tool with adequate psychometric properties for children under the age of 5 is the Autism Diagnostic Interview-Revised (Lord, Rutter & LeCouteur, 1994). The interview data gathered should be specific to the age of the child, which further highlights the need for highly experienced and knowledgeable clinicians. For example, Lord (1995) found that standard diagnostic criteria tended to be overly inclusive at age 2 for children having severe cognitive disability and not inclusive enough for those without clear stereotypic/repetitive behaviors or narrow interests. The same phenomenon has been observed with another popular instrument, the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, and Daly, 1980). Thus, it is important for the clinician to be well versed in the developmental manifestations of the disorder at different ages to be able to frame useful and diagnostically relevant questions.

The Autism Diagnostic Interview, Revised

(ADI-R). The Autism Diagnostic Interview, Revised (Lord, Rutter, LeCouteur, 1994) is a semi-structured interview for parents or caregivers of persons with ASD. The ADI-R provides a diagnostic algorithm for both the DSM-IV and the ICD-9/ICD-10 definitions of autistic disorder (American Psychiatric Association, 1994; World Health Organization, 1992b). It is appropriate for children and adults with developmental ages of at least 18 months. The interview takes approximately one and one-half to two hours to administer. Use of the instrument requires extensive training and demonstrated reliability.

The Parent Interview for Autism, PIA.
The Parent Interview for Autism (Stone & Hogan, 1993) is another structured interview for parents or caregivers of children with autism. Unlike, the ADI-R, the PIA is intended for use specifically with preschoolers. Items were derived from diagnostic checklists available for autism. The instrument takes thirty to forty-five minutes to complete. The PIA is in the preliminary stages of development and is best utilized as an organized means of gathering clinically relevant information. The authors are currently working on a revision of the instrument, which includes extension of the age range to infants and toddlers.

Best Practice:
Diagnostic accuracy improves when the diagnostic team uses formal diagnostic tools, clinical experience and clinical judgment in diagnosing children suspected of ASD.

In summary, formal clinical measures can be accurate in placing young children on the autistic spectrum but they do not differentiate well within the spectrum (Stone, 1999). Thus, clinical measures are best used by or under the supervision of specialists in diagnosing ASD. Results from standardized instruments should always be incorporated with clinical information and judgment, particularly in children under 3 years of age. The use of formal evaluative measures is not a replacement for clinical experience and judgment.

Family Medical and Mental Health History
The focus of this portion of the interview is to ascertain the presence or absence of any medical, developmental or psychiatric disorders in the family history that may be related to the current concerns or assist in differential diagnosis. While many genetic conditions may have variable expression within members of the family, a knowledgeable clinician should determine which conditions might be relevant to the child's primary diagnoses or other concurrent medical conditions and require further information. Some conditions, such as tuberous sclerosis, are frequently due to a new genetic mutation, while other conditions, such as fragile X syndrome, may have variable expression in family members. Particular attention should be paid to other family members who have developmental disabilities or metabolic disorders or who died at an early age.

Current research clearly indicates a genetic component associated with ASD, in addition to related developmental disabilities (i.e., mental retardation), lesser variants (i.e., language disorder, learning disability) and phenotypic traits (i.e., schizotypal). A strong psychiatric history within a family (i.e., schizophrenia, mood disorder) may indicate a different diagnostic trajectory outside the autistic spectrum that may be difficult to differentiate in a young child. These factors are critical to a comprehensive diagnosis since diagnostic classification is a guide to treatment planning. Parents and caregivers should be well informed regarding why such information is necessary for diagnostic clarity and treatment planning, as well as implications for future family planning. As a medical or psychiatric history is often a sensitive topic, particularly for parents of children suspected of having ASD, the clinician should be attuned to discomfort and be able to discuss the clinical

necessity and implications of the findings. With regard to confidentiality, information should be shared only with providers that have clinical use for the information with parent consent.

3. Medical Evaluation

Rationale

The American Academy of Pediatrics (AAP) has made recommendations on the role of the pediatrician in the diagnosis and management of ASD (American Academy of Child and Adolescent Psychiatry, 1999). According to the AAP, the purpose of the medical evaluation for children with ASD is to assist with determining the etiology of the disorder, associated medical conditions and any other health conditions that may also be present. Determination of the etiology and associated medical conditions may have numerous important potential benefits, including genetic counseling, family counseling to help the family understand the cause of the disorder, possible treatment options, information about prognosis, potential for prevention (both primary and secondary) and facilitation of the development of a comprehensive database which can be used for epidemiological purposes. Over time, new information, including new clinical genetic syndromes, is expected to be available. It is therefore important for clinicians seeking expertise in ASD to stay involved with the care of children with ASD and to remain informed about current research results.

Components of a Medical Examination

General Physical and Neurodevelopmental Examination

A comprehensive physical examination including a neurodevelopmental examination is an essential part of the medical evaluation of children with ASD. It should be performed by a qualified health professional with expertise in the area of ASD.

One purpose of the general physical examination is to evaluate the child for signs of genetic disorders including dysmorphic features (which individually can be fairly subtle); specific growth impairments such as microcephaly, macrocephaly or organomegaly; abnormalities of the sensory organs such as cataracts; and manifestations of neurocutaneous syndromes such as neurofibromatosis or tuberous sclerosis. Some examples of the more common disorders, which may be associated with ASD, or must be considered in the differential diagnoses of ASD, and their common manifestations, are as follows:

- **Fragile X Syndrome:** Physical features present in young children with fragile X syndrome may include prominent ears (70 percent), high arched palate (63 percent), hyperextensible fingers (49 percent) and a long face (64 percent) (Hagerman, 1999). Features may be present in girls as well as boys, and may present in more subtle ways.

- **Fetal Alcohol Syndrome:** To qualify for a diagnosis of fetal alcohol syndrome (Institute of Medicine, 1996), there must be a confirmed history of maternal alcohol exposure during gestation, evidence of growth retardation, characteristic facial features and evidence of central nervous system neurodevelopmental abnormalities. The growth impairment may be evidenced by low birth weight for gestational age, decreasing weight over time (not due to nutritional factors alone) or disproportional weight for height. The characteristic facial features include short palpebral fissures, thin upper lip and flattened philtrum. Children who do not meet these specific criteria may be considered for other diagnoses such as alcohol-related birth defects (which may be cardiac, renal, skeletal, ocular or auditory), or alcohol-related neurodevelopmental disorder.
- **Tuberous Sclerosis:** Facial nodular lesions (fibrous angiomata) are present in 50 percent of children by the age of 5 years, and may include hypopigmented lesions in an "ash-leaf" macular pattern in other areas of the skin. Teeth may show pit-shaped enamel defects. Hamartomas can develop in any organ, including cardiac, renal, gingival and subungual. Seizures frequently develop in infancy or early childhood.
- **Congenital Infections**: Children who have developed symptomatic or asymptomatic congenital infections may later develop symptoms of ASD. Conditions such as congenital cytomegalovirus infections, for example, in young children can manifest, in addition to other medical problems, such physical findings as microcephaly, later onset hearing loss or hepatomegaly.

Developmental Neurological Examination

The purpose of the developmental neurological examination is to determine whether there is evidence of developmental neurological abnormalities, as compared to the neurologic function expected of a child at a specific chronological age, which may be associated with other specific developmental disabilities, co-occurring conditions or warrant further neurological laboratory testing. The essential components of the examination are as follows:

- Head circumference
- Cranial nerve function
- Cerebellar function
- Deep tendon reflexes
- Postural responses
- Primitive reflexes

- Motor examination, including active and passive tone, strength, involuntary movement
- Tests of gross and fine motor coordination
- Presence of abnormal reflexes and signs, such as Babinski response

Laboratory Tests

Medical laboratory testing should be decided upon the basis of the clinical history and physical examination, including the family history. In particular, behaviors such as pica might lead to a decision to perform lead screening. In addition, evidence of growth impairment or failure to thrive might lead to further investigation of thyroid function, and history of cyclic vomiting or protein intolerance might suggest further metabolic screening including amino acid chromatography. Careful consideration should be given to a history of developmental regression, especially if family history or neurological examination provides indication for further testing.

Genetic Testing and Consultation

It was the opinion of the *Guidelines* advisory panel that routine laboratory testing, at a minimum, should include performing a high-resolution karyotype and fragile X probe (DNA probe for FMR-1 gene). This will enable the clinician to determine if major chromosomal disorders are present, but not eliminate the possibility of non-chromosomal genetic disorders. For that reason, the medical clinician should determine whether further consultation with a geneticist is indicated or whether further testing should be undertaken to delineate the etiology of mental retardation, if present. An experienced medical clinician should decide further laboratory testing as appropriate and as further research demonstrates the utility of such measures as FISH testing for chromosome 15q abnormalities. The clinician should also consider whether the clinical presentation could be consistent with Rett's disorder, for which a specific genetic test is now available (MECP 2). Since other chromosomal abnormalities have been associated with ASD as well (including 7q abnormalities) in a small number of cases, the benefits of further laboratory investigation should be evaluated, and discussed with the family. The importance of genetic testing cannot be overemphasized, since families with a child with ASD have an increased risk of having further children with ASD. The overall risk is considered to be 6 percent, but can be considerably higher (or lower) if a known genetic etiology is determined. This etiology can have implications for genetic risk of ASD for other family members as well. As further research is completed, more specific tests, more specific genetic information for families and more specific treatments for ASD depending upon the etiology may be available.

Neurological Laboratory Evaluation

Other non-routine tests, which should be considered on an individual basis, include an EEG if there is a history consistent with seizures, documented developmental

regression of language or behavior (beyond that consistent with ASD presentation) or clinical neurological abnormalities. A cranial MRI or CAT scan should be considered if clinical neurological abnormalities are present, such as microcephaly, neurological asymmetries or rapidly increasing head circumference. Isolated macrocephaly is not generally an indication for neuroimaging. Special studies, such as a sleep or video EEG may be indicated if the clinician suspects Landau Kleffner syndrome (acquired epileptic aphasia), where subclinical seizure activity leads to a progressive loss of receptive and expressive language. Further laboratory studies, such as urine organic acids, may be appropriate if a degenerative neurological disorder is suspected.

Best Practice:
A comprehensive medical assessment including health history, physical examination and developmental/neurological examination is performed as part of the diagnostic evaluation.

Other Laboratory Investigations

Other tests, such as allergy testing, trace mineral analysis and immunological investigations should be considered only if clinically indicated based upon the presence of clinical history or additional symptoms or signs. Unless clinically indicated, intrusive neurological testing should not be the routine course of referral before evaluation with a specialist in ASD.

Sensory Evaluation

Vision.

Questions or observations about the child's functional vision should be asked during the diagnostic process. Since strabismus, hyperopia and myopia are common in children with developmental disabilities, the evaluation of visual function is an important part of the medical evaluation. As part of the physical examination, the clinician should perform an eye examination, documenting the extra-ocular movements and pupillary responses as well as the eye morphology. In addition, the child's vision should be screened using acceptable methods for infants, toddlers and preschoolers.

This may be functional vision screening or use of other standardized methods.

If there are concerns from the parent or diagnosticians, a referral to a pediatric ophthalmologist or optometrist should follow during the assessment for intervention planning phase. The procedures used should correspond to the professional standards of the field.

Hearing.

All children suspected of ASD should have their hearing screened using appropriate methodology and should be referred for a formal hearing assessment if concerns are present. The child should be referred to a pediatric audiologist as part of the diagnostic work-up if hearing screening

cannot be performed or if the child fails hearing screening. Since some children with ASD have difficulties with compliance and cooperation with these procedures, it may be necessary to sedate the child to perform auditory brainstem evoked potentials. Newborn screening tests are insufficient for assuring adequate hearing as some children may have hearing impairment due to injury or illness (such as repeated ear infections) in the infancy or toddler years, which was not present at birth.

Best Practice:
All children as part of their developmental assessment are screened for vision and hearing with referral to specialists as appropriate.

4. Direct Behavior Observation

Rationale

Direct observation of the child's behavior is essential to a diagnostic evaluation for several reasons. First, it allows the clinician opportunities to directly observe the child in unstructured situations. After a period of adjustment, children often display typical play behaviors (or lack of) and other behavior anomalies that may be of concern. Observations can also clarify issues that may come up during the parent interview by helping to elicit observation that is more explicit or ascertaining whether such behavior is typical. Parents may have difficulty interpreting questions on screening questionnaires or other information collection procedures. With direct observation, situations can be structured or created to clarify these issues (e.g., by a parent or clinician saying "look" to draw attention to an interesting toy, understanding of the gesture can be assessed). Observation can add additional data to parent report. Parents have the utmost knowledge of their child and, often, the highest degree of adaptation to their child's pattern of communication and behavior. They may not realize how they unknowingly compensate for subtle child deficits (e.g., by standing in front of or close to the child when calling his/her name, thus ensuring eye contact). Finally, observations allow the clinician to observe patterns of interaction with family and unfamiliar adults. Ideally, siblings should be encouraged to attend such diagnostic evaluations to observe these interactions as well. This is not essential, but should be accommodated if appropriate.

Play Environment

Toys

Available toys should be geared towards a range of developmental levels (i.e., sensory, functional, symbolic, etc.) due to the wide variability in functioning levels of these children. Materials should also be age- and gender-appropriate. Again, information provided before the evaluation can help guide in material selection so that children are neither overwhelmed nor under-challenged. Gearing toys and materials as closely as possible to the child's functioning and interest levels will lead to a greater likelihood of observing representative behaviors and typical play for that child.

Degree of Structure

Observations should include structured and unstructured observations of the child. Structured observations allow the clinician to press for specific behaviors common to children with ASD. They also allow for more standardized documentation of symptoms and behaviors to the extent that the observation measure provides psychometric data. This allows for documenting behavior in comparison to similar children as well as more easily tracking intervention response in the future. However, structured observations may inhibit more typical child behavior due to noncompliance, unfamiliarity with materials and difficulty with changes in activity and interactive partners.

Unstructured observations of child behavior often provide the clinician with a more representative sample of the child's typical behaviors and use of play materials in the absence of specific adult demands or intrusions. For the purposes of establishing functioning levels, unstructured observations provide information regarding behavior that is typically displayed rather than that which is evidenced in response to specific environmental press.

Space

The space available should include the parent interview room and space for formal cognitive assessment and play observations. The interview room should be large enough to comfortably accommodate the parents, clinicians, other interested parties and the child. The room should be "child-friendly" with a variety of toys that correspond to various developmental levels available to the child. This setting encourages informal observations of the child's play and interaction with others. Informal observations yield information that is often more valuable than that gained from more structured procedures and significantly informs the diagnostic process.

Medical exam rooms that are small and lacking in materials generally inhibit children and severely limit behavioral expression. The room should be large enough to allow the child to play away from the adults. Space for formal testing should be relatively free of distractions. Two rooms may be necessary if the space is not large enough in one.

Observation Domains

A naturalistic setting should be arranged so that the child is able to engage with the environment and others as comfortably as possible. Specific behaviors to be observed include:

1. Reciprocal turn-taking
2. Shared attention
3. Social reciprocity
4. Pretend play

5. Sustained interaction
6. Gaze aversion
7. Spontaneous giving/showing
8. Imitation of novel acts
9. Ability to have examiner direct attention
10. Use of toys and objects

This list is not exhaustive, but is intended to describe a sampling of behaviors supporting and associated with diagnostic criteria for ASD. Other behaviors to observe include preoccupations and repetitive play, motor stereotypies and sensory preferences. Again, it is critical that all behavior be interpreted within the context of the age and developmental level of the child. Videotapes of other experiences supplement observations and can be helpful either to corroborate behavior observed during formal clinic observations, or to indicate typical behaviors in comfortable, familiar surroundings.

Procedures and Tools

The Autism Diagnostic Observation Schedule –Generic (ADOS-G)

The Autism Diagnostic Observation Schedule—Generic (Lord, Rutter & LeCouteur, 1999) is a semi-structured observation and interview measure designed to assess children and adults suspected of having ASD. The instrument is divided into four modules intended for very young children through adults. A module is chosen based upon the age and language level of the individual. Tasks range from those designed to assess preverbal social/communicative behaviors in very young, nonverbal children (pretend play, joint attention) to tasks of pragmatic language, social and emotional understanding in verbally fluent adults. The ADOS-G is designed to complement the ADI-R. Use of this instrument requires extensive training in administration and reliability. Users must also have a high degree of familiarity with ASD.

The Behavior Observation Schedule (BOS)

The Behavior Observation Schedule (Freeman, Ritvo, Guthrie, Schroth & Ball, 1978) is an unstructured, free play session. A variety of toys is available to encourage a wide developmental spectrum of play behaviors ranging from sensorimotor through symbolic/fantasy play. Materials and toys that typically attract children with ASD are also available. This observation is useful in that it places few demands on the child to respond in a particular way. It is extremely helpful in identifying more low-frequency behaviors such as motor stereotypes or atypical uses of toys. It is not particularly helpful in identifying difficulties related to social situations such as language or nonverbal communication anomalies. However, the BOS is an excellent complement to other more structured observations and is highly recommended.

It requires little training in administration but does require the availability of a variety of play materials and knowledge of ASD.

The Ethological Observation Schedule (ETHOS)
The Ethological Observation Schedule (Siegel, 1991a) is a series of timed segments of activity between the child with ASD and a parent and observer. Segments are divided into two-minute increments designed to elicit social behaviors such as ability to engage without material and cooperative play. Sequences are carried out with an unfamiliar adult and parent/caregiver to ascertain differences in child response and level of engagement. Standardized scoring criteria are provided. Minimal training is required for administration; however, solid knowledge of ASD is required for reliability in coding and interpretation. This measure often accompanies the BOS and provides a rather complete sampling of behaviors in both unstructured and structured situations.

Best Practice:
Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of ASD.

The Childhood Autism Rating Scale (CARS)
The Childhood Autism Rating Scale (Schopler et al., 1980) is an observational rating instrument for children and adults suspected of having ASD. Fifteen items are rated through observation of the child, and cutoffs are suggested for diagnoses within the autistic spectrum. The CARS, a product of long-term empirical research, provides quantifiable ratings based on direct behavior observation and caregiver report. These ratings are an important element in the systematic diagnosis of autism.

5. Cognitive Assessment

Rationale

Initial descriptions of children with ASD (Kanner, 1943) suggested that general intellectual functioning was not affected and that these children often possessed superior intelligence. This was often due to the presence of highly specific or "splinter" skills often demonstrated (e.g., counting, memorization). Since that time, it has been repeatedly established that children with ASD vary widely in their cognitive potential with estimates of 70 to 80 percent functioning in the mentally retarded range (Ballaban-Gill, Rapin, Tuchman & Shinnar, 1996; Lord & Rutter, 1994; Rapin, 1991; Volkmar, Burak & Cohen, 1990). Among children who demonstrate normal or superior nonverbal skills, a significant proportion demonstrates verbal and/or adaptive skills in the impaired range of functioning.

It is now recognized 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. An estimation of potential is necessary for the following reasons:

- Functioning level, which includes cognitive and adaptive evaluation, is important for differential diagnosis and intervention planning. A diagnosis of ASD is appropriate when a child shows communicative, social or interest deficits that are inconsistent with overall cognitive functioning. For example, a child of 4 who is functioning at a 12-month developmental level would not receive a diagnosis of ASD if he or she displayed communicative and play behaviors similar to that of other 12-month-old children. It is also extremely difficult to document significant social and communicative deficits below this age level.
- Treatment research generally has supported the notion that response to various treatment approaches has some relation to overall cognitive functioning (Gabriels, Hill, Pierce, Rogers & Wehner, 2001). For example, certain intensive behavioral approaches have been shown to be less successful with children at lower cognitive levels who are unlikely to develop spoken language.
- Degree of cognitive functioning may indicate expected rates of progress. This, of course, is dependent upon the relative degree of certainty with which cognitive impairment can be established.

The reliability and validity of assessment instruments with children under 5 and, specifically, children suspected of having ASD, will be discussed further in this section as cautionary factors in cognitive testing.

Standardized Direct Measures

The use of both standard and informal assessment procedures is recommended. The goal of standardized assessment is to ascertain where the child is truly functioning relative to his/her same-age peers.

Formal cognitive/intelligence testing should include an assessment of both verbal and nonverbal functions. Children with ASD often demonstrate relative strengths in nonverbal tasks as opposed to those more dependent on receptive and expressive language skills. It should also be noted that as children get older, cognitive assessment instruments rely more heavily on language comprehension and related skills (e.g., capacity for abstraction, sequencing). The choice of an assessment instrument is dependent upon a careful estimate of the child's developmental level. This requires a careful review of previous records and descriptions of observed behaviors and is particularly true for very young children.

Mental retardation should be included as a concomitant diagnosis when appropriate. The clinician should use qualifying statements when discussing the diagnosis, particularly concerning the reliability and validity of the assessment for the particular child. Variables affecting performance could include distractibility, interpersonal and affective engagement and repetitive behaviors. When considering mental retardation as a diagnosis for children under 3, it should be emphasized that

cognitive functioning is subject to a certain degree of fluctuation, particularly with respect to intervention response and maturation. Adding conditional terms such as "baseline" and "provisional" to a mental retardation diagnosis during the initial evaluation may help parents better understand that rate of development is more informative as a prognostic indicator regarding intellectual and academic achievements.

When a useful estimate of cognitive functioning is not possible, developmental levels (based on less direct procedures) should be included. A diagnosis of mental retardation may still be appropriate. However, it should be stated to the parents that current functioning is consistent with such a diagnosis and include recommendations for periodic reassessment.

After the preschool period, terms such as "developmental delay" should not be substituted for a diagnosis of mental retardation. This term implies that the rate of learning can be expected to approach age level, an assumption that can lead to unrealistic expectations and erroneous intervention plans.

Formal Procedures and Tools

- Bayley Scales of Infant Development–II
- Wechsler Preschool and Primary Scales of Intelligence, Revised[1]
- Stanford-Binet, 4th edition
- Mullen Scales of Early Learning
- Kaufman Assessment Battery for Children
- Leiter International Performance Scale, Revised
- Merrill-Palmer Scales of Mental Tests

Issues in Cognitive Testing with Young Children with ASD

The assessment of children with ASD using standardized, formal testing procedures has been criticized on many levels. To begin with, it is difficult to identify instruments that have been normed using special populations. Administration often requires modification of instructions to accommodate the child, which alters the reliability and validity of the instrument and limits the inferences that can be made. For example, administration of the Wechsler Preschool and Primary Scales of Intelligence, Revised (WPPSI-R) to a young child with ASD or any language comprehension difficulty is challenging due to the "wordiness" of task instructions and the volume of language that must be processed to complete a simple imitation task. Often, compliance, cooperation and comprehension are the skills being assessed

[1] The Wechsler Preschool and Primary Scales of Intelligence, 3rd edition is available in Fall 2002.

during such standard administrations, as opposed to child ability. For most purposes, the goal of the cognitive evaluation should be to ascertain the ability of the child.

Terms such as "untestable" should be avoided. This typically indicates that the child was unable to conform to standardized procedures. A best estimate of cognitive functioning is crucial to the diagnostic process and can be reasonably obtained by clinicians experienced with this population.

Issues of Reliability and Validity in Testing Protocol with Young Children

The IQs obtained by children with ASD have the same properties as those of other typically developing and special needs children (DeMyer et al., 1974). Scores are moderately stable throughout childhood and adolescence and become increasingly stable after the age of 5. This issue is extremely important with regard to assessing and discussing cognitive functioning in children with ASD. Despite the preponderance of research to the contrary, professionals and the public alike continue to harbor misconceptions pertaining to mental retardation in children with autism. These misconceptions include:

- Low IQ scores are obtained because children are untestable or uncooperative. As discussed throughout these *Guidelines*, appropriate test selection and adaptation of procedures result in accurate estimates of cognitive functioning.
- Very specific, or splinter, skills are often equated with general intelligence. Children with good rote memory skills for activities such as calendars or counting are often perceived as being of normal or superior intelligence. It should be stressed that these skills often do not generalize to other areas of ability or adaptability such as functional language use or applied math skills.

This is not to suggest that all children with ASD have significant cognitive impairments. Approximately 20 to 25 percent demonstrate normal to superior functioning in at least one of the major cognitive domains (verbal and nonverbal). These children typically have more advanced language and social skills relative to same-age peers with ASD before intervention. However, these *Guidelines* discourage the common practice of dismissing the results of cognitive assessment with these children, regardless of the validity of administration. The importance of recognizing cognitive potential and relaying realistic information to parents and caregivers cannot be overemphasized in terms of future expectations and appropriate intervention planning.

Collating information from multiple sources can protect against threats to ecological validity, which can occur with variability in test performance and the existence of conflicting information. Credibility and usefulness of diagnostic findings is generally obtained through greater consistency across multiple sources of assessment.

Informal Procedures and Tools

Other measures that may be of use in determining level of functioning are those that typically ascertain developmental milestones through parent report and/or direct observation. Such instruments do not purport to measure intelligence or an "IQ" per se. They are often most useful in those situations where direct cognitive testing cannot be completed.

- Brigance
- Developmental Profile II
- Early Learning Accomplishment Profile

Informal measures include those developed by clinicians and researchers in ASD for the diagnostic interview of parents and caregivers. Most are designed to elicit specific information regarding developmental and behavioral sequelae often consistent with ASD in young children. Informal measures also allow more flexibility in questioning and reframing inquiries. This ensures greater comprehension for the parent or caregiver and can often clarify discrepancies between observed behaviors and responses to standardized interviews or checklists. More importantly, informal measures substantially increase the comfort level of parents and enhance rapport with the clinician.

Nonstandardized Cognitive Indicators

Informal observation should be used to strengthen confidence in estimating the child's cognitive level. This requires extensive knowledge of the literature and child development to identify which features of behavior are often associated with significant cognitive impairment. Some examples would include:

- Level of Exploration. Children at lower cognitive levels often have less of an exploratory drive, which results in decreased learning experiences.
- Complexity of Behavior. Often children with elaborate routines or with tendencies to categorize and arrange objects and toys are functioning toward the higher end of the spectrum.
- Rates of Stereotypic Behavior. It has been established repeatedly that excessive motor stereotypy (i.e., flapping, spinning, rocking) is associated with greater degrees of cognitive impairment and is often found in the nonautistic, mentally retarded populations (Howlin, 1998; Wing, 1988).

The above clinical features are intended as guides and are not absolute indicators in every case. However, they are useful for making observations that provide a better estimate of cognitive potential.

The clinician can also use informal procedures such as testing of limits, modification of instruction and tangible reinforcement. With testing of limits and modification of instructions, the clinician goes beyond the standardized instruction

language and time allotted to ascertain what modifications may be necessary to gain a response or improve performance. Using the WPPSI-R, an example may be to reduce the language of the instructions on such tasks as Block Design or Object Assembly. Many children with ASD are able to respond correctly when simply instructed, "do this," or "make the same." The clinician should always note that such modifications were necessary and describe the resulting IQ score as an estimate. Another modification that may be necessary with children with ASD is the use of tangible reinforcement. Young children with ASD are rarely motivated to perform for social praise or for the pleasure of pleasing the adult. Oftentimes, tangible reinforcement such as food or brief play with a toy is necessary to gain compliance. Asking parents and caregivers to bring along highly motivating treats or toys for their child for this purpose is helpful. If external reinforcers are used, it is crucial that they reinforce effort rather than correct responding.

Best Practice:
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.

6. Adaptive Functioning

Rationale

Adaptive functioning refers to capacities for personal and social self-sufficiency and problem solving in real life situations. For children with suspected ASD, this component is essential because it provides information regarding the child's typical functioning at home or school and may contrast markedly with data obtained through formal assessment procedures. It offers the clinician indications of the child's ability to adapt to environmental demands such as the formal testing situation. Children with autism often demonstrate large discrepancies between their nonverbal cognitive potential and their ability to function successfully in their families and communities. Oftentimes, serious deficits in adaptive functioning are overlooked in treatment planning when children demonstrate nonverbal strengths. Research does not support the assumption that relatively higher cognitive potential will eventually lead to acquisition of adaptive skills. To the contrary, children with autism often continue to demonstrate significant deficits in daily functioning when adaptive skills are not directly assessed and targeted (Carter, Gillham, Sparrow & Volkmar, 1996).

Several research studies (Carpentieri & Morgan, 1996; Klin, Volkmar & Sparrow, 1992; Stone et al., 1999; Volkmar et al., 1987) have revealed the characteristic adaptive profile of children with autism. Skill profiles of these children are often uneven, with relatively better performance on motor and daily living skills than socialization and communication. More recent studies (Klin et al., 1992; Volkmar, Carter, Sparrow & Cicchetti, 1993; Volkmar, Klin, Marans & Cohen, 1996) have replicated this pattern and demonstrated the utility of measurement of adaptive functioning for diagnostic purposes in children suspected of having ASD as well as the utility of the Vineland Adaptive Behavior Scales (VABS) normative data for this population.

Furthermore, large gaps between adaptive functioning and intellectual potential elucidate areas to target for intervention and highlight the need for learning to occur in naturalistic situations.

In summary, the following points should be considered regarding adaptive behavior assessment:

- Consistencies between adaptive functioning and intellectual potential also enhance the convergent validity of formal test findings.
- A measure of adaptive functioning, in addition to assessment of intelligence, is also necessary to render a concomitant diagnosis of mental retardation.
- The clinician may choose to use a more standardized measure of functioning or conduct a more informal assessment. However, it should be emphasized that informal assessments should adhere closely with developmental skills expected to be achieved by children of similar ages. The functioning of children with ASD must be interpreted in light of normative developmental expectations and the typical deviant and delayed patterns of behavior associated with these disorders.
- The assessment of multiple domains of functioning is essential to a complete diagnostic picture.
- Assessment of adaptive skills is especially imperative in this population due to their extreme difficulty with formal assessments of intelligence.

Domains of Adaptive Function

1. Communication—receptive/expressive and pragmatic language
2. Socialization
3. Fine and gross motor development
4. Self-help/daily living skills—eating, toileting, dressing, hygiene
5. Social-emotional functioning

Procedures and Tools

Broad Based Measures of Functioning

Vineland Adaptive Behavior Scales – (VABS)

Scales of Independent Behavior – Revised (SIB-R) (Bruininks, Woodcock, Weatherman & Hill, 1996)

Domain Specific Measures

The clinician may also choose to utilize specific measures of social and emotional development specific to young children to clarify the diagnostic picture. These instruments clearly specify in more detail, aspects of functioning in key areas that are often affected in children with ASD.

Vineland Social-Emotional Early Childhood Scales

Issues of Reliability and Validity

Reliance on Third Party Reporting

The majority of standardized adaptive behavior scales rely on third-party reporting of child behavior (i.e., parent, teacher). While parents are the most reliable source of information regarding their child, there may be difficulties reporting typical child behavior, which can occur for any number of reasons, including language and cultural barriers, lack of opportunity to observe the behavior and difficulty in recall. Teachers and daycare providers as informants may also have limited information regarding child behavior outside of the school environment.

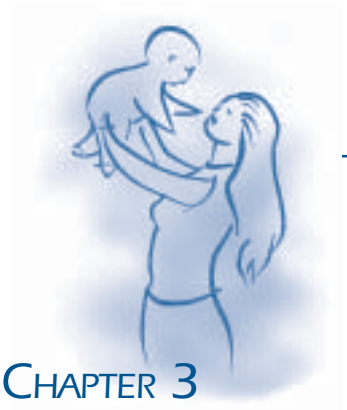
Convergent Validity

A representative assessment of typical adaptive functioning would include information from as many sources as possible. While it is common practice for mothers to be the primary informants, it is often more informative to interview parents (and other primary caregivers as applicable) together. Reports from daycare providers and/or school is also helpful and should be obtained whenever possible. Children typically vary widely in their behavioral repertoire from setting-to-setting or person-to-person. It is not uncommon for a child to perform some activities for one parent that he or she would not demonstrate to another caregiver. Similarly, children who use the toilet at school but not at home or vice versa are also common. This information is highly informative for establishing levels of functioning and diagnostic clarity. Finally, informal assessment of adaptive behavior should always be used to supplement and expand the results of formal measure.

Best Practice:
Domains of adaptive function are evaluated for all children, as they are pivotal in diagnosing ASD and/or coexisting mental retardation.

Formulating Conclusions and Presenting Information on the Diagnostic Evaluation

The final stage of the diagnostic process involves formulating conclusions and presenting information to the family and other service providers. As both diagnostic evaluation and assessment for intervention planning involve a careful synthesis of data and clear communication of information, the next chapter details concluding procedures.



CHAPTER 3
ASSESSMENT FOR INTERVENTION PLANNING

Framework

As indicated earlier in these *Guidelines*, the activities and procedures for screening, diagnostic evaluation and assessment for intervention planning may well occur simultaneously. However, for purposes of clarity and discussion, the three processes are treated separately. Among the three, the distinction between diagnostic evaluation and assessment are undoubtedly the most difficult to articulate.

Assessment for Intervention Planning Derives from the Diagnostic Evaluation Process

Diagnostic evaluation refers to the process of gathering information via interview, observation and specific testing in order to arrive at categorical conclusions. While the diagnostic classification is necessary for access to supportive services (e.g., regional center, school district, third-party payers), it does not capture the heterogeneity presented by young children within a diagnostic category. As such, it is often insufficient for service providers to plan individualized intervention services for young children.

Assessment for intervention planning, on the other hand, expands upon the diagnostic evaluation by defining the child as an individual within the diagnostic category. This is especially relevant for children with autistic spectrum disorders (ASD) given the wide variability in expression of symptoms and functioning. Assessment of a child with an ASD consists of a careful examination of strengths and weaknesses across several domains of functioning with the express objective of directing treatment planning and intervention based upon the child's individual profile. The outcome of the assessment process should be an individualized profile that can be incorporated into an intervention plan that maximizes child development and functional skills within the context of his or her family and community environment.

Assessment for Intervention Planning is an Interdisciplinary Process

An interdisciplinary team assessment is a critical component of the assessment for intervention planning and the larger system of services and supports for children and families. Particularly with ASD, it is important to gain insights from a variety of disciplines regarding the child's development within the context of the family and

community. ASD affects communication, social/emotional behavior, cognitive and sensory processing and motor development. Assessing intrasystem functioning is difficult without knowledge of *intersystem* functioning. For example, social and emotional difficulties are difficult to characterize and interpret without information regarding overall cognitive and language levels in toddlers. These systems are highly interconnected in children, especially those under 3 years of age. This is extremely important with very young children as developmental domains are often difficult to separate and intra-individual scatter between developmental areas typically characterizes ASD.

The recommendation for an interdisciplinary team assessment for children with ASD is in keeping with current clinical experience and research that indicates that these children respond best to a combination of intervention approaches that address particular challenges on an individual basis. Thus, individual team members are able to make contributions that are more valuable to a complete intervention approach when they are a part of a comprehensive assessment process.

The assessment team should closely adhere to the following guidelines:

1. Collate past and present information in a timely, sensitive and accurate manner. It is helpful to designate a team member, such as the primary clinician, as the coordinator. Information should be integrated effectively, and plans should be flexible to allow for change.

2. Before the meeting with the child and family, review the data collected, identify further areas of concern and finalize the assessment plan.

3. As members begin assessment in their particular area of expertise, they must be cognizant of information gathered from other members in order to adjust and alter their data collection as needed. Oftentimes, members are able to combine portions of their individual assessments to reduce redundancy and use time more efficiently.

4. Each discipline should provide a written and verbal summary of findings and tentative recommendations based on their experience. Throughout the assessment, informal communication between members often occurs and is helpful for the final formulations.

5. The final step in the assessment process includes integrating information from the various disciplines. A cohesive summary is then presented to the family in the form of specific feedback regarding the observations, conclusions, recommendations and answers to questions. It should be noted that although this is termed the "last" step in the formal assessment process, assessment is an ongoing dynamic process that must be able to flex with child and family change.

The Goals of a Best Practice Comprehensive Assessment for Children with ASD

The purpose of a comprehensive assessment for intervention planning is multifold.

1. Establish the child's health and developmental patterns and profile family functioning within the community context.
2. Determine areas in which additional information is needed.
3. Detail the child's individual strengths and opportunities.
4. Develop an intervention plan that meets the needs of the child and family within the community.

Applied Principles of the Assessment Process

Assessment is an Ongoing Process That Gathers Information Across Time, Environments and Interactions

Best Practice:
Ongoing assessment of a child's behavior and developmental profile is maintained in order to reformulate assessment conclusions and plan appropriate intervention.

Assessment is often perceived as a discrete process. As such, the profile of the child is applied for intervention planning for long periods of time. Yet, as children and families develop and change, so does the need for adaptation of the intervention program. Regardless of the scope and thorough nature of a single assessment, the individual child's profile is inevitably subject to fluctuation based upon a host of factors including development, response to intervention and family and community factors. Thus, assessment should be viewed as an ongoing, flexible process that is able to adapt with the child. The flow and configuration of the process should allow for contingencies and new information that may arise during the course of the assessment.

The Family is an Essential Member of the Assessment Team. Consideration of Family Ecology and Cultural Values Forms an Essential Element of the Assessment Process

Assessment for intervention planning recognizes the family as an integral part of the team. The involvement of parents as knowledgeable informants is essential in the assessment process. Recommended services and intervention plans are most successful with family collaboration as team members as it is through the parents' actions that recommendations will be realized and child and family functioning maximized. Individuals will come and go through a child's life, but the family is constant. The importance of family participation is the defining force of Part C of IDEA. Part B, for children age 3 to 5, includes parents and caregivers as necessary participants in the Individual Education Plan.

The purpose and process of the assessment must be designed with initial concerns of parents and caregivers prioritized. This includes careful consideration of the role and perspective of the family and recognition of parents as the primary source of information on their children. Treatment recommendations must fit within the family environment and capabilities for implementation. This entails ascertaining that parents understand their child's difficulties and that professionals maintain respect for the parents' perspectives. Parental values must be explored as well as a thorough appraisal of their expectations for their child and prognostic beliefs. This is particularly important regarding treatment for ASD. Parents will be exposed to a vast amount of information from a variety of sources. Yet, little scientific information exists on the efficacy of a variety of treatment approaches, and autism treatment is replete with literature pertaining to approaches with questionable validity and empirical bases of support. Many parents report seeking further assessment due to dissatisfaction with the process and the perceived failure of professionals to provide information on how to best help their child—information which considers parents' needs, beliefs and fears regarding coping with a child with a lifelong disability.

Best Practice:
The involvement of parents is essential in the assessment process as they are most knowledgeable regarding the child.

Developmental milestones, expected achievements of adaptive skills and expectations for behavior are largely derived from Western value systems and must be considered in the context of diverse family systems. Cultural and family values should be considered throughout the assessment process, as they will guide team recommendations and intervention planning. Furthermore, socioeconomic factors may prohibit some families from accessing the available resources to implement and supervise time-consuming home programs. Busy parental work schedules may also interfere with the ability to structure and supervise activities for a challenging child after long hours at a job. Still other families have philosophical and belief systems that are antithetical to behavioral or more structured approaches that are often recommended for children with ASD. This multitude of factors must be considered throughout the assessment process as they directly influence the child's presentation as well as the direction of the assessment protocol.

Best Practice:
Cultural and family values are considered throughout the assessment process, as they will guide team recommendations and intervention planning.

The Interdisciplinary Team Leader Should be a Trained Specialist in ASD and Possess Familiarity and Experience with the Assessment Process and Synthesis of Data From Participating Disciplines

The assessment team should be guided by clinical expertise in ASD. While it is unnecessary and unrealistic to require all team members to be ASD specialists, the primary clinician, or team leader, must be qualified as outlined in the Introduction of these *Guidelines*. Participating clinicians (e.g., speech or occupational therapists) must be qualified and licensed as is appropriate to their particular discipline. In addition, they should have experience conducting assessments with children on the autistic spectrum.

The Assessment Process Should Strive for Ecological Validity to Ensure Generalization in Typical Environments

The assessment needs to utilize procedures that not only capture developmental milestones, but also capture emerging abilities and skills that may be expressed through more naturalistic, informal procedures—i.e., ecological validity (Bailey & Wolery, 1989). Direct, naturalistic observations of behavior, interaction with familiar others and appreciation for functional, adaptive skills should always supplement and support standardized tools.

Most standardized instruments fail to capture skills a child may demonstrate with other contextual or environmental supports, or inflate a child's skill level as an artifact of the testing protocol. This is evident in the child who demonstrates little receptive language understanding in an orally administered test but whose comprehension increases with the use of visual or other contextual supports. The phenomenon is also apparent with the child who can recite multiplication or addition tables but is unable to manipulate them in applied settings. Failure to consider these factors in the use of standardized instruments will result in erroneous program components for both children. While standardized assessment tools continue to be essential components of the assessment process, they must be used in a manner that recognizes their limitations both for a particular child and of the applicability of the information obtained for program planning.

Parameters of the Assessment Environment

The environment in which assessment occurs often has dramatic implications for the results obtained, particularly for very young children who have not had previous therapeutic or educational intervention. Rarely do young children, regardless of disability status, perform optimally in an unfamiliar environment with a strange adult. While it is not always possible to do home assessments due to time and personnel constraints, distance and/or family preference, the assessment should strive to gather as much information as possible from informal observation, parent and other service provider interviews and videotape, if available. Adverse responses to formal testing situations must always be considered in the interpretation of results. For children with ASD, some modifications may be necessary to adapt the formal testing situation. Above all, it is imperative to obtain a measure of the child's functioning to the best of his or her ability. Measurement of cooperation and compliance, which is often gained through rigid adherence to standardized testing procedures, provides little useful information for the purposes of intervention planning (although it does describe learning readiness). Some suggestions for optimizing the formal assessment situation are as follows:

- Allow a parent or familiar caregiver to remain with the child. The caregiver should be instructed to remain as inconspicuous as possible and provide

support as needed. Parents often become anxious while observing their young child in formal testing situations and often want to "help" when they perceive the child is not performing well. The examiner must be skilled in placing both the parent and child at ease.

- Instructions should be adapted to the child's language level. Young children with ASD often have difficulty with language comprehension. The wordiness of some instructions for tasks on standardized assessment instruments may be reduced (not changed) to the language required for task comprehension.
- Reinforcement is often necessary. Young children with ASD are rarely motivated to comply with instructions to please others. Typical social praise ("good boy!") means little to these children. Tangible reinforcement is often necessary to maximize compliance and cooperation. It is helpful to ask parents and caregivers before the assessment to bring favorite treats and/or toys or other objects for this purpose.
- The assessment rooms should be free of distractions and materials not relevant to the tasks. This includes toys, posters and other materials that may distract a young child with ASD (or any child). Children with ASD are particularly hard to redirect once their attention is occupied by something else.

Best Practice:
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.

Components of Assessment for Intervention Planning

Assessment for intervention planning includes the following components:

- Communicative: speech and language
- Motor skills/sensory/processing
- Behavioral functioning
- Adaptive functioning
- Learning styles/cognitive abilities
- Family functioning and coping resources

Although all the above listed domains should be explored for each child, the necessary components for an in-depth assessment are determined by the interdisciplinary team based on clinical need and family priorities.

1. Communication: Speech and Language

Rationale

Impairments in all aspects of communication are central to ASD. It is vital to stress the concept of "communication" in contrast to the more common focus of speech and language assessment and intervention. The range of language skills in different children with ASD is vast, and it is clear that the fundamental difficulty is with communication, of which speech and language are components. Nonverbal communication is affected as well as the pragmatic uses of language. This is apparent in children described as having Asperger's disorder (who often have relatively intact structural language skills). Children with autism lack an understanding of intentions and beliefs that typical children acquire through social processes. Communicative understanding is a necessary precursor for language learning that often is not achieved in children with ASD (Prizant & Wetherby, 1993). This is readily apparent in the nonsocial uses of language in those young children who seem to acquire some language. These may be youngsters who seem to "lose" old words in favor of new words, or the child who can recite a video but cannot request juice. It is highly likely that these youngsters fail to appreciate the communicative powers of speech. Thus, replacement of a previously used word with a new one may simply indicate that the novelty has worn off the older vocalization.

Delays in speech and language alone are not specific to autism, nor are the presence of intact language skills contraindicative of an ASD (Cohen, Volkmar, Anderson & Klin, 1993; Lord, Bristol & Schopler, 1993; Siegel, Vukicevic, Elliott & Kramer, 1989). Social deficits and atypical use of objects at an early age are differentiating features, as are the child's deficits in nonverbal communication. Social deficits further delineate language oddities. Thus, attention to the development of speech is insufficient without addressing underlying communication difficulties. This is often a difficulty encountered in many behavioral intervention programs. Difficulties in nonverbal communicative behaviors such as eye gaze and gesture often accompany language deficits. These children are significantly impaired in their ability to understand how their behavior may influence another.

The fluency and flexibility of language skills and achievements in useful language by age 5 are often correlated with future child functioning (Rutter, 1970). A thorough assessment of communicative functioning is crucial to differentiating between other psychiatric disorders across the age span (Lord & Venter, 1992). There is also a strong positive relationship between social, nonverbal communication skills and rate of verbal skill acquisition. For example, preschool children with more advanced nonverbal communicative skills tend to develop more verbal receptive skills at an earlier age (Lord & Schopler, 1989; Mundy, Sigman & Kasari, 1994).

A total communication approach should be utilized in describing communication abilities in children with ASD. This includes assessment of nonverbal and preverbal precursors to language development such as communicative intent, use of gesture and eye gaze and vocal behaviors. It is also important to evaluate the contexts within which children understand and use language (e.g., home, school, daycare) and the functionality of communicative overtures. In children with some verbal ability, it is important to examine more domain-specific abilities such as receptive and expressive skills, as well as pragmatic use and understanding.

Core Assessment Domains of Communication

Four broad areas of communication warrant particular attention. (Wetherby, Prizant & Schuler, 2000):

1. ***Language and Communication***
   Expressive language and communication

   Gestural means

   Vocal repertoire

   Verbal means (words, sentences, conversation)

   Modality strengths and preferences (speech, gestural, visual)

2. ***Receptive Language and Communication***
   Nonlinguistic response strategies

   Understanding of conventional meanings

   Comprehension of vocabulary, sentences and discourse

3. ***Sociocommunicative and Socioemotional***
   Range of communicative functions expressed

   Reciprocity of communication (rate of communicating, use of repair strategies)

   Social-affective signals for social referencing and to regulate interaction

   Comprehension of and expression of emotion in language and play

   Self and mutual regulatory strategies to modulate arousal and emotional state

4. ***Language-Related Cognitive Domains***
   Attention in social and nonsocial contexts

   Symbolic representation in symbolic and constructive play

   Imitation strategies

   Anticipation of routines and event knowledge

Procedures and Tools

The following recommendations are a sampling of what is available for speech, language and communication assessment. Regardless of the procedures chosen, the assessment team should strive to obtain a sampling of communicative abilities across domains and environments. This entails the use of suggested standardized assessment instruments along with more informal interviews with caregivers and child observations.

1. ***Parent-Interview/Observation***
   Rosetti Infant Toddler Language Scale

   Communication and Symbolic Behavior Scales

   Autism Diagnostic Observation Schedule, Generic

   Early Social and Emotional Scales

2. ***Direct Child Assessment***
   Peabody Picture Vocabulary Test—III

   Preschool Language Scales, 3rd edition

   Receptive and Expressive One Word Picture Vocabulary Tests

   Sequenced Inventory of Communicative Development, Revised

   Pre-Clinical Evaluation Language Fundamentals (Pre-CELF)

   Reynell Developmental Language Scales

2. Motor Skills and Sensory Processing

Motor Skills

Rationale

For most children with ASD, motor skills are a relative strength. There are children, however, who may demonstrate lags in fine motor skills and a small minority who are significantly delayed in gross motor skills. Motor challenges seem to be apparent at the extreme poles of the spectrum. It is well documented that significant motor stereotypy is associated with lower cognitive functioning in the nonautistic and autistic mentally retarded population (Wing, 1988). There are also children at the higher functioning end of the spectrum who seem to have difficulties with gross motor skills and/or motor planning and are often less socially impaired.

Generally, difficulties in motor functioning are evidenced through parent report and child assessment. Direct observation may reveal a child who seems to explore the environment orally or has difficulty with motor tasks such as holding a crayon or

pencil or manipulating objects. When these concerns are present, occupational and/or physical therapy evaluation specific to the issue becomes an essential component of the assessment. Challenges in motor functioning often lead to difficulties processing and obtaining information from the environment. Fine motor deficits make it extremely difficult for children to acquire alternative communication systems such as sign language. Children who perseverate for long periods engaging in motor stereotypy are missing countless learning opportunities throughout the day, which further hinders developmental progress. Given the importance played by coordination between visual motor processing and motor performance for optimal learning, these areas should be an essential component of a comprehensive assessment process. The depth and scope of testing is based upon evidence from other sources and direct observation that these issues may be challenging for the child. With all children, particular attention to functional motor skills is necessary.

Procedures and Tools

1. Peabody Developmental Motor Scales
2. Bruininks-Oseretsky Test of Motor Development
3. Beery-Buktenica Developmental Test of Visual-Motor Integration

Sensory Processing

Rationale

Many children with ASD appear to have difficulty modulating and processing sensory and environmental input. This is evident with children who are highly disturbed by sounds, those who crave movement and those who visually regard straight edges, to name a few. Hyper and hyposensitivity to sensory stimuli and problems maintaining arousal, focused attention and shifting attention are well documented both empirically (Baranek, 1999; Ornitz; 1989; Yeung-Courchesne & Courchesne, 1997) and through anecdotal accounts (Grandin, 1986). Differing neurological mechanisms have been proposed to account for these difficulties (Akshoomoff & Courchesne, 1992). Sensory challenges can be an extremely limiting factor for a child's current functioning and ability to benefit from intervention. For example, children who are hyposensitive to visual input may engage in repetitive finger flicking or flipping objects in front of their eyes. This severely limits their ability to attend to and process other information in their environment necessary for cognitive development and learning. Children who are overwhelmed by noise and crowds may severely limit the family's ability to engage in community activities. The comprehensive assessment must include a description of the child's sensory profile and the interrelationship between current functioning and accommodating intervention strategies.

Procedures and Tools

1. Parent Interview and Observation. The most efficient way to gather this data is to talk with parents and caregivers and observe the child's responses to toys, physical sensations and the environment.
2. Sensory Profile
3. Infant/Toddler Sensory Profile
4. Analysis of Sensory Behavior

3. Behavioral Functioning

Rationale

Young children with autism often display serious behavioral difficulties that interfere with family functioning and severely limit full community participation. These difficulties are often a major source of stress on the family in terms of relationships among members and emotional and financial strain. Often, typical community participation is limited as is that with extended family members. Marital and partner relationships can suffer through disagreement regarding discipline and etiology of the behavior. Parents often report difficulties with securing appropriate childcare and/or babysitters. Often, a parent is unable to work, which can cause financial strain from reduced income. Siblings often suffer due to the intrusiveness and attention afforded to the challenging behaviors of the child with ASD. A significant assessment component must be devoted to addressing the priority concerns of families and promoting functional skills in children with ASD.

Behavioral problems can develop for many reasons, including:

- Communication failures. Tantrums, aggression and self-injury often occur in lieu of more socially acceptable communicative means that are beyond the child's skill repertoire.
- Environmental stressors. Some children with ASD may experience sensory hypo/hypersensitivity. These children may scream or have a tantrum when they hear a doorbell or the telephone or become overwhelmed in a crowded supermarket.
- Need for routine and structure. Children with ASD often have difficulty making sense out of their environment or shifting attention to cope with rapid change. Changes in routines or the environment are often difficult for them to comprehend, particularly when presented through communication avenues that are challenging.
- Unwanted behaviors may be used to gain attention, escape undesirable situations or gain access to objects or activities.

It should be noted that a single challenging behavior could suffice for all of the above purposes in some children.

A large body of research has developed which supports the frequently purposeful and functional nature of challenging behavior. It may be purposeful in that it is often an adaptive response designed to gain a desired action, object or effect (Carr, 1994). For children with ASD, this represents a marked change from the viewpoint that difficult behavior was solely maladaptive or self-stimulatory. Intervention was often focused primarily on eradication of the behavior with little regard for the communicative function it served or the contexts within which it occurred. Failure to assess behavioral challenges appropriately at times resulted in interventions that were primarily punitive in nature and did little to provide the individual with an alternate skill. This is particularly salient for children with ASD due to their extreme difficulties with social cognition and communication. When viewing typical child development, challenging child behaviors (crying, tantrums) often precede the development of alternate communicative means. Increasingly mature communicative behaviors can replace maladaptive ones as a more efficient means to an end. In children with ASD, this developmental trajectory is often deviant, which results in persistence of more atypical communicative means without the benefit of careful assessment and intervention.

Definitions

Positive Behavioral Support

Positive behavioral support is a process for understanding the purpose of challenging behavior and developing a plan that promotes the development of new skills while reducing the child's need to engage in adverse behavior (Carr et al., 2002; Koegel, Koegel & Dunlap, 1996). The focus of the assessment centers on evaluation and intervention within the context of daily life. It considers the broader context of family, caregiver interactions with the child and the need to develop interventions that are realistic and can be implemented by the child's caregivers in the natural environment. This approach is consistent with a family-centered approach that recognizes the interrelationships between family and child and between families, children and the community (e.g., daycare, school).

Functional Analysis of Behavior

This is the process used to understand how a child with challenging behavior functions successfully in their environment. It requires a careful analysis of antecedent and/or setting events that predict the behavior, a concrete description of the behavior and the consequences that maintain the behavior. The assessment should be conducted by a qualified psychologist or certified behavior analyst on the team who has experience with behavior challenges in young children with ASD. It includes developing a partnership with family members and others who have a stake in positive child functioning and outcome. It is rare to complete an assessment

within a day; it often includes child observations across settings and times and careful documentation of antecedents, behaviors and consequences. Family and other care providers, with support and consultation from the professional, often carry out this task. It is crucial that data gathering fit within the family structure and resources.

Procedures and Tools

Tools that can guide the assessment and aid the data gathering process include:

- **Functional Assessment Interview** (O'Neill et al., 1997). This structured interview allows for the systematic collection of information surrounding the nature of challenging behavior. This format can be helpful to clinicians and families as it provides a framework for organizing and sorting information, which may seem overwhelming. It solicits information regarding antecedents, behaviors, and consequences; the child's communicative abilities and a history of previous interventions or approaches parents may have used to deter the behavior.
- **Functional Assessment Observation Form** (O'Neill et al., 1997). This form provides a simple means for tracking the occurrence of challenging behavior, antecedents, consequences and perceived functions of the behavior.

  Data can be collected and gathered in many ways. Of utmost importance is that the data collection procedures be functional within the family system. Data collection systems that are cumbersome, time consuming or difficult to complete will likely result in noncompliance from the family, which does little to address their challenges and meet their needs. It is often necessary for the clinician to make home visits on a weekly or biweekly basis to engage in direct observation as well as assist the family in managing data collection.

The product of the behavioral assessment will include hypotheses regarding the functions of behavior, which are tested for accuracy. When functions have been identified, a plan is developed to help the child develop alternative behaviors and assist the family in management. Although the details of this process are beyond the scope of this document, addressing challenging behavior is a necessary component of the comprehensive assessment.

4. Adaptive Functioning

Rationale

Adaptive functioning, which encompasses self-care and daily living skills, is also an important focus for assessment. Procedures and tools used as part of the diagnostic evaluation process (e.g., Vineland), as well as informal interviews, are appropriate

for gathering this information. Oftentimes, parents prioritize issues such as potty training, feeding and dressing, which are amenable to behavioral intervention. Adaptive skills are a necessary component of the total developmental profile and often have a significant impact on family functioning and the child's inclusion within community activities. The person conducting the assessment should provide recommendations and resources in order to assist parents in developing functional skills in their child with ASD.

Procedures and Tools

Please refer to the "Diagnostic Evaluation" chapters of these *Guidelines* for information on specific measurement tools for adaptive and developmental skills.

5. Family Functioning and Coping Resources

Rationale

Assessment of the family environment is a crucial element of any comprehensive assessment of young children with ASD, as it is for any child with developmental or behavioral challenges. Family members are the primary and constant care providers in a child's life. The child with ASD influences the family as much as the family configuration influences the child. Issues that stress the family system directly influence their ability to support their child with disabilities. Family assessment with the goal of providing family-centered intervention is designed to strengthen the family's ability to influence their child's development and well being (Dunst, Trivette & Deal, 1988).

Adaptation to a child with a disability is a lifelong process that manifests quite differently from family to family and among members within families. Perceptions of loss, anger and grief also vary considerably and have little association with degree of child impairment (Bristol, Gallagher & Schopler, 1988; Harris, 1994b). Cultural values influence acceptance of the child as well as ability to support intervention. Families can diverge considerably from the professionals' perceptions of primary challenges for the child as well as prognostic expectations. Conflicted family situations may be exacerbated or strengthened by the presence of the child. The time and attention needed to coordinate intervention and manage behavior often detract from care for siblings, which lead to further conflict and stress. Community and family outings are often severely restricted due to child behavioral issues. Parents often find themselves in the situation of educating strangers regarding the child's disability after a public tantrum or outburst. Contacts with friends are often diminished which further curtails much needed social support.

In addition to consideration of the child as a part of the larger family system, other family characteristics, which existed before, or in spite of, the presence of the child with the disability will also have a significant impact on development and adjustment.

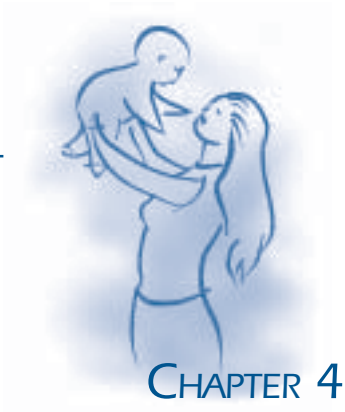
Single parents and those with limited financial resources are often overwhelmed by the challenges of a child with ASD. Personality patterns and coping strategies in the family will also affect child relationships, adjustment and ability to monitor intervention. The identification of these factors during the assessment process alerts the team to family needs for additional support or counseling and influences the formulation of recommendations and intervention plans.

Best Practice:
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.

Procedures and Tools

1. Family Environment Scale
2. Questionnaire on Resources and Stress
3. Parenting Stress Index

As the primary educators and care providers for their children, families require support in their efforts. Interventionists must necessarily design their programs by considering the constraints of the family environment as well as the family's capacity to assist their children.



CHAPTER 4

FORMULATION, PRESENTATION AND DOCUMENTATION OF FINDINGS

Formulation

Diagnostic formulation refers to the process through which child evaluation and assessment data are collated and integrated into a cohesive, clinical description of findings. The guidelines presented in this section delineate basic elements of this collaborative team process.

Clinical Judgment Informs Conclusions

DSM-IV criteria must be interpreted with respect to clinical judgment and integration of data. Research has suggested that diagnostic conclusions rendered by professionals with considerable expertise in autistic spectrum disorders (ASD) have a high degree of reliability and validity as children develop. In some studies (Gillberg, 1990; Lord, 1995), clinical expertise was more predictive of diagnostic stability than formal diagnostic instruments in young children with ASD.

The assessment for intervention planning considers additional clinical features (e.g., auditory or tactile hypersensitivity) and coexisting diagnoses. The primary goal is to integrate assessment findings into an individualized profile of the child and family that is translated into intervention objectives, methods and modalities, as clinically indicated.

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 and his/her family and assist in access to service delivery systems. They are also required by many third-party payers. Appropriate use of *DSM-IV* codes to document diagnoses by service providers and third party payers can facilitate provision of services. At the present time, the accepted classification systems are *DSM-IV* and ICD-9/10 (for Axis III). This format is not intended to restrict the team in providing further qualifying information or nonstandard diagnostic nomenclature. These *Guidelines* acknowledge the controversy and dissatisfaction with the adequacy of the *DSM-IV* in its ability to capture the breadth of difficulties in young children, including children with ASD.

In fact, in *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood* (DC 0-3), a number of researchers and clinicians have identified and described additional diagnostic categories that are particularly relevant to children under 3 years of age (Zero to Three, 1994). Many of these categories are descriptive in nature and limited to describing difficulties in specific developmental domains.

Assessment conclusions in the form of plans and recommendations for intervention should be based upon the synthesized data. Furthermore, recommendations and objectives should be formulated based on clinical judgment and knowledge of accepted and empirically supported intervention options for persons with ASD.

Developmental Expression of Diagnostic Criteria Inform Diagnostic Formulation

The diagnostic formulation and assessment profile must be based on review of all relevant data as it applies to the diagnostic criteria for ASD. Again, the team must consider the age of the child, the developmental expression of diagnostic criteria and the validity of testing results. Diagnostic criteria are best interpreted with respect to their expression in typical development and the developmental age of the child (Siegel, 1991b). Results from standardized testing should be carefully reviewed for their ability to provide a reasonably accurate, representative picture of child functioning.

Formal Diagnostic Criteria Has Limitations when Applied to Young Children

Clinical judgment must supersede and inform data gained by tools, 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 ASD, often do not meet all formal diagnostic criteria at age 2 (Lord, 1995). Specifically, these children often do not display clear repetitive interests or stereotypic motor movements. At age 2, these children often demonstrate more deviancies in social-communicative, 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.

It is essential that the developmental profile of the individual as part of the assessment (i.e., within the broader label of ASD) be conveyed to parents and caregivers as accurately as possible. Helping parents understand their individual child and his or her profile is more important than helping them understand their child as a diagnostic category. The oversimplification of findings can be extremely misleading, particularly with the extreme heterogeneity of ASD.

Uncertainty Calls for Further Assessment, Information and Follow-Up

At times, a definitive diagnostic presentation is not readily apparent in a young child. This is often true for very low and very "high functioning" children. In this instance, the team should formulate a plan of action for gaining further information. This can include referrals for further assessment, obtaining information from other sources and/or follow-up. At no time should the team diagnose a child without confidence in that clinical conclusion. They should be prepared to discuss with parents the reasons underlying ambiguity and the provisions for clarification. Terms such as "baseline" and "provisional" in conjunction with a diagnostic code assist both the family and other clinicians in reinforcing the importance of annual monitoring of intervention responsiveness and follow-up evaluations.

Differential Diagnosis Is Challenging and Must Be Thorough

Diagnosis in young children can be complex given the rapid developmental growth that occurs during this period as well as other environmental factors that may influence behavior. Differential diagnosis includes ASD, intellectual and adaptive functioning, developmental disorders of language and psychiatric disorders.

Best Practice:
The final diagnostic formulation derives from using clinical judgment to integrate clinical data with DSM-IV/ICD-9 diagnostic criteria.

Presentation of Findings

Family-Centered Discussion of Findings

One of the most important aspects of the diagnostic and assessment processes is communicating findings to the family (Freeman and Cronin, 2002). Clinical skill in talking with and supporting parents during this process is crucial. The purpose of the feedback session is for parents and families (as well as other supports such as education personnel, when present) to gain a comprehensive understanding of their child's developmental profile and recommendations for future assessment and intervention. Information assimilation is best accomplished if the family's comfort and confidence in the process is optimal. The following guidelines are suggested:

1. In choosing team members to participate in the discussion, consider the individual's communicative style and ability to contribute non-redundant information. A large number of individual team members may be overwhelming to parents and inhibit their ability to ask questions.
2. Parents' confidence and comfort may be increased with the inclusion of advocates, friends or other significant persons at the parents' discretion.
3. Of primary importance is the relevance and usefulness of information provided in a manner that is sensitive to parents' needs during this difficult time.
4. Deliver conclusions in accord with the parents' education and cultural background.

5. Discussions should include explanations of procedures used to arrive at conclusions in comprehensible language. Professionals should be able to clearly explain the reasoning that led to diagnostic conclusions and intervention recommendations within the context of the child's history and discuss the meaning of the diagnosis for the child and family in terms of intervention options and service delivery.
6. Parents should be informed about where the child fits on the autism spectrum, including strengths and weaknesses as well as information regarding prognosis. They should be encouraged to ask questions as needed.
7. The optimal timing to discuss the findings with the family should be carefully considered. If practical, for example, the family may need a separate session with the clinician or team to debrief. The interdisciplinary team should give diagnostic information to parents and caregivers as soon as possible to avoid needless anxiety and stress.
8. Family ecological factors such as culture, language and coping styles need particular attention.
9. The feedback session is an opportunity to initiate the collaborative working relationship between clinicians, agencies and the family.
10. The feedback session should be conducted in such a way a manner that optimizes receptivity and maximizes parental comfort, and ability to ask questions. For example, if the feedback session is held on the same day as the completion of the diagnostic and/or assessment process, the team needs to consider an environment in which the family can attend fully to the discussion without distractions such as childcare demands.

Prognostic Expectations

The clinician must also be able to guide parents in realistic expectations for their child based upon the findings, empirical literature and clinical experience. This may entail a realistic discussion of the presence of cognitive limitations as an indicator of outcome and response to intervention methodologies. A finding of cognitive impairment should be conveyed honestly and accurately to parents and caregivers along with the team's confidence or reservations about the findings. When the cognitive presentation is unclear, it is best to state it as such and avoid underestimating or overestimating potential without evidence. If the team has reasonable confidence in the findings, this should be stated along with supporting documentation and implications for intervention planning. Prognostic expectations should be discussed and projected for a realistic period, particularly with very young children. It is helpful to emphasize that evaluation must be ongoing and progress continuously reassessed as the child develops and receives intervention services. As mental retardation is difficult to ascertain in very young children, it is important to stress

the necessity of refining conclusions at different developmental points in time. This allows for changes due to growth and maturation and response to intervention.

Family Support

The diagnostic evaluation and assessment for intervention planning processes should incorporate a family and parent support component. This could be provided directly through the clinician, team member, advocate or other qualified referral source. The selection of modality is entirely dependent on the experiences, training and resources available to the team. Families also vary considerably in their need for support. That support needs are considered and attended to throughout all phases of the diagnostic evaluation process is essential. The literature documenting and supporting the impact of a disabled child on parents and families is vast and beyond the scope of these

Guidelines (Konstantareas, 1992; Seligman & Darling, 1997). There is also a substantial research base describing the similarities and differences of the experience regarding a child with ASD (Bristol, 1993; Gill & Harris, 1991; Harris, 1994a).

Knowledgeable Discussion of Intervention Options Particular to the Child and Family

Parents and caregivers of children with ASD want information about what can be done for their child. Parents vary in their levels of knowledge regarding intervention alternatives. In today's technologically driven society, parents have often gathered information on ASD and have decided on potential intervention options before the evaluation. The team should be able to provide information regarding documented efficacy of different approaches, as well as applicability to the particular child.

The discussion of treatment options for ASD can become complicated. Both professional and lay literature is replete with controversy regarding appropriate educational strategies, as well as alternative treatments and theories with scant documented evidence as to their efficacy. Discussions with families who broach the subject can be delicate, and offhandedly dismissing or ridiculing parent inquiries about controversial alternative therapies or "cures" may negatively affect the clinician's relationship with the family. Families should be provided with access to information about various treatment approaches and accompanying empirical support.

Links to Further Assessment, Intervention and Follow-up

Both the diagnostic evaluation and assessment for intervention planning should create a bridge to the next step for the child and family. This may be assessment for intervention planning if it is not incorporated into the evaluation or links to intervention. The team should be prepared to confer with the family regarding their options for intervention planning and/or further assessment. This may include referral to other professionals (including a collaboration plan), to a regional center

Best Practice:
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.

(if the regional center is not already involved) and/or to the local school district. The roles of other providers and their respective contributions to the child's development and intervention should be explained. The clinical team should be able to assist the family as necessary in obtaining future assessment. Such assistance may entail communications through a written report or other formal referral procedures as appropriate.

Documentation: Elements of the Written Report

The guidelines for the written reports are flexible in order to accommodate the spectrum of disorders and different institutions. Support for diagnostic conclusions must be cited in the report and correspond to *DSM-IV* criteria for pervasive developmental disorders. Recommendations and intervention objectives should be comprehensible to parents and those responsible for implementation. This would include specific behavioral descriptions in conjunction with reports from parents and the results of formal testing and observation. It is further recommended that severity ratings be applied to diagnostic criteria, as children differ in degrees of impairment. This is useful in tracking the effects of treatment, as well as in guiding future diagnostic evaluations. A complete summary describes a rationale for arriving at the diagnosis, as well as reasons for discarding other possible explanations.

A complete report should include the following elements in clearly demarcated sections:

1. Identifying information
2. Review of previous findings, records/assessments
3. Health/developmental/behavioral history
4. Results from standardized testing
5. Results from direct observation
6. *DSM-IV* criteria
7. Summary and diagnostic impressions
8. Recommendations

In keeping with these *Guidelines* for best practices, written reports should be family-centered. The language should be comprehensible to parents and convey adequate information to service providers.

It is essential that the interdisciplinary team convey to parents the developmental profile of the individual child (i.e., within the broader classification of ASD) as accurately as possible. The oversimplification of findings can be extremely misleading, particularly with the extreme heterogeneity of ASD.

The written report should include specific, concrete suggestions, detailed where appropriate, and specific to the child and family, which encompass (but are not limited to):

- Strengths and needs
- Further testing and assessment needs
- Intervention strategies
- Program implementation
- Learning styles
- Timeline suggested for implementation
- Linkages to information and resource
- Link to regional center and school district

Best Practice:
Written reports document diagnostic conclusions keyed to specific DSM-IV criteria. Evaluation and assessment reports are comprehensible to parents and providers and contain practical recommendations for the next phase in the process.

Section III

Age Six and Older

Chapter 5
Issues and Concepts in Referral, Diagnostic Evaluation and Assessment

The initial diagnosis of an autistic spectrum disorder (ASD) for older children presents unique challenges to the clinician and diagnostic team. Several factors may prompt an initial diagnosis over the age of 5. Often, children are identified as toddlers and preschoolers with language and developmental delays, mental retardation or other behavioral disorders. At other times, cultural, demographic and family factors deter or delay an appropriate diagnostic classification. Disentangling the multitude of issues at the initial stage of evaluation, leading families and children toward an accurate description of the child, and initiating services is a complicated but necessary goal for clinicians and interdisciplinary teams.

Appropriate Evaluation and Assessment of Older Children and Adolescents Begins with an Efficient Referral Process

The success of the diagnostic and assessment process for older children and adolescents depends on close collaboration among all service agencies and community professionals responsible for providing services to the individual. The older individual suspected of ASD will require a more in-depth investigation and typically requires straightforward access to a specialist clinical team. Regional centers and other ASD evaluation clinics offer the clinical expertise needed to evaluate complex cases presented by older individuals (see Appendices J and K for a list of agencies specializing in ASD evaluation).

Best Practice:
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.

Professionals, who make the referral for a diagnostic evaluation, i.e., physicians, school psychologists, private practitioners, should have knowledge of conveniently located clinic resources that have the expertise to conduct formal diagnostic procedures. The referring professional should be prepared to transmit their concerns regarding the need for a diagnostic evaluation. The specialist clinic team that accepts the referral must have the capacity to consult with the referring professional regarding the reasons why the child or adolescent is presenting at an older age. The clinic team should assist the referring professional with gathering background information and allow the professional to participate in developing the evaluation plan. The focus of this process should be to initiate the evaluation in a timely manner.

The Interdisciplinary Team is Critical to the Diagnostic Evaluation and Assessment for Intervention Planning in Older Children and Adolescents

The complexity and variation in presentation of older children and adolescents requires a coordinated team approach. It is unrealistic to expect that individual practitioners have expertise in ASD and the multitude of concomitant and coexisting psychiatric conditions that are often in question. Therefore, a team approach is critical to provide a comprehensive evaluation and assessment for children in this age group. Repeated referrals to multiple professionals increase the number of potential interventions, which is difficult and frustrating for the child and family.

Furthermore, a critical need exists in both quantity and quality for experienced clinical teams. While clinical competence is critical to all age groups in the evaluation and assessment of children with ASD, it is particularly crucial in children and adolescents ages 6 through 22 where the challenges and difficulties are diverse and complex. A second crucial component is availability of clinical expertise and/or consultation with professionals competent in other disorders of childhood and adolescence.

Best Practice:
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.

Differential Diagnosis is a Necessary and Complex Component of the Evaluation and Assessment of Individuals Over the Age Of 5

While considerable experience and knowledge with ASD were accentuated in earlier chapters, differentiating ASD from other diagnostic alternatives becomes a critical clinical issue with older children and adolescents. It is important to examine possible factors that prompted suspicions of an ASD and ask why this child has either presented at this age or not been identified earlier. Knowledge of the qualitative and quantitative indicators of autism as well as the developmental expression of behaviors in both typical and atypical development in childhood and adolescence must be considered. Since comorbidity and differentiation of psychiatric diagnoses are so vital in this age group, knowledge and/or consultation with expertise in child psychiatry is required.

The differentiation of ASD from other difficulties of childhood is useful in that a diagnosis of ASD provides clinically relevant and useful information to guide intervention planning and quality of life for the child. If the child's difficulties can be better accounted for by alternative explanations and/or a coexisting diagnosis, it is crucial to delineate these challenges as far as they aid in intervention planning and outcome.

Diagnostic evaluations must address those factors that lead to an initial diagnosis at this age. The reasons for requests for diagnostic evaluation in older children are various and cannot be simplified through conceptualizations of "missed" or "misdiagnosed" ASD. While this does occur, clinical expertise along with improve-

ments in diagnoses and identification in the last decade indicate that these occurrences are in the minority. Other possible explanations include the following:

- The child previously was identified with significant cognitive impairment. Children with significant impairment often display more "autistic traits" or "autistic tendencies." The high visibility of autism in the media (i.e., news, Internet) and the suggestion of increasing prevalence rates may prompt parents and service providers to consider the possibility of an ASD as a more accurate diagnosis for services and intervention guidance.
- The child has been identified as having other psychiatric or learning disorders of childhood. Often, children who carry several diagnoses present as having a possible ASD as a way of providing a more cohesive description of their difficulties. Furthermore, clinicians may differ in their options of an appropriate classification.
- The knowledge base regarding the developmental trajectories of various childhood disorders has not advanced to the same degree as that of ASD. For example, relatively little is known about the earlier histories of individuals later diagnosed with schizophrenia, although most would agree that there should be earlier developmental and behavioral atypicalities. An increase in the rate of Asperger's disorder and PDD-NOS in children over the age of 6 may be a function of the lack of adequate descriptions of children with other disorders at various developmental stages.

Best Practice:
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.

Identification of a Coexisting Diagnosis Becomes Central for Quality Educational and Intervention Planning

As children mature beyond the preschool years, understanding the influence of coexisting conditions becomes more important for establishing a clear diagnosis, planning a quality intervention and understanding the prognosis. It is important to recognize that clinically significant symptoms can coexist and can affect intervention planning and treatment outcomes for the child. The diagnostic evaluation should validate separate diagnostic impressions that would have implications for intervention planning except where contraindicated in *DSM-IV* classification guidelines (i.e., "not better accounted for by…"). Intervention planning should proceed by accurately identifying the symptomatology that is a focus of intervention.

Best Practice:
Accurate identification and description of coexisting psychiatric conditions and consequent symptoms establishes the basis for quality intervention planning.

An Accurate and Detailed Developmental and Family History is Crucial for Children in this Age Group

Developmental history construction at later ages is challenging. This is particularly true for children and adolescents with milder difficulties who are unlikely to have had previous evaluations (Mesibov & Handlan, 1997). Parent recall of early milestones is generally weaker as children get older. Thus, it is especially applicable

to include corroborating sources of information collated with current observations and other sources of information. Major discrepancies between history and direct observations must be carefully reviewed while keeping in mind that the child's behavior may indeed be highly variable (Volkmar, Cook, Pomeroy, Realmuto & Tanguay, 1999). Furthermore, although an early history of developmental anomalies is necessary for a diagnosis of ASD, a diagnosis should not be made on history alone in the face of incompatible information. Interpretations about areas of earlier development may also be viewed in the context of current concerns.

In addition, a detailed family medical and psychiatric history is essential. In particular, major psychotic disorders are often accompanied by a family history of similar challenges, which has not been found in families of children with ASD. Accurate diagnosis and appropriate intervention planning are predicated on the delineation of these factors.

Best Practice:
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.

Children and Adolescents Provide Clinicians with More Sources of Information for Observation and Assessment Procedures

Children in this age group are more likely to be in a wider range of educational and/or other treatment environments than are younger children. This allows clinicians more opportunity to observe child behaviors (either on videotape or in person) under different conditions of demand, structure and familiarity. Direct interview with the child is also possible, and a necessity, in those with adequate language and communication. Direct child interviews also increase convergent validity through multiple sources of information and can greatly aid in differential diagnoses where symptoms and difficulties are not directly amenable to observation. (Such an interview does not replace the interview with the family or primary caregivers.)

Best Practice:
The collation and integration of multiple sources of information strengthens the reliability of the diagnosis; conclusions are weighted with respect to all evidence.

Diagnostic Evaluation and the Assessment for Intervention Planning are Often Conceptualized as Integrated Processes in Children and Adolescents

For persons age 6 and older, these *Guidelines* will discuss diagnostic evaluation and assessment as integrated processes. The diagnostic process confirms common characteristics in children with ASD, whereas, assessment describes the child's profile of unique strengths and weaknesses (Mesibov & Handlan, 1997). Diagnostic assessment in this group consists of a wider variety of assessment procedures for purposes of a) establishing the diagnosis, b) determining current levels of functioning, and c) delineating differential or coexisting diagnosis. More than for younger children, language and educational assessment play a substantial role in the diagnostic evaluation and intervention planning assessment. Furthermore, psychological assessment focused on cognitive, social, emotional and behavioral functioning is warranted.

The Maintenance of Communication and Collaboration Among Service Delivery Systems and Families Should be Stressed in Older Children and Adolescents

The service systems with which school age children may come into contact is significant in both quantity and complexity. While interdisciplinary, interagency collaboration and communication have been emphasized in the birth to 5 section, it is critical that service providers establish and maintain collaboration across disciplines, agencies (regional centers, school districts, mental health) and programs. Collaboration should focus on resolving conflicts among legal mandates, avoiding duplication of effort, maximizing efficient use of time and obtaining the best possible results for the child and family (California Department of Education, 1997). Evaluation and assessment should be directed toward establishing the needs of the child and collaborating with service providers. Thus, a higher-functioning child without adaptive impairment may require social skills training or mental health services that would best be provided through the educational or health care system. When service delivery systems are working in concert, diagnostic and assessment findings can be attuned to appropriate treatment modalities.

As children reach school age, it is crucial to maintain the importance of the family as partners in service delivery and planning. The shift from an Individual Family Service Plan for young children to an Individualized Education Plan for those ages 6 through 22 seems to inadvertently lose the focus of the child within the context of the larger family system. Thus, families must remain primary partners in the planning process as well as targets for change in the promotion of enhanced outcome and optimal service delivery. Furthermore, working with school age and older individuals necessarily includes the school, mental health services and other community providers. A thorough evaluation of academic and mental health functioning should be coordinated with a specialized clinical team with expertise in ASD. With school-age individuals, the school is an essential component of the clinical team.

BEST PRACTICE:
The developmental disability and mental health service systems collaborate and cooperate to be effective in addressing the unique service needs of children with ASD.

Functional Impairment Warrants Documentation through Careful Evaluation and Assessment of Strengths and Needs

A necessary prerequisite of best practices in service delivery to children with ASD in this age group is a complete and thorough assessment of functional skills and challenges. Given the range of symptom expression within this diagnostic classification, services should be delivered based upon the functional impairment of the child or adolescent. Thus, evaluation and assessment should be directed toward establishing the needs of the child and toward efficient collaboration with service providers.

Establishment of adaptive impairment also plays a pivotal role in differential diagnosis. It is important to delineate differences between those who meet criteria

for an ASD to the degree that social and behavioral difficulties cause significant impairment in academic and social functioning and those who engender traits where deviances are mild and the person is able to function adaptively in society. Such persons can be quite successful through channeling their personality idiosyncrasies into constructive endeavors. For example, socially awkward traits are often found in families of children with Asperger's disorder (Volkmar et al., 1996; Volkmar, Klin & Cohen, 1997). However, the individual who possesses traits or features similar to Asperger's would not be described as meeting criteria for a disorder unless adaptive impairment resulted from social, communicative and behavioral deficits. Thus a higher-functioning child without adaptive impairment may require social skills training or mental health services that would best be provided through the educational or health care system. Similarly, the adolescent who developed independent living skills as a child may experience greater functional impairment later on as developmental changes and environmental expectations increase.

The Assessment for Intervention Planning Reviews Skills Necessary for Successful Life Transitions

The components of the diagnostic evaluation and intervention planning processes should assess skills and abilities within a transition framework when appropriate. Thus if a child presents for evaluation and is moving to middle school the following year, team members should conduct their various evaluations with an eye to the skills the child has and will need for the next level. The same application is relevant to older adolescents who may be transitioning out of the school system to other programs, work or residential living. An awareness of these issues will help direct intervention efforts toward acquisition of necessary skills for later success.

Evaluation and Assessment Procedures Should Address the Functionality of Skills and the Ability to Generalize to Relevant Domains

Evaluation and assessment procedures for children and adolescents in this age should begin to juxtapose the skills demonstrated with their ability to be useful in daily living and functional domains. Children with ASD often may have considerable strengths in specific areas (i.e., rote memorization, labeling), but be unable to use these abilities in more functional and socially appropriate ways. The task of the clinical assessment team is to detail the child's individual profile and evaluate curricular goals to make them appropriate to the child's learning style, ability and the functional needs of the child and family.

Best Practice:
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.

Best Practice:
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.

Chapter 6
Referral Process

In essence, the diagnostic process for persons age 6 and older is somewhat different from that for younger children and may involve a reformulation of earlier diagnostic impressions. Initial queries may originate with parents, medical or school personnel. As stated for younger children, the referral process should be streamlined so that children and families gain access to a comprehensive evaluation as quickly as possible.

The referral should lead to an initial evaluation that is most appropriate for the child and family in terms of efficiency, cost and initiation of services. Depending upon the background information, referral to a clinic that specializes only in ASD may not be the first step.

Issues Precipitating Referral in the Older Child

Children who first present for evaluation at school age or older generally do so with parental and/or school concerns regarding social deviance. For children who have never received a clinical diagnosis, school may be their first experience in a structured setting. Behaviors that are acceptable in a familial or cultural context may be incompatible with the school environment. Children with Asperger's disorder, who previously may have been regarded as eccentric, unusual or exceptionally bright, are identified when social difficulties with peers and behavioral anomalies become incompatible with formal learning environments. Factors that lead to referral in this age group may be summarized as follows:

- Evaluation of change
- Initial diagnosis of autistic spectrum disorder
- Social deficits
- Academic expectations
- Ecological considerations
- Diagnostic considerations

Tracking and Evaluation of Change

The phenotypic expression of autistic spectrum disorders (ASD) in children is subject to change with developmental maturation, intervention and environmental responsivity. For example, sensory abnormalities appear to be more relevant to younger than to older children (Eaves & Ho 1996; Lord et al., 1993). It is not uncommon for children with an early childhood diagnosis of autistic disorder or PDD-NOS to grow and respond to intervention to a degree that they no longer meet criteria for an ASD or meet criteria for another ASD or learning/behavioral disability. Diagnostic evaluation serves the purpose of conceptualizing the child's current profile to guide intervention planning and to reevaluate service delivery needs. Parents and educators will have different questions and concerns for the older child that differ somewhat than those for younger children.

Initial Diagnosis of Autistic Spectrum Disorders

Children presenting at this age for initial diagnosis may have been overlooked altogether or described as having childhood difficulties outside of the autistic spectrum (see issues related to differential diagnosis). Given the improvements in diagnostic and screening procedures over the last decade, it can safely be hypothesized that the former group is in the minority. Often, these tend to be children functioning towards the higher end of the spectrum. Children with Asperger's disorder are typically referred for assessment relatively late in their development. Because their limitations go unnoticed, or are not perceived as impairing, these children are often not referred until school age (Volkmar et al., 1996). However, by the time these children enter school, their behavior is likely to be more discrepant from that of same-age peers as demands increase for social and communicative conformity and competence.

Furthermore, children who were later diagnosed with Asperger's disorder evidence fewer adaptive impairments during the preschool years. Although parents and early childhood educators may have noticed differences, the differences were not so exaggerated as to cause significant distress for the child and family and warrant specialized evaluation. Ecological variables such as family, community and cultural environment may also mediate the apparent dysfunctional quality of adaptive behaviors. In particular, first-born or only children may not be identified until later as these parents may have little or no basis for comparison.

Social Deficits

Compared with children birth through age 5, individuals age 6 and older typically demonstrate signs and symptoms of interactive social deviance and/or behavioral anomalies in marked contrast to same-age peers. Language, social and, often, cognitive deficits manifest differently in older children. "Higher-functioning" children may not have been identified due to normal cognitive functioning and social features that manifest as more atypical with increasing social and behavioral

demands. Similarly, children with mild cognitive impairment (either undetected or misrepresented) are sometimes placed in socially inclusive situations where the inability to interact at an age-appropriate level becomes apparent. Only as social expectations increase with chronological age do clear difficulties with environmental adaptations begin to emerge. Similarly, this is often perceptible in children with other behavioral disorders where difficulties with social interaction are marked as expectations increase. Developmentally, children are more selective in friendships at school-age and are less tolerant of oppositional, hyperactive or fearful behaviors that set a child apart from peers. "Failure to develop peer relationships" is a common reason for an initial referral in children over the age of 5. Such a referral should be carefully reviewed with respect to all relevant domains of functioning and situational factors.

Academic Expectations

Furthermore, academic expectations change as children progress through elementary school. Able children, i.e., those with less pronounced social and behavioral deficits, might experience challenges when learning becomes more dependent on abstract thinking rather than concrete information. Such a child may be referred when special education or resource services are suggested or when acting-out behaviors and further distancing from peers becomes distinct in response to increased learning and social challenges. Similarly, a child in third grade—a time when social expectations among peers have increased significantly—may exhibit significant behavioral disturbance or difficulties with social activities. This is often the time when learning becomes more abstract and less reliant on concrete operational skills.

Ecological Considerations

Occasionally, delays in identification are a result of familial, cultural or other demographic factors. Families that are in significant psychosocial distress may be either less attuned to subtle differences or extremely tolerant of aberrant behavior in the midst of chaos. Still others may well recognize that their child's development is different or atypical from siblings or other children. When these differences are subtle, parents or caregivers may knowingly or unknowingly compensate for deviances through adaptation, rationalization or by ensuring the child is within a protective environment such as a private preschool. It is not until school age when teachers and educators recognize that learning needs cannot be met or that behavioral problems develop in response to social challenges, that families are prompted to seek evaluation.

Although parents have the greatest knowledge of their child, they often demonstrate a high degree of adaptation to their child's pattern of communication and behavior (American Academy of Child and Adolescent Psychiatry, 1999). Many other parents, depending on their level of education and other cultural and socio-

economic factors, have neither sought a diagnosis nor accepted an alternative explanation. Consequently, it is more plausible to think of these children as "incompletely" diagnosed rather than misdiagnosed. These may be children who have been evaluated through the education system for services and who did not receive other evaluations. The educational classification may be appropriate for initiation of services at a given time, and child response was such that parents did not feel the need for further evaluation. It is when intervention must be reconsidered or access to services requiring a more "official" (i.e., *DSM*) diagnosis is needed, that a formal evaluation is sought.

Diagnostic Considerations

The clinician must be alert to the possibility of diagnosing one or more coexisting conditions even when clinical features that are specific to criteria for ASD are present. Sometimes children are referred based on symptoms associated with a coexisting condition. While these diagnoses are not incorrect, they are incomplete. An example would be children given diagnoses of mental retardation in early childhood. The initial diagnosis may be correct but not fully capture the impact of an ASD on rate and style of learning. Still others present with attention-deficit/hyperactivity disorder, oppositional defiant or other behavioral disorders. In a small percentage of cases, these may be an unrecognized ASD. In others, an ASD is accompanied by other coexisting features that should remain a significant focus of clinical attention and intervention.

Many times, children cannot be placed precisely within a single diagnostic category, but seem to have features of similar but associated conditions. This is not the fault of the clinician or service systems, but rather, the fallibility of diagnostic classification systems and the difficulty in disentangling the components leading to clinical difficulties in children. Diagnostic and classification schemes are plagued with challenges to well-established reliability and validity for childhood disorders (Mash & Dozois, 1996). These concerns include 1) under-representation of disorders of infancy and childhood; 2) the failure of systems to represent the diagnostic overlap and interrelationships that exist among childhood disorders; and 3) limited sensitivity to the developmental, contextual and relational parameters that are known to characterize most forms of psychopathology in children. Consequently, children with more than one diagnostic description are referred for an evaluation for ASD in a search for diagnostic unity.

Referral Considerations

In light of these factors, it is apparent that the referral process is infinitely more complex among school-age children and adolescents. Diagnostic evaluation should encompass the primary goal of characterizing difficulties that can lead to the most appropriate intervention services for the child and family. This may not always be

realized through a diagnostic label, but rather through a detailed account of child strengths and needs along with intervention objectives. Referral for an ASD evaluation requires many considerations and a careful review of the circumstances before an evaluation is scheduled. Referring providers are not expected to have considerable expertise in ASD. Therefore, referral to a specialist is an appropriate consideration.

Additional points to consider for the referral process are as follows:

- The increasing numbers of children identified with ASD has created enormous demand for comprehensive and accurate evaluation. This has made it difficult to serve children and families appropriately. Referring entities should expect to be able to provide sufficient information as requested by the specialist clinic to determine the most appropriate course of action for a child in this age group.
- Referring clinicians and entities should be familiar with specialist resources and the scope of services provided. A careful review of the questions and concerns raised through parent, child and school report should be integrated with a review of previous records.
- The referral question drives the selection of referral resource. For some children, a referral to a clinic that specializes only in autism may not be the appropriate first choice. Undue stress is placed on parents when they are not given answers (in a case where a child does not have ASD or other issues are the focus of intervention) and are referred out. Where psychiatric concerns have been raised and/or identified in the past, it may be necessary to either have a child psychiatrist available for consultation or recommend a full psychiatric evaluation before an autism-specific evaluation is scheduled.
- The use of screening tests appropriate for younger children (e.g., M-CHAT and PDDST-II) is not particularly useful in this age group. The reliability of such instruments in this age group is poor due to difficulties in recall and the availability of information that may influence recall and perceptions of early difficulties.
- In recent years, the diagnosis of ASD has become increasingly "instrumented" in that referrals are made and children diagnosed based on the plethora of diagnostic and checklist instruments that have emerged. The reliability and validity of recently published autism/Asperger screening tools in the 6 through 22 age group has yet to demonstrate adequate reliability and validity. Measures such as the Gilliam Autism Rating Scale (Gilliam, 1995) may be used as screening devices that prompt the provider to gather more information. When used, referring parties should augment these measures with other objective sources of information to make an appropriate referral.

- Child behavior checklists such as the Achenbach (CBCL) or the Vineland Teacher Survey may provide qualitative information useful in the intake evaluation. However, it should be noted that these instruments do not have a normative database for ASD. They may be useful for describing behaviors of concern and used as a point of discussion during the intake or evaluation. It may be difficult to characterize internal resources on these measures for children who are less verbal and from which these resources must be inferred.

Best Practice:
Referring parties clearly identify the reason for referral, select the most appropriate evaluation resource, and share relevant information in a timely manner.

CHAPTER 7

COMPONENTS OF A DIAGNOSTIC EVALUATION/ASSESSMENT PROCESS

Diagnoses in Older Children and Adolescents

Best practice for conducting a diagnostic evaluation of autistic spectrum disorder (ASD) in individuals age 6 and older incorporates components of the diagnostic evaluation process for ages birth to 5 but differs in specific ways:

- Autistic spectrum disorders are associated with a tremendous range in syndrome expression—that is, symptoms change over the course of development and in relation to the degree of any associated mental handicap (American Academy of Child and Adolescent Psychiatry, 1999). The presence of autistic symptomatology is difficult to assess in children who are either functioning at a very low or very high level.
- Differential diagnosis is more challenging due to the increasing possibilities for alternative diagnoses and the long-term effects of environmental interactions on behavior. The clinician must be familiar with ASD, as well as the range of psychiatric, neurodevelopmental/behavioral disorders that are either primary or are coexisting conditions. While 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 will emerge more frequently as a potential diagnosis.
- 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 health care entities will often be a necessary component of the diagnostic process.

Primary Components

Specific activities of the diagnostic evaluation will vary depending on the child's age, history, previous evaluations and assessments and referral questions. Though the preponderance of literature reflects research and clinical observation of children birth through 5, a review of the literature and consultations with clinicians suggest the following steps as the primary best practice components for diagnostic evaluation of individuals aged 6 and older.

- Record Review
- Medical Evaluation
- Parent/Caregiver Interview
- Direct Child Evaluation
  - Interview
  - Direct Observation
- Psychological Evaluation
  - Cognitive Assessment
  - Adaptive Functioning Assessment
  - Mental Health Assessment/Psychiatric Functioning
- Communication Assessment
- Evaluation of Social Competence and Functioning
- Restrictive Behaviors, Interests and Activities
- Family Functioning

The presenting concerns offer a point of departure for the clinician in his or her investigation. While a review of records typically occurs after a decision has been made to evaluate a younger child, it is an essential component of the intake/triage process in older children. (For a listing of diagnostic and assessment instruments, see Appendix G.)

1. Record Review

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 (i.e., behavioral, speech, etc.) are also valuable sources of information. The child will also have had more contact with the community outside the family (i.e., school, neighborhood, etc.), which provides opportunity for more collateral information.

To a larger degree than working with younger children, the clinician must juxtapose descriptions of current behaviors against 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 ASD 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 milestone 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 diagnostic conclusions. The logical progression from assessment and observation to diagnostic formulation and conclusion varies with the source of information. Finally, the review of records and clarification of definitions in the parental narrative can lead to a more concise conceptualization of the current concerns.

2. Medical Evaluation

The medical evaluation necessarily includes all components addressed in these *Guidelines* for younger children. Similar to the evaluation of younger children, the medical evaluation is divided into four major components: a comprehensive medical history, the family medical and mental health history, the physical and developmental neurological examination, and the laboratory testing. In older children and adolescents, past medical records should be carefully reviewed for evidence of neurologic or systemic disease, particularly disorders that may be episodic or insidious in their onset. This might occur, for example, in children with late onset neurodegenerative disorders such as metachromatic leukodystrophy or other metabolic storage disorders. It is important to determine the temporal course of the symptoms and signs by reviewing the previous records and to establish whether previous physical, neurological and cognitive examinations have been completely normal.

Comprehensive Medical History

As is true with younger children, the comprehensive medical history has as its goals: 1) to determine any clues to the underlying etiology of the disorder; 2) to assist in the differential diagnosis; 3) to determine whether any co-morbid develop-

mental disorders are present; and 4) to determine whether any other medical or health conditions are present and /or need further evaluation or management. In addition, determining what previous testing and treatment modalities have been undertaken and their results may be very useful in determining both the differential diagnoses considered by other health providers and the family's orientation toward traditional and non-traditional approaches to health treatment.

In the neurological part of the health history, specific information should be sought about the presence of coordination difficulties and their onset. Inquires should be made about handwriting changes, participation in sports activities and ability to perform activities such as bike riding. Changes noted in the child's personality, mood or temperament should be further explored, noting any temporal relationships to other changes. Similarly, it is important to clarify whether attention span, distractibility or impulsivity is present and if so, when they were noted and under what conditions they are manifested.

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

Family Medical/Mental Health History

Family medical history is important to assist with diagnosis and with identifying potential coexisting conditions. Questions should specifically probe the nuclear and extended family for autism, mental retardation, fragile X syndrome and tuberous sclerosis complex because of their implications regarding the need for chromosomal or genetic evaluation. Learning problems should be further explored, including the need for special education services in family members. The presence of learning problems may indicate the possibility of undiagnosed conditions such as mild mental retardation. Similarly, full exploration of the presence of mental health disorders in the extended family should be performed. Disorders such as schizophrenia and bipolar disorders have a high heritability component, and this information may be helpful in the differential diagnosis of the child.

Physical and Developmental Neurological Evaluation

A complete physical and neurological exam should be completed as outlined for younger children. This should include an expanded medical and neurological evaluation which is important to rule out other medical conditions that may cause the current symptoms, as well as to compare developmentally appropriate behavior with deviance. Neurological dysfunction is common in children with ASD, with abnormal neurological signs occurring in 75 percent of autistic subjects in a 1996 Bieber-Martig study (Volkmar & Klin, 1998). These may be abnormalities in deep tendon reflexes, abnormal muscle tone, or in optomotric control, which will be seen in the traditional neurological examination. In addition, however, many children with ASD will have neurological dysfunction manifest on the developmental neurological examination, consistent with research studies that found mild abnor-

malities in the cerebellum in adults with ASD. In particular, the clinician should look for difficulties with gait or postural positioning and fine motor impairments such as dysdiadochokinesia or intention tremor.

Medical Tests

The need for additional medical and/or laboratory tests may become obvious, based upon the history and physical examination. In many cases, children under the age of ten may have had significant medical testing. This is particularly true in those with identified cognitive impairment for which the presence of an additional ASD is in question. The results of these tests should be reviewed, and the methodology employed, to determine whether there is a need to repeat them. Some conditions, such as fragile X, have had newer tests developed in the recent past which may warrant them being performed again. In addition, some metabolic conditions may have inconsistently positive results during the early years and warrant repeat testing if the condition is suspected even with a previously negative test result. As recommended by the College of Medical Genetics, selective metabolic testing should be initiated only in the presence of suggestive clinical and physical findings (Curry *et al* 1997).

Similarly, cases where several years of normal development are followed by a marked developmental regression may suggest the need for further neurological evaluation (Volkmar et al., 1999). With adolescents, one should evaluate the possibility of a seizure disorder, particularly in the face of behavioral deterioration and lower cognitive functioning (Mesibov & Handlan, 1997; Minschew, Sweeney & Bauman, 1997). Hearing and visual acuity should be rechecked as part of the medical evaluation, since both are common impairments in children with developmental disabilities and impair function.

3. Parent/Caregiver Interview

Initially, the clinician should clarify the nature of the evaluation and its consistency with parental expectations. Many times, older children present for evaluation as the result of conflict with service providers as to the nature of the child's difficulties and the most appropriate course of intervention. A comprehensive developmental history, generally in the form of a parent or caregiver interview, is the cornerstone of the diagnostic evaluation process. Adequate and reliable historical information facilitates the process of diagnostic evaluation and differential diagnosis. Traditionally, the parent/caregiver interview has served as the source for historical information. Securing the sequence of developmentally appropriate behaviors is also important. The parent interview should also include a careful review of medical and family history.

Parent interviews 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 challenged is the memory of a parent, sibling, family member or other caregiver. 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 to have both parents and/or another significant caregiver, such as a teacher or close family friend, present. 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.

In addition, while parents have the utmost knowledge of their child, they also often have the highest degree of adaptation to their child's nature of communication and behavior for "low-" and "high-functioning" children. Compensation for subtle or more pronounced child deficits may not be apparent (Volkmar et al., 1999). Further, some parents may reframe concerns in terms of their own experiences or that of relatives or friends (e.g., "I wasn't popular at school either, but I never did..."). Such reframing is particularly likely if personal projections are less disturbing than an alternative conceptualization.

Guidelines for Interview

1. Whenever possible, it is important to obtain objective rather than subjective descriptions of behaviors. For example, family videotapes and/or fifteen minutes of video with another child are a good basis for discussion. Review of child behavior in this manner with the parent also helps them to understand the types of behavior and style of interaction that are the focus of clinical attention and develop a common language to guide the interview.

2. In addition, probing specific events like a birthday or holiday celebration can be more helpful in eliciting detail than a broad question that demands a caregiver reflect on years of memories (Klin, Sparrow, et al., 2000).

3. Formal interview instruments play an increasingly important role in retrieving and reconstructing a child's early history, particularly as time lapses between the child's early years and current evaluation (Lord et al., 1997). Consequently, familiarity with standardized interview measures, in addition to awareness of the range of symptom expression and appreciation of the complexities of developmental change, are crucial for diagnostic evaluation purposes.

To date, the Autism Diagnostic Interview, Revised is the most reliable standardized measure to obtain an early developmental history of autistic behaviors (Lord,

Rutter, et al., 1994). The same cautions presented in the section on birth through age 5 regarding the use of the ADI-R apply to its use with older children as well: its validity is strongly dependent on appropriate training and familiarity with autism. The ADI-R is able to detect the likelihood of an ASD. However, as it is not normed on other populations of children or designed to differentiate between other clinical groups, it may yield false positive results when administered to parents of children with other difficulties. As indicated in the birth through age 5 section, parent interview should not rely solely on diagnostic instruments, although these can serve as a way of organizing discussions and behaviors. Instruments designed to ascertain the likelihood of ASD are generally not sufficient to gather information regarding differential diagnosis or symptoms of other disorders.

The developmental information needed to diagnose children birth through age 5 presented in Chapter 2 is appropriate for older children as well. In addition, the clinician will need to gather more information regarding current functioning in school and at home, as well as child activities and interests. However, no single measure provides a definitive diagnosis: data from an instrument must be interpreted in context as a component of the diagnostic process.

The parent interview should also include a thorough history of other developmental, learning and/or psychiatric problems in the family. Autistic spectrum disorders are not unique in heritability (Pulver, Brown & Wolyntec, 1990; Werry, 1992). Specifically, data has shown that no increased risk of psychotic or mood disorders exists in families of children with autism. However, an increased risk does exist in families of children with similar psychiatric problems. Issues such as these should be considered carefully in the differential diagnostic process in order to determine the description of child needs. In ambiguous child presentations, a significant psychiatric history may indicate difficulties other than an ASD that warrant attention and intervention.

4. *Direct Child Evaluation*

Interview

With verbal children and adolescents, information may be gathered through direct child 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 communicative skills and style of the verbally fluent child. These factors are particularly enlightening regarding differential diagnosis and exploration of pragmatic deficits. They include:

1. The ability to manage conversational interchange—topic management, initiation: response ratios, shifting, maintenance and extension

2. The ability to recognize and respond to clarification or requests or to request clarification
3. The ability to interpret non-literal language accurately, humor, sarcasm, irony, etc.
4. The ability to recognize indirect and polite forms
5. The awareness of a need for shifts in register—i.e., teacher/student; peer/peer (this may be observed in other contexts)
6. The capacity to modulate tone and volume and other prosodic features
7. The flexibility in dealing with a range of situations and ability to modulate response
8. Nonverbal communication—this includes shifts in eye gaze, body positioning, etc. (Marans, 1997)

These factors are often helpful in establishing differential diagnostic features of communicative style, regardless of language content. For example, very few persons with Asperger's disorder are reluctant to discuss their area of interest with minimal prompting. They are also not usually prone to allow the interviewer to expand or add information or share their own interest. 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. Experienced clinicians in ASD have found that adolescents who have conditions other than ASD typically evidence extreme reluctance or refusal to be videotaped or observed.

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. The ADOS-G (discussed in more detail in the birth to 5 section) has been designed specifically to elicit language and behaviors consistent with ASD. The module chosen is based upon the language level of the child or adolescent. It should be noted that the ADOS-G is not designed to identify or diagnose other clinical disorders. Techniques to supplement this instrument may be necessary to obtain further information. In children where disorders of thought processing are probable, interviews designed to elicit this information may be more appropriate (refer to "Mental Health Assessment/Psychiatric Functioning" in this chapter).

Clinical expertise in interviewing children is crucial at this stage. This includes an understanding of the response style of children at various ages and developmental levels, children with ASD 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 in 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 autism. Reluctance to participate may be marked in children with significant anxiety and those where oppositional or conduct disorders are prominent. Play interviews are entirely appropriate with children in the 6 to 10 age range and may be particularly revealing. Internal concerns of children are often more amendable to play assessment rather than direct questioning.

Direct Observation

Observation of play and activities is relevant to children and adolescents but is particularly applicable to younger children where play is age appropriate, to children with significantly impaired verbal skills and to children functioning at lower developmental levels. Major aspects of social behaviors are elicited through unstructured and structured observations and interactions with the child or adolescent. Child observation occurs throughout the evaluation and intervention planning assessment process. The findings from the observations are incorporated into the examination of all domains (communication, behavior, mental status, social, etc.). Objectives of the observation include:

- Identifying behaviors and symptoms relative to *DSM-IV* criteria
- Corroborating information received through other data sources
- Recognizing behaviors as points of discussion with parents. Discussion should focus on representativeness of behavior and whether or not the behavior is typical of the child in familiar environments.
- Gaining a sampling of behavior in both structured and unstructured conditions/interactants

BEST PRACTICE:
Accuracy of assessment of older children and adolescents with adequate language skills requires a face-to-face interview.

It is important to emphasize that behavior may not be representative of the child in typical environments and with familiar others. If not readily available, the clinical team may request videotapes or arrange observations of the child in naturalistic environments. If the child has siblings, it is helpful to encourage parents to bring them to the evaluation. This is of course dependent upon the comfort level of the parents and upon clinic resources. Observations of the child with siblings, while not a substitute for peer interaction, can reveal useful information that would not otherwise be apparent through interactions (or play) with adults.

5. Psychological Evaluation

Cognitive Assessment

Establishment of cognitive potential is crucial for determining differential diagnosis and intervention planning purposes. While the use of any single score to describe the abilities of an individual with ASD is clearly inappropriate, a measure of overall

intellectual level, or subtests, helps to establish a framework against which specific diagnostic criteria can be judged and within which other aspects of behavior can best be evaluated (American Academy of Child and Adolescent Psychiatry, 1999). Measures of cognitive functioning should include more standardized assessments, to ascertain response to structured situations, as well measures of adaptive functioning to examine the application of abilities to everyday life skills.

The purposes of cognitive assessment vary somewhat with respect to the child's age, needs and referral questions. Many children in this age group are in the special education system of their local school district and may have had recent psychoeducational evaluation. The decision to repeat testing is based upon the recency of past testing and the extent to which it is a valid representation. When questions concerning the validity of recent testing prompt repetition of a test, it is wise to select an alternative but comparable instrument.

There are occasions with older children and adolescents where cognitive and academic performance is not a source of concern. These are children who are functioning at grade level and who do not present with academic or learning challenges. Referral questions in this group typically center on significant behavioral and/or social concerns. In these examples, other assessment domains (adaptive, psychiatric interview, etc.) may be a focus of clinical attention. When records of standardized testing indicate stable cognitive abilities across time, the Wechsler Abbreviated Scales of Intelligence (WASI) may provide sufficient data for evaluation purposes.

Several issues are pertinent to the assessment of older children with ASD:

- Children with ASD can vary widely in terms of cognitive functioning. However, the clinician at this stage of development can be more certain regarding the validity and stability of testing results (Klin & Shephard, 1994) which are extremely valuable in terms of intervention planning, prognosis and differential diagnosis. Tests matched to the child's level of developmental functioning indicate that cognitive assessments are as reliable in children with autism as in other groups (Rutter, 1995).
- Issues of diagnosis are particularly more complex at the extremes of the cognitive range. Similar to the younger age group, it is important to refrain from extrapolating from highly specific, or splinter, skills to other areas of cognitive and adaptive functioning.
- For purposes of differential diagnosis, establishment of cognitive abilities is key. Children and adolescents with significant mental retardation often display features of autism and pervasive developmental disorders. A diagnosis of an ASD is warranted in these cases when the social and communication skills are impaired relative to the child's overall developmental level.

- Specific profiles have been noted in the results of cognitive assessment of children with ASD and other behavioral and learning challenges (Minschew & Goldstein, 1998). For example, children with Asperger's disorder often have higher verbal than perceptual organizational abilities, in contrast to the opposite profile seen in children with autism and pervasive developmental disorder. Furthermore, children may achieve "normal" IQ scores in both verbal and nonverbal processing on standardized tests. Yet, examination of subtest scores indicates significant scatter, with one or two extremely high scores on some subtests and significant impairment on others. This often is not reflected when examining either full scale IQ or separate verbal/performance IQs. Children in the higher functioning range often test in the normal ranges of verbal functioning through skill in recalling rote material but have significant impairments in generating relevant social information.
- Recognition of the floor effects inherent in many standardized IQ tests for children and adolescents is another key issue. This is particularly relevant when assessing those children who function at lower developmental levels. A 12-year-old who has been assessed previously at a 2- to 3-year-old level may test within the moderate to mild mentally retarded range of functioning on the WISC-III with no correct responses, due to the insensitivity of the measure at lower levels of functioning. This engenders an extremely erroneous view of the child's functioning and is essentially not helpful for intervention planning. Tests must be chosen in accordance with the child's estimated level of development and language ability.

With older children, the clinician has a wider array of assessment choices than that for a younger child. In the selection of tests, appropriate consideration should be given to the goals of the assessment and the strengths and weaknesses of the child. This may involve the use of instruments that are appropriate for younger children or nonverbal instruments. Higher-functioning children often continue to need assessment with instruments that minimize verbal requirements.Selected tests are listed below. Please note that the list is not mutually exclusive nor is it exhaustive.

- **Standardized Tests**

  Wechsler Preschool and Primary Scales of Intelligence, Revised

  Wechsler Intelligence Scale for Children, 3rd Edition

  Wechsler Adult Intelligence Scale, 3rd Edition

  Stanford Binet, 4th Edition

  Kaufman Assessment Battery for Children

  McCarthy Scales of Children's Abilities

- **Nonverbal Tests**

  Leiter International Performance Scale - Revised

  Merrill-Palmer Scales of Mental Tests[1]

- **Standardized Tests with Minimal Verbal Requirements**

  Kaufman Assessment Battery for Children

- **Tests for Younger Children**

  Bayley Scales of Infant Development-II

  Mullen Scales of Early Learning

  Merrill-Palmer Scales of Mental Tests

The Wechsler tests are preferred for higher-functioning and older individuals with relatively good verbal language (Volkmar et al., 1996). These instruments separate functioning into verbal and performance scales and provide further indices of attention and distractibility, as well as speed of processing. This information is useful for differential diagnostic purposes and identifying areas of strength and deficit in an otherwise normal profile. Examination of subtest scores may reveal relative strengths in recalling rote information and significant deficits in sequencing social stimuli and demonstrating social judgment. Findings of a normal IQ in light of extreme scatter among scores and regression to the mean should be interpreted with caution and may not be indicative of adequate skills for everyday situations.

Tests that minimize verbal comprehension and expression are indicated for children with minimal language. The KABC, although less psychometrically sound then the Wechsler series, requires minimal oral language, but some ability to attend to and process instructions. The incorporation of achievement subtests into the battery is helpful in assessing academic skills in school age children and their relationship to overall cognitive level and ability.

Other instruments are designed to require little or no receptive and/or expressive language. The Leiter International Performance Scales, Revised is a test of nonverbal intellectual functioning ability for children ages 2 through 20. By design, the instrument requires no expressive or receptive language on the part of the child.

Regardless of the chosen instrument, the goal of the cognitive evaluation is to gain insight into the child's ability to solve problems, apply and process information and tolerate structured learning demands, as well as identify the child's strengths, weaknesses and processing preferences (visual, auditory). Review of other clinical data throughout the diagnostic evaluation should be appraised with respect to current developmental level.

[1] Norms for this instrument are significantly out of date. It is included due to its utility in estimating nonverbal functioning in children at lower levels of ability and its minimal reliance on verbal comprehension. A useful measure for identifying significant strengths and weakness but tends to overestimate IQ.

Adaptive Functioning

Adaptive skills are those necessary for personal and social self-sufficiency in real-world situations (Sparrow, Balla & Cicchetti, 1984). Assessments of adaptive functioning obtain a measure of a child's typical patterns of functioning in familiar and representative environments and provide the clinician with an essential indicator of the extent to which the individual is able to use his or her potential in the process of adaptation to environmental demands (Klin, Sparrow, et al., 2000). For example, many higher functioning children with autism, while scoring in the normal range on IQ tests, are functionally impaired in that they are unable to generalize or demonstrate their abilities in daily situations.

A diagnosis of mental retardation requires deficits in adaptive functioning in addition to intellectual impairment (American Psychiatric Association, 1994). In the absence of mental retardation on traditional intelligence testing, a child may still be considered functionally impaired if the extent of their difficulties causes clinically significant impairment in daily functioning (personal, social, academic). Thus, a profile of adaptive skills is crucial for diagnosis as well as differentiating other conditions.

There is evidence to suggest that overall cognitive ability has a stronger relationship to adaptive functioning in children at lower developmental levels. Higher-functioning children demonstrate wide discrepancies (Liss et al., 2001). Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills (AAMR, 2002). Often with ASD, social and communication domains are significantly below estimated cognitive potential (Liss et al., 2000). This appears to be more marked in children of higher ability. Suggested adaptive behavior scales are listed below:

1. The Vineland Adaptive Behavior Scales (VABS)
2. Alpern-Boll Scales
3. AAMD Adaptive Behavior Scales
4. The Scales of Independent Behavior – Revised

In summary, a thorough evaluation of adaptive skills is necessary for purposes of diagnosis and intervention planning. Particularly with higher-functioning children, large discrepancies between cognitive performance and adaptive behavior indicate immediate targets for intervention and changes in instructional strategies. Continuing deficits in adaptive skill areas will have a major impact on the child's adjustment and on family stress. Risk of adjustment problems increases as the child grows older and environments are more complex.

Mental Health Assessment/Psychiatric Functioning

It is important to obtain information that will eventually help differentiate ASD from other psychiatric disorders and/or determine the presence of coexisting psychiatric conditions. Some of these are depression, anxiety disorders, attention-deficit/hyperactivity disorder, Tourette's disorder, bipolar disorder and psychotic disorders. In the case of school-age children, parents can provide historical information regarding these symptoms. With adolescents, both parents and the child can provide historical information.

Clinical Diagnostic Interviews

Psychiatric interviews designed to confirm or rule out other diagnoses in children and adolescents are useful provided that careful consideration is given to differentiation of communication patterns typically found in ASD. Some of these interview tools include:

Diagnostic Interview Schedule for Children (DISC)

Diagnostic Interview for Children and Adolescents, Revised (DICA-R)

Schedule for Affective Disorders and Schizophrenia for School Age Children (K-SADS)

Interview Schedule for Children (ISC)

The use of such instruments should be supplemented with more clinical interviewing and play/activity-based assessment as appropriate. As with instruments for ASD, the use of structured interviews for children requires training in their use and knowledge of the constructs they purport to assess.

Projective Tests

Projective assessments may be helpful in the differential diagnosis. While traditional methods of projective assessment are of no particular use with children with ASD, they may be informative when the clinical team suspects other childhood difficulties. As with all psychological tests with children and adolescents, considerable experience and training in the administration and interpretation of such instruments is essential. In differential diagnosis, this additional source of data may be compared and contrasted with other information.

Other Instruments

Other self-report measures appropriate for use with children and adolescents may be helpful in the differential process, particularly with those who have difficulty with more direct methods. The majority of these instruments are appropriate for

older children and adolescents. The same precautionary measures apply as for the use of all psychological tests. A sample of such instruments would include:

- The Minnesota Multiphasic Personality Inventory—Adolescence (MMPI-A)
- The Millon Clinical Multiaxial Inventory—Adolescence (MCMI-A)
- The Piers Harris Self-Esteem Scale
- The Achenbach Child Behavior Checklist—Youth Self-Report

Mental Status

A mental status examination should also be a component of the evaluation process for persons with suspected ASD. This will help the clinician focus on non-autistic psychiatric symptoms. These include mood, affect, current suicidal and homicidal ideation, thought disturbances, overactivity, distractibility, oppositional behaviors and motor and vocal tics. When interpreting the mental status examination, the individual's social deficits, level of concreteness and overall cognitive abilities must be taken into account. For instance, a person with language deficits who is asked if they ever hear voices may reply yes, even though they do not truly have auditory hallucinations, because they were referring to their own thoughts.

BEST PRACTICE:
When the evaluation and assessment requires differential diagnosis of psychiatric disorders, the clinician seeks further referral and/or consultation when indicated.

In summary, the evaluation and assessment of older children and adolescents requires clinical familiarity with the symptomatology of psychiatric disorders. The diagnostician prepares to conduct a review of psychiatric symptoms (e.g. vegetative symptoms of depression, suicidal ideation, sleep disturbance, motor and vocal tics, difficulties concentrating, hyperactivity, impulsive behaviors) with the family and child, if appropriate. If a review of psychiatric symptoms is not possible, further referral or consultation should occur before rendering a premature diagnostic conclusion.

6. Communication Assessment

For older children and adolescents, the communication assessment is fundamental to the comprehensive diagnostic evaluation. The assessment of communication should provide information on the communicative abilities of both verbal and nonverbal children. This component of the evaluation should not be restricted to the more formal, structural aspects of language such as articulation and receptive/expressive vocabulary. Particular attention should be paid to the pragmatic, social communicative functions of language as well as to nonverbal skills used to communicate and regulate interaction.

Children suspected of having an ASD can present with a wide range of language abilities at school age and in adolescence. With verbally fluent children, the evaluation should focus on the social pragmatic uses of language in addition to more structural skills.

Verbal Children and Adolescents

For differential diagnosis, an assessment of language use is essential. For children with language skills, the evaluation should strive to delineate patterns consistent with ASD across the range of language level from those seen in children with other challenges. Often this involves a detailed assessment of nonverbal communicative behaviors, as unusual language features (e.g., echolalia, neologism, stereotyped speech) are not specific to autism (Bishop, 1994). Standardized speech, language and communication assessments conducted in formal testing situations may provide important information about specific parameters of speech and language functioning. However, such assessments may provide only limited information about social-pragmatic abilities (i.e., use of language and communicative abilities in social contexts), which are characteristically limited and difficult to detect in more verbally fluent children with ASD. Reliance on traditional measures of language may lead to findings that are incomplete or misleading. Therefore, communication assessment in this group of children is more reliant on an ecological approach, which incorporates understanding of communicative behaviors within the context they occur (Wetherby, Schuler & Prizant, 1997). The identification of discrepancies across environments provides important information as to how to help the child generalize and adapt skills across a variety of functional contexts. Therefore, a variety of strategies should be used, including direct assessment, naturalistic observation and interviewing significant others, including parents and educators, who can be invaluable sources of information (Prizant & Wetherby, 1993; Stone & Carol-Martinez, 1990). Observations could include a child's interactions with a variety of persons, including family members and peers, as well as professionals, because variability in communicative functioning across persons and settings is to be expected (Wetherby et al., 1997).

Developmental Language Disorders

Children with expressive language disorders invariably have difficulties with peers although there is typically compensation through nonverbal means of communication, appropriate imaginative play and social reciprocity. Children with receptive language disorders can be more difficult to differentiate. In this group, social skills and imaginative play are consistent with language level and are often delayed relative to same-age peers. They may demonstrate echolalia and stereotyped speech. Ritualistic behaviors may be present but are not as severe as those seen in autism. These children typically have few peer relationships and may gravitate towards younger children who are closer to their language level. While a language delay may have been noted in the preschool years, social difficulties may become more pronounced, as peers become more language competent. Clinically, skill deficits begin to ameliorate as language improves and are typically more in line with language level. While these skills also improve in children with ASD through development and intervention, imaginative and social capacities are often markedly behind language level.

Asperger's Disorder

Children with Asperger's disorder, more so than autistic children with verbal skills, may demonstrate age-appropriate skills on traditional tests of language, including articulation, fluency, vocabulary, syntax and reading (Minshew, Goldstein & Siegel, 1995). In Asperger's in particular, the lack of clear language delay usually leads to later clinical recognition than with other ASD (Volkmar & Cohen, 1991b). Yet, the language in Asperger's clearly is not normal in that it is not used effectively for communication. Speech is often concrete and literal, and answers often "miss the point." Clinical and empirical review has identified the following characteristics commonly found in children with Asperger's disorder (Klin, Sparrow, et al., 2000):

- Speech marked by poor prosody, although inflection and intonation is not as rigid and monotonic as in autism (Fine, Bartolucci, Ginsberg & Szatmari, 1991).
- Rate of speech that is unusual or lacking fluency.
- Frequent failure to appreciate the nuances of social situations in modulating voice volume.
- Tangential and circumstantial speech. This often occurs in Asperger's disorder due to failures to provide background for comments and to clearly demarcate changes in topic. It is extremely important that this be carefully differentiated from the looseness of associations and incoherence characteristic of persons with schizophrenia.
- Marked verbosity. This is particularly apparent when the child or adolescent begins to discuss a topic of interest and engages in a one-sided monologue. Except in extreme circumstances, it is highly unusual that a person with Asperger would be reluctant to discuss a particular circumscribed interest should the clinician mention the topic. It is helpful for the clinician to identify supposed circumscribed interests before the assessment to gauge the quality of the child's interest and ability to shift topic.

Other Disorders

When differential diagnosis is the major clinical question, the language assessment must consider communication manifestations in children with other difficulties. Children with cognitive impairment often demonstrate language skills commensurate with their overall mental age. Those with attention-deficit/hyperactivity disorder (ADHD) often blurt out responses impulsively and may have concomitant language disorders. Anxious children may be reluctant to speak or do so in a whisper or low tone of voice. A similar situation may occur with an adolescent with a history of conduct problems who demonstrates a refusal to speak or answers in monosyllables. Finally, the language of higher-functioning children with autism or Asperger's disorder must be carefully disentangled from that of schizophrenia

spectrum disorders when characterized by tangential speech or loose associations, but lack the other hallmarks of ASD.

Nonverbal/Minimal Language Children and Adolescents

Children with limited or no functional language presenting after the age of 6 also require detailed language assessment. Such a child may have unidentified autism or may be equally likely to have a non-autistic developmental disorder. An accurate assessment of comprehension is especially important. Therefore, as much information as possible should be gathered regarding the child's preferred mode of communication (e.g., augmentative, gestural). For differential diagnosis, the clinician must examine the child's level of language skills relative to overall developmental level. More traditional language tests may be used to gain an understanding of comprehension skills. These language tests should also include a detailed examination of nonverbal communication, particularly deficits typically associated with autism (discussed below).

Communication Assessment Tools

Traditional Language Assessment

- Clinical Evaluation of Language Fundamentals, 3rd Edition
- Test of Auditory Comprehension of Language, Revised
- Peabody Picture Vocabulary Test, 3rd Edition

Assessment of Pragmatics

The lack of standardized assessment tools to measure some of the more subtle aspects of speech and communication necessitates the use of more informal procedures and thus demands considerable skill and experience on the part of the clinician.

- Test of Language Competence—Expanded Edition
- Test of Problem Solving—Elementary; Test of Problem Solving—Adolescents
- Test of Pragmatic Language

Nonverbal Communication Assessment

The assessment of nonverbal communicative behaviors consists of analysis of sociocommunicative and socioaffective behaviors. These include:

1. Eye contact and the use of gaze to communicate intent and share attention
2. Gestures such as pointing and coordination of gesture with eye gaze
3. Body language—recognition of personal space
4. Turn-taking skills

5. Use of facial expression to communicate. It is important to note the range of facial expression understood and used by the child. Depending on developmental level, some children with autism can comprehend extreme interview emotions (happy, sad, angry) through facial expression or intonation. Subtler expressions such as guilt shame, disapproval or mild approval may be missed and are seldom used except in the most able children.

Observation of the non-language aspects of communication should ideally occur across settings and under differing degrees of structure and interactive partners. Whenever possible, videotapes of the child in familiar comfortable surroundings can suffice when direct observation is not feasible. Videotapes from educational settings are extremely helpful but are subject to confidentiality constraints (recording non-target students). In the clinical setting, observations should be obtained of the child interacting with parents and other family members as well as professionals. If possible, this should occur during both structured (interview) and unstructured times (waiting room or hallway). The goal is to generate maximum information regarding the child's capacity for social communication (with or without language) and the level of support and structure needed for optimal performance.

Assessment of these domains is particularly crucial when differential diagnosis involves children at the extremes of verbal fluency and associated compound issues. Children who have well-developed language skills may demonstrate increased competence under structured testing conditions. Their difficulties are often apparent when situations require more flexibility and the rapid processing of social information. Difficulties will likely be encountered in unstructured settings with peers or novel situations. When practical considerations contraindicate observation of the child in more natural settings, unobtrusive observation of the child with family members during waiting periods may offer insight. Children who do not have ASD often demonstrate competence in sociocommunicative behaviors regardless of language quality. This may also be more apparent in naturalistic settings and unstructured observations of the child or adolescent in the clinic setting.

With nonverbal children and adolescents, a diagnosis of ASD is predicated on social and behavior deficits significantly below developmental age. In this population, it is crucial to have a current assessment of cognitive functioning and adaptive skills. The communication assessment should focus strongly on the nonverbal aspects of communication, communicative intent and symbolic skills within the context of overall development. Children with mental retardation present quite often for an initial diagnosis of an ASD in this age group. This likely is due to the failure of earlier diagnostic evaluations to accurately convey information to parents and educators. The child's developmental level may be in question or poorly understood. In differential diagnosis, the key task is to evaluate communication

within the overall level of development. Children with mental retardation often show communicative behaviors commensurate with their mental age.

Measures with nonverbal/preverbal communicative components include:

- Communication and Symbolic Behavior Scales
- Autism Diagnostic Observation Schedule

7. Evaluation of Social Competence and Functioning

The determination of social functioning is fundamental to the diagnostic evaluation in the school-age child. Children with ASD vary widely in their capacity for social comprehension and successful interaction. Variance is primarily related to degree of cognitive and language impairment and response to and quality of intervention. Social problems are also a common occurrence in many other childhood disorders and must be qualitatively evaluated against the pervasive impairment found in ASD. Furthermore, difficulties with peer relationships are a common basis for referral of children in this age group. Consequently, the assessment of social functioning requires data collection from multiple sources. These include:

- **Observation during the evaluative assessment.** Appraisal of capacity for social relatedness occurs throughout the assessment of the school-age child. Thus, formal testing, interviews, play observations and all other opportunities to observe interaction are times to be aware of social skills.
- **Teachers and other care providers.** Information from teachers as to typical behaviors in school and relationships with peers adds valuable information to a comprehensive appraisal of social functioning. School personnel also have the advantage of rating the child in comparison to peers. Data can be collected through questionnaires, interview or narrative.
- **Parent interview.** Parents can provide vital information as to the child's typical interactions and behaviors with siblings and peers, in familiar settings and in the community.
- **Naturalistic setting.** Once more, direct observation of the child in school or home situations is ideal. This allows the clinician to gather information regarding interest in peers and interaction and is less reliant on third-party reporting.

Social deficits are also present in numerous childhood disorders and often affect children's ability to interact successfully with peers. For example, children with ADHD or oppositional defiant disorder may be bullying, aggressive and/or intrusive with same age peers, a pattern that may lead to rejection. Such children may interact more with younger peers who can be controlled somewhat, or with older

Best Practice:
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.

peers who are more directive. Children who are anxious, depressed or fearful, or who evidence psychotic features may be withdrawn and timid about joining peer groups. Furthermore, their isolating behavior patterns may lead to ostracism by peers, resulting in rejection when they do attempt to join. Children with mental retardation are often significantly behind their same-age peers in social skills. These many factors must be carefully considered when evaluating deficits in peer relationships of the type seen in ASD in this age group. A comprehensive description of the child across settings and interactions is critical to put behavior in perspective for differential diagnostic purposes.

Measures

- Vineland Adaptive Behavior Scales (Teacher and Parent Edition)
- Child Behavior Checklist

8. Restricted Patterns of Behavior, Interests and Activities

The evaluation of repetitive behaviors, interests and activities should be evaluated within a developmental and contextual framework. Repetitive, or stereotyped, behaviors can occur in many children with ASD, as well as in the non-autistic, mentally retarded population. Therefore, the child's behavioral repertoire must be interpreted with respect to mental age. Persons with Tourette's or other movement disorders, as well as attentional impairment, may also display stereotyped movements or excessive activity. Although a relationship has been suggested between Tourette's syndrome and Asperger's disorder (Berthier, Bayes & Tolosa, 1993; Kerbeshian & Burd, 1986; Marriage, Miles, Stokes & Davey, 1993), other research has found it to be less prevalent than previously believed but higher than in the general population (Volkmar et al., 1996). Assessment of Tourette's symptomatology must be carefully evaluated within social contexts (where it may be anxiety-induced) and with respect to overall functioning in other situations and awareness of the inappropriateness of the behavior. A coexisting diagnosis of Tourette's, or other movement disorder, should be made if appropriate, as psychopharmacological intervention can improve quality of life.

Stereotyped behaviors and preoccupations with parts of objects and sensory stimuli can be observed in children and adolescents with ASD and in those with significant cognitive impairment. In children with ASD, motor excesses such as hand flapping, twirling, spinning and rocking typically are found in children at lower cognitive levels. The clinical team must distinguish between behaviors characteristic of an ASD (nonverbal mental age generally higher than communicative and social ability) and those that are consistent with an overall global impairment. These also must be separated from the over activity seen in younger children with attention deficits.

Routines, rituals and restricted activities and interests can be observed across the autistic spectrum and may be features of other childhood disorders (social anxiety and phobia, obsessive-compulsive disorder, etc.). The clinical task is to:

- Assess the functionality of routines (i.e., a bedtime routine must be distinguished from a need to tap the wall before going through a door).
- Establish the developmental appropriateness of interest and activities. Thus, it is not uncommon for younger children to have considerable knowledge of dinosaurs and to spend most of their waking hours involved in some type of dinosaur activity. A more atypical interest may be bus schedules, calendars or advanced knowledge of the solar system. Similarly, adolescent interests must be interpreted in light of the popularity of fads during any given time and the adolescent's need to become overly involved or overly identified with a certain musical figure or personality in order to be part of a group.
- Note restricted interests in other clinical conditions. Restricted and obsessive interests may be found in children and adolescents with other disorders such as obsessive-compulsive disorder (OCD), bipolar disorder and schizophrenia. Children and adolescents with OCD generally are aware of the inappropriateness of obsessive thoughts and behaviors and are often in a state of distress. Although it is difficult to infer an internal state for a nonverbal child with ASD, careful history taking and observation can generally differentiate between behaviors found in children with OCD. Furthermore, children and adolescents with bipolar disorder, schizophrenia or a host of other conditions characterized by psychotic and/or delusional features may present with highly bizarre interests or intense preoccupations.

9. Family Functioning

An assessment of family functioning is important for the diagnostic evaluation and intervention-planning assessment of children ages 6 through 22. Ecological contexts must be considered within both processes because the child does not live or behave in a single non-interactive context. The referral of a child or adolescent for possible ASD is likely to be highly stressful for the family, regardless of diagnostic outcome. For example, a 13-year-old who may be suspected of having an ASD but whose diagnostic presentation is actually more consistent with a conduct disorder is still a potent stressor in the family system. As families are partners in the intervention process, their functioning and ability to adapt to the child with special needs is crucial for assessment.

It is important to note that assessment of family functioning does not denote causality in the child's development of symptoms. This is a particularly sensitive area in the history of ASD. In the early descriptions of autism, families (particularly

mothers) were seen as the source of the child's difficulties in that a particular parenting style exacerbated a biological predisposition to developmental disability. Fortunately, this theory has been discarded for some time although there may be traces of this belief in some theories of etiology and treatment for autism (Bettleheim, 1967; Greenspan, Wieder & Simmons, 1998).

In essence, assessment of family functioning has two major components. The first may be described as assessment of the family system in terms of strengths and needs in fostering development of the child within the context of the family and community. This would include family needs for support, respite and management of child challenges within the home. For children with ASD, research has consistently identified the significant stressors placed on families in terms of coping with child demands, intervention and service delivery (Koegel, Schreibman, Britten, Burke & O'Neill, 1982; Schreibman, Koegel, Mills & Burke, 1984). Research has also described the positive effects of parent training and support in ameliorating stress and engendering outcomes that are more positive for the child and family (Plienis, Robbins & Dunlap, 1988).

For purposes of differential diagnoses, the assessment of the family system is important, given the strong association between environmental factors and biological vulnerability known to occur in other childhood disorders. For children whose diagnosis is a dilemma, assessment of the family system is important to identify environmental and biological factors that contribute to the disorder. The family assessment provides information relevant to their service needs and enables parents to become effective partners in their child's development.

Secondary Components

The following components may be incorporated into the diagnostic evaluation in some cases, but are more suitable for intervention planning assessment. In diagnostic evaluation, academic and neurological testing may be useful for differentiation and overlap of ASD with nonverbal and other learning disabilities.

Academic Assessment

Educational assessment in the school age child or adolescent is often useful during the intervention planning process. Furthermore, academic testing is an integral component of the intervention planning assessment. With older children and adolescents, achievement testing and examination of the functionality of curricula becomes important for transition planning.

Although a school system may not make a conclusive diagnosis of ASD, its primary role is to assess a child's strengths and needs for appropriate educational intervention. In an older child or adolescent, the results of any tests or instruments may add significantly to the knowledge base about the individual. Obtaining as many

records as possible from educational settings is important. In addition, gathering information directly from educators and others involved with the child may add specific information useful in establishing a diagnosis.

Achievement

The assessment of academic achievement plays an important role in planning intervention and educational services and a somewhat lesser role in the diagnostic evaluation process. Achievement testing is heavily dependent on formal learning and samples specific skills (reading, writing, mathematics) and mastery of information. For the child who is found to have an ASD, discrepancies may arise between the child's performance on an intelligence measure, which samples the ability to apply new information, and school skills, which may rely on more rote information. Because children with Asperger's disorder and higher-functioning children with autism tend to have good rote memories and an uncanny ability to amass great quantities of facts, these children typically do well on typical tests of educational achievement in the elementary school years. However, their academic achievements may be somewhat greater than their demonstrated adaptive or cognitive capabilities, suggesting a limited ability to apply acquired knowledge into functional skills. Identifying areas of strength and weakness through achievement testing has important implications in the decision-making processes pertaining to teaching methodology and curricular content. For children with wide discrepancies between academic functioning and adaptive skills, results from achievement measures can be used to identify areas of strength and learning styles and to promote generalization of skills by translating curricular content into functional application.

For differential and concomitant diagnosis, achievement testing may also identify specific learning disabilities, which may be either a differential explanation for the child's difficulties or concomitant with an ASD. Results from achievement testing should be reviewed with respect to curricular content and teaching methodology for differential diagnosis.

Best Practice:
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.

Neuropsychological Assessment

Neuropsychological assessment may be used in the differential diagnostic process when concerns exist about specific behavioral deficits such as attention and impulsivity, when indications of neurological involvement affecting specific systems are present or to explore the nature of a learning disability. The choice of instrument and/or selection of particular tests are dependent upon the amount of additional information needed to either establish a diagnosis or gather data for the intervention planning assessment. Although specific executive function deficits have been found in autism (Ozonoff, 1998), a full neuropsychological examination is rarely warranted to establish a diagnosis, although it may be required to arrive at an accurate description of the child's difficulties after an ASD has been ruled out. However, selected tests or partial batteries may be warranted to either rule out ASD

or to identify concomitant learning difficulties such as non-verbal learning disorder, or NVLD (Volkmar & Klin, 1998). Neuropsychological assessment may play a significant role when a NVLD is suspected. As indicated earlier, the literature describing this profile in Asperger's disorder is continuing to grow (Klin, Volkmar, Sparrow, Cicchetti & Rourke, 1995).

Motor Skills

An assessment of motor skills should be included for intervention planning when such deficits have been identified through the history-taking process, direct observation and testing protocols. In children with ASD, there is a vast range and complexity of stereotypic movements, repetitive behaviors, motor deficits and sensory integration skills. Age and developmental level exert a strong influence on the expression of motor phenomena in a particular child. However, the presence of motor anomalies is not diagnostic. This point cannot be overemphasized, as a significant number of children in this age range are suspected of having an ASD based on a history of "clumsiness" or "stereotyped behaviors" in the absence of core diagnostic features. Thus, an evaluation of motor functioning is not an essential component of the diagnostic evaluation to identify an ASD but is a significant component of the intervention planning phase. The primary function of such an assessment can include:

- Identify difficulties that interfere with learning and ability to perform adaptive skills
- Identify concomitant disabilities or the overlap of associated phenomena (nonverbal learning disability) relative to their contribution to a differential diagnosis or intervention modification.

Executive Functions

Several studies have documented the impairment in executive function in persons with ASD (Ozonoff, Pennington & Rogers, 1991; Ozonoff, 1998; Szatmari, Tuff, Finlayson & Bartolucci, 1990) as well as other disorders of childhood (Ozonoff, 1997). Furthermore, these difficulties are more pronounced in children and adolescents with autistic disorder than in those with Asperger's disorder and differ somewhat from deficits found with ADHD (Buchsbaum et al., 1992). For children suspected of having Asperger's disorder, further neuropsychological testing might be included as part of the intervention planning process to explore deficits in planning, organization and cognitive flexibility that may not have been apparent through traditional cognitive testing. Single tests from traditional neuropsychological batteries may be used when time and resources do not permit a full assessment. These include:

- Wisconsin Card Sort Test (WCST)
- Tower of Hanoi

CHAPTER 8

DIFFERENTIAL DIAGNOSIS

In establishing an accurate and reliable diagnosis in children and adolescents, autistic spectrum disorders (ASD), particularly PDD-NOS and Asperger's disorder, must be differentiated from each other and, more importantly, from other developmental disorders such as language and sensory impairments (American Academy of Child and Adolescent Psychiatry, 1999). The current professional controversy surrounding the concept of Asperger's disorder justifies including it as a point of discussion. Asperger's is a disorder that frequently requires differential diagnosis from other psychiatric conditions. This chapter reviews this issue and explores other disorders that are considered important in establishing a differential diagnosis.

The emphasis in earlier chapters on the necessity for considerable experience and knowledge in working with ASD becomes a critical clinical issue with older children and adolescents in differentiating ASD 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 autism, as well as the developmental expression of behaviors in both typical and atypical development in childhood and adolescence. Since comorbidity and differentiation of psychiatric diagnoses are so vital in this age group, knowledge and/or consultation with specialists in child psychiatry is required.

Differential Diagnosis

Significant overlap exists in the behavioral phenotype of autism and numerous behavioral and/or developmental disorders. Behavioral issues can co-occur with ASD, mask the underlying problem or mimic features of autism. Social impairment as either primary or secondary sequelae is also present in a variety of childhood disturbances. The variability of expression of symptoms can confound a diagnosis. In addition, many individuals will have multiple diagnoses and they will not have been evaluated by a specialist in ASD. Therefore, upon presentation, the diagnostic issues are complex and require careful examination and clinical expertise.

Diagnosing Coexisting Conditions

Some children and adolescents with ASD have behavioral, cognitive and psychiatric challenges in addition to ASD. These coexisting symptoms can be:

1. Secondary to the experience of having an ASD (this is often the case with "higher-functioning" children and adolescents who have an awareness of their differences and inability to succeed in social contexts), OR

2. Conditions that coexist with an ASD. Research literature has identified psychiatric disorders and cognitive impairments in subgroups of children with ASD. These may be viewed as interactive rather than sequelae of the disorder. For example, significant mental retardation may be a rate-limiting factor in terms of skill acquisition and rate of learning. Other times, anxiety, depression, obsessive-compulsive disorders and other difficulties reach clinical proportions and themselves become the focus of intervention.

Differential Diagnoses

As children mature, language acquisition and cognitive experience varies widely. Developmental trajectories in key areas become relatively more differentiated than that for younger children. Furthermore, the developmental expression of other disorders of childhood is better known in school-age children than in younger children. Thus, the possibilities for differential diagnosis become greater with increased variability in symptom expression, language ability and social demands. Additionally, the inclusion of Asperger's disorder in the *DSM-IV* and the recent reports of increased rates of ASD in the state of California have promoted a significant number of children and adolescents to present to regional centers and specialty clinics for initial diagnosis of ASD. The clinical team therefore must delineate behaviors and symptoms consistent with an ASD from those more characteristic of coexisting or other diagnoses.

Common Differential Dilemmas

Asperger's Disorder

Asperger's disorder refers to a constellation of behaviors characterized by impairments in social interaction, difficulty in verbal and nonverbal communication and intense interest in circumscribed topics. The disorder is pervasive in that it invades all areas of the child's functioning and development in terms of early onset and symptom presentation that changes with maturation. (For a detailed discussion of Asperger's Disorder, see Appendix H.)

Unfortunately, there is a lack of agreement regarding the clinical picture of children and adolescents with Asperger's disorder. Ghazudian, Tsai & Ghazzudian (992) have pointed out that the diagnostic criteria used by authors (Gillberg & Gillberg, 1989; Wing, 1983; Szatmari, Bremner & Nagy, 1989) to diagnose Asperger's disor-

der are often quite variable which makes it difficult to draw comparisons. Various academics have theorized differing interpretations of Asperger's original description of children (Gillberg & Gillberg, 1989; Wing, 1981). There is also debate as to the separation of Asperger's disorder from "high-functioning" autism. This has given rise to literature that indicates the utilization of strict *DSM-IV* criteria stipulates that Asperger's disorder is virtually identical to "high-functioning" autism, and an actual diagnosis of Asperger's should be more rare than is currently reported (Miller & Ozonoff, 1997; Schopler, 1998; Szatmari, 1992).

The inclusion of a definition and diagnostic criteria for Asperger's in the *DSM-IV* in 1994 was controversial; lack of inter-rater reliability across the twenty-one selected sites for a number of diagnoses in the *DSM-IV* field trials was problematic. However, consensus in the field trial determined that enough information existed to warrant its inclusion. Strict adherence to *DSM-IV* criteria has resulted in far fewer diagnoses of Asperger's disorder than is currently reported in the literature and popular media (Szatmari, Archer, Fisman, Streiner & Wilson, 1995). It is difficult for a child to meet social and behavioral criteria for autism without meeting communicative criteria.

One could also surmise that the confusion surrounding the diagnostic picture leads to an increase in descriptions of associated features, which themselves may become diagnostic. For example, associated features such as sensory atypicalities, clumsiness and obsessions, which are associated with but are not features specific to ASD, may lead to clinical interpretations of other specific symptoms (i.e., social features, restricted interests) as "autistic." Misinterpretation of features not specific to ASD is apparent in the referrals of children and adolescents who are diagnosed based on responses to popular rating instruments.

Mental Retardation

Mental retardation as a differential diagnosis requires careful examination of child functioning with respect to overall developmental level and expectations. Consensus in the literature indicates that, while autism and mental retardation frequently co-occur (Lord & Rutter, 1994), it is difficult to differentiate autism from mental retardation in children with mental ages below 2 years of age (Lord, 1995; Rutter & Schopler, 1992). Nonspecific features of autism (e.g., hand flapping) also co-occur with mental retardation (Cherry, Matson & Paclawskyj, 1997; Deb & Prasad, 1994; Wing, 1981).

The specificity and degree of cognitive impairment for children with mental retardation who present after age 5 years for initial contemplation of an ASD are likely inadequately described in the infant, toddler or preschool years.

Children with milder global impairment may have been initially classified as developmentally or language delayed or were not identified at all. As these children enter kindergarten and elementary school, their differences from peers become

marked. When a previous suggestion of cognitive impairment has been ambiguous, teachers and other providers may refer the child based on comparisons with same age peers.

Some children with previous diagnoses of mental retardation present to diagnostic clinics in the hope that difficulties may be better accounted for by an ASD and intervention planned accordingly. As toddlers or preschoolers, this group of children is often assessed as developmentally or globally delayed. They often do not receive comprehensive early evaluations or services appropriate to their needs. At school age, it may become apparent that the social, communication and behavioral demands are beyond the skill levels of these children, necessitating a reevaluation. Unfortunately, this scenario is more likely in geographically remote areas where access to services and specialists is limited.

It is important both to discriminate mental retardation from ASD and to describe the cognitive abilities of children and adolescents who are found to have ASD.

Schizophrenia

In the past, autism was considered the early manifestation of childhood schizophrenia (Volkmar & Cohen, 1991b). Until introduction of the *DSM-III* in 1980, infantile autism was classified with other childhood disorders under the broad rubric of childhood schizophrenia. Although it has been clearly established that autism and schizophrenia are unrelated, the relationship between the two disorders and the diagnostic representation becomes more puzzling in those individuals who are higher functioning. Additionally, the behavioral phenotype of early onset schizophrenia bears marked similarity to that of autism in some children, while the criteria for schizophrenia in children is identical to that of adults. Thus, a differential diagnosis may be relatively straightforward in a verbal adolescent but is less clear in a younger child. This differential dilemma is commonly seen in higher-functioning children and adolescents with a referral question of Asperger's disorder or PDD-NOS (rarely autistic disorder).

The research literature in recent years has expanded greatly with respect to the onset of schizophrenia in young children (Asarnow & Asarnow, 1996). Unlike ASD, the onset of schizophrenia before the age of 7 is extremely rare. As the child approaches adolescence, frequency increases so that a differential diagnosis is much more plausible (Burd & Kerbeshian, 1987). Furthermore, the early onset of the disorder has been described as more insidious than the more common acute onset seen in adolescence or early adulthood. As with ASD and other developmental disorders, there is a finding of significantly more affected males, which suggests a biological vulnerability similar to other developmental disorders (Lewine, 1988).

Watkins, Asarnow and Tanguay (1988) noted some characteristics of children later diagnosed with schizophrenia that are highly similar to those seen in children with ASD. Of note are the findings of language impairment in infancy and early child-

hood and impairments in fine and gross motor functioning. Difficulties with social behavior and theory of mind deficits have also been noted (Mazza, De Risio, Surian, Roncone & Casacchia, 2001; Pickup & Frith, 1996; Pilowsky, Yirmiya, Arbelle & Mozes, 2000). Watkins et al. (1988) found that these children were characterized as socially unresponsive as infants and had problems with excessive clinginess, mood lability and unexplained rage reactions in early childhood. Difficulties with peer relationships, academics, school adaptation and restricted interests are described by Asarnow & Asarnow (1996). Finally, premorbid social withdrawal, aloofness, detachment and developmental disorders of speech, language and motor functioning were found in adolescents with schizophrenia (Hollis, 1995, 1996).

Guidelines for Differential Diagnosis of Schizophrenia

- In ambiguous cases, where there is clinical evidence for "high-functioning" autism, Asperger's disorder or schizophrenia, a high familial loading of psychiatric illness (schizophrenia, bipolar, etc.) indicates a strong possibility of a schizophrenic rather than autistic process. Extensive psychiatric examination and careful detail to family history is warranted before establishing a diagnosis.
- Children and adolescents with schizophrenia typically function within the borderline to low normal ranges of cognitive functioning on standard intelligence tests with nonverbal strengths relative to their language skills.
- The social impairment in schizophrenia is more adequately described as one of withdrawal. Children with schizophrenia are able to understand nonverbal social cues and the pragmatics of communication (conversational turn-taking, eye gaze to regulate interaction, etc.) with careful, sensitive interview techniques. While these skills may be lower than in typical developing children, they are generally less impaired than children found to have ASD.

Depression

Depression is one of the most common coexisting syndromes found in children and adolescents with ASD. This is particularly true for "higher-functioning" children who have an awareness of their difficulties (Lainhart & Folstein, 1994). Conversely, children with primary mood disorders often display social withdrawal and limited interest in their environment. Again, the clinical task necessitates a careful history of development and detailed descriptions of current symptomatology. Children with mood disorders are not typically characterized by a history of developmental delays; they often enjoy a period of relatively normal functioning preceding the onset of symptoms. Again, examination of family history generally reveals a greater preponderance of mood disorders that is not typically seen in families of children with ASD.

Anxiety Disorders

Anxiety

While anxiety disorders can commonly co-occur with ASD, they frequently present a differential dilemma. Children and adolescents with anxiety disorders can display extreme social withdrawal, sleep problems, agitation and worry that interfere with social and academic functioning. The primary distinction for the clinician is between the extreme shyness and social avoidance displayed by children with anxiety disorders and the primary impairments in social functioning seen in children with ASD. Again, differences must be highlighted between impaired capacity for interaction and avoidance or lack of skills. For example, anxious children are often capable of typical relationships with their parents and other familiar people. Their deficits become apparent in interactions with peers and/or other situations of which they are extremely fearful or uncomfortable. The social impairment characteristic of ASD is apparent throughout the child's relationships. While certain deficits may be more or less significant depending on the interactive partner, the core disability in understanding and using social communicative/cognitive behavior is still present. Finally, children with primary anxiety disorders rarely display the developmental delays characteristic of ASD.

Obsessive-Compulsive Disorder

The differentiation of ASD from obsessive-compulsive disorder (OCD) seems to vary in complexity with developmental level. Several features of OCD have considerable overlap with behaviors seen in ASD. A fine line often separates obsessions and compulsions from stereotypic movements and restricted/repetitive interests and activities. Baron-Cohen (1989) suggests the term "obsessions" is inappropriate in autistic disorders as it is difficult to discern the degree of resistance or extent to which the behavior is ego-dystonic. This is also dependent upon the degree to which the child is able to articulate distress.

Behavioral Disorders

Attention-Deficit/Hyperactivity Disorder

It is frequently suggested that children with ASD, Asperger's disorder in particular, presenting in the school years have been misdiagnosed with attention deficit disorders. This may be due to reduced empathy, impulsivity, excessive verbalization and disregard for personal space. Children with ASD, particularly those with more ability, may also display reduced attention and focus, which may be due to lack of motivation or comprehension. Furthermore, Gillberg, Rasmussen, Carlstrom, Svenson & Waldenstrom (1982) identified a group of children characterized by normal IQ, motor clumsiness and attention deficits. In subsequent study, Gillberg & Gillberg (1989) found that 57 percent of these children either met criteria for an ASD or displayed autistic traits. Differentiation can be particularly challenging in those children with moderate to severe mental retardation who may display

excessive motor activity. A careful developmental and school history is important for distinguishing between these disorders as intervention can be misguided. Particular attention should be paid to the quality of attention in novel and familiar situations and descriptions of typical social breakdowns with peers.

Guidelines for Differential Diagnosis of ADHD

- Children with ADHD often have the capacity for social relationships but may isolate peers in a negative fashion. They often do not interact in socially acceptable ways unless they are able to control the situation. Their means of achieving control may be somewhat different from those with ASD in terms of increased aggression and bullying of those perceived as weaker.
- Children with ASD continue to display nonverbal deficits in social communication in familiar, comfortable and structured situations. In contrast, children with ADHD are able to display typical social and communicative behaviors in structured and, oftentimes, novel settings. This may be especially apparent in a structured evaluation venue with an unfamiliar adult.
- Children with ASD are often able to focus on activities that are particularly interesting to them. For example, they may be able to maintain attention on repetitive operation of a toy for an extremely long period. This is uncharacteristic of children with ADHD, who often have difficulties remaining with any activity for extended periods.
- Children with ASD often appear inattentive and unfocused in situations where the demands of a task are not clear or are beyond their capabilities. They are also less likely to be attentive without strong motivating factors or when there is less relevance to the task.
- Many children with ASD display excessive motor activity, which may take the form of jumping, spinning or flapping. This is more likely to occur when their time is not structured and when they are not actively engaged.

Oppositional Defiant Disorder/Conduct Disorder

Some literature describes associations between violence, aggressive behavior and criminality with Asperger's disorder (Baron-Cohen, 1988; Scragg & Shah, 1994). Other reviews have found little evidence for an increased incidence (Ghaziuddin, Tsai & Ghaziuddin, 1991). Hypotheses surrounding the relationship suggest that criminality may stem from a combination of high intelligence and verbal skills and a lack of empathy and awareness of social convention. Clinical experience and research surrounding the profile of children and adolescents with Asperger's

disorder is that this association is unlikely. Children and adolescents with ASD often have a rigid adherence for rules and are often victims rather than victimizers.

It is not uncommon for school age children, especially adolescents, to present for an initial evaluation of ASD with a significant history of aggression, violence and/or obsessions with violence. Unfortunately, these children have likely received several diagnostic labels in the past and have been a source of confusion to schools and clinicians and of stress for their families. A diagnosis of Asperger's disorder or PDD-NOS offers a way to characterize such behavior as poor understanding of social rules and restricted interests. However, careful evaluation and review indicates the existence of substantial differences in these groups of children which can be summarized as follows:

Guidelines for Differential Diagnosis of Oppositional Defiant and Conduct Disorders

- Persons with ASD can be aggressive when they perceive intrusion into their personal space and activities. Physical aggression may also accompany difficulties with communication and frustration with situational demands. In persons with ASD, aggressive behavior is found predominantly in those children and adolescents who are functioning at lower developmental levels where communication problems and poor comprehension of the environment are significant. Aggressive behavior is not as common in those who are able to communicate their needs and have the cognitive resources to seek a more appropriate solution. Children with ASD rarely exhibit malicious intent or aggression on another person with explicit intent to cause harm.
- A lack of understanding of social rules and conventions by children and adolescents with ASD may also lead to inappropriate social encounters with strangers in the form of inappropriate verbalizations.
- When children and adolescents with ASD become aggressive or engage in criminal-type behaviors, they make little attempt to hide or disguise their actions. A child on an elevator may hit someone who has gotten too close, or might smell a stranger in a crowded supermarket line. This behavior must be contrasted with behavior wherein the adolescent or child has taken steps to conceal or lie or otherwise indicates knowledge that the behavior is socially unacceptable.

Tourette's Disorder

Some authors have commented on the association between Asperger's disorder and Tourette's disorder (Kerbeshian & Burd, 1986; Littlejohns, Clarke & Corbett, 1990). However, the data reported refer to either single case reports or anecdotal data on extremely small samples. Furthermore, the description of vocal and motor tics in children with ASD may be qualitatively distinct from those found in Tourette's.

Although Tourette's disorder can co-occur with an ASD, the data regarding higher occurrences in this population are inconclusive. Knowledgeable and experienced clinical expertise is required to differentiate vocal and motor tics from the stereotyped and repetitive behaviors and language anomalies found in ASD.

Schizoid Personality Disorder

Wolff and Barlow (1980) describe a group of children seen in psychiatric practice in the 1960s that bore some resemblance to Asperger's disorder as characterized by Hans Asperger. The clinical term used at the time was schizoid personality disorder. Through several follow-up studies, Wolff identified marked differences between clinical presentation and outcome of schizoid PD in children and Asperger's disorder as defined by current diagnostic criteria. The differences include the following:

- Schizoid children were much less socially impaired than children now defined as having Asperger's disorder. Children with schizoid personality disorder were markedly disinterested in social relationships in contrast to Asperger's disorder.
- Lack of empathy with emotional detachment.
- Increased sensitivity with paranoid ideas.
- Rigidity with single-minded pursuit of special interests.
- Unusual or odd styles of communication (not speech).
- Unusual fantasy life.
- High rate of conduct disorders with malicious intent.
- Better outcome in adulthood.
- Higher rates of schizotypal personality and schizophrenia development in adulthood.
- Higher familial loading of schizophrenia spectrum disorders (Wolff, 2000).

Disorders outside the DSM-IV Nomenclature

Some clinical presentations of impaired reciprocal social interaction may seem "autistic-like" but do not meet criteria for the ASD (Scheeringa, 2001). Children with these characteristics are often referred because of disruptive behaviors and social interaction deficits, but they are inadequately described by current diagnostic categories. These categories can be problematic for clinicians, children and families in that they describe features that are invariably subsumed in other diagnostic categories (i.e., semantic-pragmatic disorder) and rarely present in isolation, or they describe a broad range of possible symptom configurations (i.e., multisystem developmental disorder). Whether they serve a clinically useful purpose for deter-

mining appropriate services and intervention strategies has yet to be established. Therefore, use of such terms is not recommended in lieu of currently accepted diagnostic categorizations. The terms may be used for descriptive clarification purposes for those children with atypical or unusual presentations, which do not meet *DSM-IV* criteria.

Semantic-Pragmatic Disorder

Semantic-pragmatic (SP) disorder is characterized by near-normal vocabulary, grammar and phonology with difficulties in the social use of language. Thus, children with semantic-pragmatic disorder have difficulties with comprehension, conversational turn taking, topic maintenance and word usage. Language development is typically delayed. Children with SP disorder manifest an overlap with autistic disorder on speech and nonverbal interaction impairments (eye contact, lack of spontaneous initiations and poor relations). They may be verbose, but the content of their language is unrelated. Meaningful interchange is missing, and the other person is used more as a springboard for tangents than as a conversational partner. It should be noted that established and agreed-upon criteria do not exist for the diagnosis of semantic-pragmatic disorder. The literature is based solely on descriptive case studies.

These children differ from other language-impaired children in that they seem to have adequate mastery of language form (grammar and phonology) and good auditory memory. Spontaneous speech is typically fluent and the individuals are sociable (Rapin, 1996). While these language deficits are also found in autistic disorders, Rapin and Allen (1983) note the presence of similar deficits in children who do not meet criteria for autism. Other authors have noted social and behavioral similarities to autism that are not seen in children with other language impairment (Bishop & Rosenblum, 1987) and state that semantic-pragmatic disorder may be a more polite term for autism (Brook & Bowler, 1992). Bishop (2000) suggested a somewhat reasonable compromise that recognizes there may be continuity between semantic-pragmatic disorder and autism either in terms of underlying causes or symptomatology. Clearly, if a child or adolescent meets other *DSM* criteria for an ASD, that would be the appropriate diagnostic designation. Semantic-pragmatic challenges may be described in children who meet criteria for PDD, NOS or other developmental language disorders in order to prompt service delivery and specific intervention planning.

Multisystem Developmental Disorder

Multisystem developmental disorder (MsDD) is the terminology used by Greenspan et al. (1998) to describe children on the autistic spectrum along with other developmental and regulatory disorders. The description is based

upon case analysis and speculation that difficulties in sensory processing, sensitivity and motor planning underlie most difficulties in young children. The sensory dysfunction may involve impairments in social and emotional relationships, verbal and nonverbal communication, auditory processing, hypo- or hyperreactivity to other sensations (visual spatial, tactile, proprioceptive and vestibular) or motor planning. According to this conceptualization, treatment that focuses on the sensory processing problem leads to marked progress in autistic and autistic-like children to the point that they no longer qualify for a diagnosis. While this diagnosis is part of the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood*, or DC 0-3, (Zero to Three, 1994) and not intended for use with children over the age of 3, it may sometimes present in the history of an older child referred for evaluation of ASD.

Four broad characteristics are used to identify children with these challenges: 1) impaired capacity for emotional and social relationships, 2) impaired capacity for communication, 3) auditory processing dysfunction and 4) dysfunction in the processing of other sensations (visual-spatial, tactile, proprioceptive or vestibular) and motor planning. Thus, it is not clear how to diagnose MsDD in a way that is reliable and valid. However, children over the age of 5 may present to a specialty clinic with this diagnosis. Clinical experience and review of case descriptions (Greenspan & Wieder, 1998) suggest that most of these children have difficulties in regulation or temperament, as described in DC 0-3, which are qualitatively, if not phenotypically, different from ASD. Thus, a comprehensive evaluation is required to clarify their challenges and design appropriate intervention.

Nonverbal Learning Disability

Nonverbal learning disability (NVLD) is a diagnostic category described by Rourke (1989). It is not yet recognized by the *DSM-IV*. NVLD has been characterized by deficits in perception, psychomotor coordination, visual-spatial organization, nonverbal problem solving and appreciation of conceptual incongruities and humor. The neuropsychological model has suggested that NVLD is exemplified by a form of right hemisphere dysfunction. An overlap of Asperger's disorder with the neuropsychological profile of persons with NVLD has been identified by Klin, Volkmar, et al. (1995).

Multiple Complex Developmental Disorder

Although the clinical features of this syndrome may include features of autism, particularly social and interpersonal challenges, children with multiple complex developmental disorder (MCDD) are noteworthy through difficulties in modulating anxiety and in peculiarities in thinking and

language (Klin, Mayes, et al., 1995; Kumra et al., 1998). Children with MCDD typically have an early onset of symptomatology combined with higher psychopathology scores on the Child Behavior Checklist and poor peer relationships (Towbin, Dykens, Pearson & Cohen, 1993). Familial history is similar to that of children with very early onset schizophrenia, with more family members evidencing schizotypal and paranoid personality disorders. In comparison with children with high-functioning autism, Van der Gaag et al. (1995) found children with MCDD to have poorer social interactions and more stereotyped and rigid behaviors in addition to more instances of psychotic thinking, anxiety and aggression.

Common Coexisting Difficulties

Other psychiatric disorders that require clinical attention can co-occur with ASD. This complicates the clinical picture and requires careful evaluation to identify additional challenges that should be a focus of intervention. The following disorders, presented previously as differential challenges, can also coexist with ASD.

Numerous studies have described the co-occurrence of affective disorders in children and adolescents with ASD (Kim, Szatmari, Bryson, Streiner & Wilson, 2000; Tantam, 2000). Much of the literature has documented findings in higher-functioning children and adolescents. This may reflect increased rates at higher developmental levels or simply the difficulty in inferring affective symptomatology in lower-functioning, nonverbal children. Nevertheless, appropriate intervention is dependent upon identifying the presence of coexisting affective disorders in that they can often exacerbate adaptive impairment in a person with an ASD. The identification and amelioration of coexisting challenges can have a significant impact on the child's functioning and well being (McDougle, Price & Volkmar, 1994).

The etiology of risk in children with ASD for coexisting affective disorders is unclear (Volkmar & Klin, 2000). Children at higher levels of functioning often are included academically with more socially adept, typical peers. In the absence of supports, these children are at increased risk for social rejection, which can cause substantial frustration, anxiety and stress. Such difficulties will increase as the child matures into later childhood and adolescence, and 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 the autistic spectrum. This has been most commonly reported in Asperger's disorder and PDD-NOS rather than autistic disorder. This is logical, given the uncertain boundaries and descriptive dilemmas surrounding both of these diagnoses. 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. Another inquiry found bipolar disorder to be more common in persons with Asperger's disorder (Tantam, 2000), while others have reported a familial association (DeLong & Nohria, 1994). Enhanced well being and functioning of the child or adolescent is incumbent upon the accurate identification and treatment of these coexisting challenges.

Chapter 9
Elements of Diagnostic Formulation, Presentation and Documentation

As with children age birth through 5, the diagnostic and assessment formulation for older children requires integration of information obtained from the intake interview and diagnostic evaluation. This enables the interdisciplinary team to focus on important issues for differential diagnosis (Klin, Sparrow, et al., 2000). Furthermore, the recommendations and guidelines for the 6-through-22 age group are identical in standard and quality to that described for younger children. Ideally, synthesis of behavioral observations obtained by the various clinicians involved in the evaluation, observation of regularities and reconciliation of points of inconsistency will result in the emergence of a single, coherent view of the child (Klin, Sparrow, et al., 2000).

Formulation

The diagnostic formulation is invariably more complex with school-age children and adolescents who have not received a diagnosis of ASD in the early years. The clinical team is faced with either identifying an autistic spectrum disorder (ASD) that has been overlooked or misclassified, delineating concomitant disorders or identifying an alternative diagnostic classification.

The formulation and conclusions are derived from a thorough integration of the data gathered by the diagnostic team. Such a process entails collaboration of team members and service providers in collating their findings into a cohesive and informative description of the child. The diagnostic formulation should bear the following elements in mind.

Informed Clinical Judgment Renders Diagnostic Conclusions

DSM-IV criteria must be interpreted with respect to clinical judgment and integration of the evaluation data. In many ways, clinical judgment is faced with more challenges in the school-age child than in that for younger children as the possibilities for alternative explanations is greater in the older group. Therefore, clinical expertise not only in the diagnosis of ASD, but also in other disorders of childhood is a necessary component of the diagnostic evaluation process. The expert clinician must be able and willing to consult with other clinical specialists (e.g., psychiatrists, neuropsychologists) in this synthesizing process.

Differential Diagnosis Is Challenging and Must Be Thorough

Diagnosis and assessment in school-age children and adolescents can be complex given the developmental and environmental interactions during this period, as well as other factors that may influence behavior. Differential diagnosis includes the ASD, mental retardation, and developmental disorders of language and psychiatric disorders. Therefore, the diagnostic evaluation is incomplete in the absence of the exploration of alternative or concomitant diagnoses. Again, diagnostic codes should be used as described in the chapters for younger children. Differential, coexisting and provisional diagnoses should be clearly stated. It is particularly important in areas of uncertainty to include a summary paragraph identifying key issues observed and future assessment needs. The diagnostic label is only useful in the context of the child's profile of individual strengths and needs.

At times, a definitive diagnostic conclusion is not readily apparent. This is particularly true for children and adolescents who present with complex and confusing diagnostic histories. In this circumstance, the team should formulate a plan of action for gaining further information and for integrating the data as well as possible to begin intervention. Particular care must be taken with the resolution of conflicting data (i.e., parent history that does not correspond to early behavioral descriptions or current functioning). Remedies may include referrals for further assessment, obtaining information from other sources and/or follow-up. At no time should the team diagnose a child without confidence in that label. They should be prepared to discuss with parents the reasons underlying ambiguity and the provisions for clarification. Premature diagnoses often result from incomplete or inaccurate description. This can lead to failure to provide intervention or treatment for symptomatology that may have a serious negative impact on child functioning.

Presentation of Findings

Family-Centered Discussion of Findings

As presented in earlier chapters, discussion of diagnostic and assessment conclusions is family centered. One of the most important aspects of the diagnostic and assessment processes is communicating findings to the family. Clinical skill in discussion and supporting parents during this process is crucial. Parents of children this age may be frustrated and confused by previous unsatisfactory or ambiguous clinical encounters. The child's difficulties are a source of great concern to them. Additionally, parenting and family factors may have a significant impact on the development and expression of disorders of childhood outside of the autistic spectrum. The purpose of the session is for parents and families to gain a comprehensive understanding of their child's diagnoses, developmental profile and recommendations for future assessment and intervention. Information assimilation is best accomplished when their comfort and confidence in the process is optimal. The setting and timing for the family's optimal receptivity in discussing the findings

should be carefully considered. If practical, for example, the family may need a separate session with the clinician or team to debrief. Emphasis should be placed upon giving parents and caregivers diagnostic information as soon as possible to avoid needless anxiety and stress.

Prognostic Expectations

The prognosis for each individual will vary with a number of factors, including intelligence and social support (Siegel, 1996). A prognosis depends on not only the usefulness and comprehensive nature of the diagnostic evaluation and thoroughness of assessment, but also on the services available to support the individual and family. More than is the case with the birth to 5 age group, variability exists in services availability for those school age and older. In addition, coexisting conditions, particularly vulnerability to a variety of psychiatric disorders, have the potential to affect any prognosis. All of these factors play a role in predictability.

The team must be able to guide parents in realistic expectations for their child based upon the evaluation findings, empirical literature and clinical experience. This may entail a pragmatic discussion of cognitive limitations as an indicator of outcome and functional achievement. After the age of 5, cognitive findings are more stable and become increasingly so as children approach adolescence and adulthood. Thus, cognitive functioning is a better prognostic indicator of outcome for school-age children and adolescents than for younger children. It is helpful to emphasize that evaluation must be ongoing and progress continuously reassessed as the child develops and receives intervention services.

It is important that findings be translated into a cohesive view of the child with comprehensible, detailed, concrete and realistic recommendations provided (Klin, Sparrow, Marans, et al., 2000). Professionals should strive to portray findings within the parameters of the child's day-to-day adaptation, learning and vocational training (Klin & Volkmar, 1995). Realistic expectations for progress within a given amount of time should be provided for parents and families. After age 6, cognitive abilities are relatively stable and results generally reliable. Coexisting features and syndromes should be integrated so that their interaction and expression with ASD is understood, as well as implications for intervention and prognosis.

Knowledgeable Discussion of Intervention Options Particular to the Child and Family

Parents and caregivers need concrete information regarding what can be done for the child. Family knowledge regarding intervention alternatives is variable. The team should be able to provide information regarding documented efficacy of different approaches as well as applicability to the particular child. In cases where the diagnostic presentation is unclear or involves multiple components, parents may need support and assistance accessing appropriate resources and intervention.

References

Akshoomoff, N. A. & Courchesne. (1992). A new role of the cerebellum in cognitive operations. *Behavioral Neuroscience, 106,* 157-168.

Allen, D. A. (1988). Autistic spectrum disorders: clinical presentation in preschool children. *Journal of Child Neurology, 3 (Suppl 1), 48-56.*

American Academy of Child and Adolescent Psychiatry. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*(Suppl. 12), 32S-54S.

American Academy of Pediatrics. (2001) Technical Report: The pediatrician's role in the diagnosis and management of autistic spectrum disorders in children. *Pediatrics, 107*, 1-18.

American Association on Mental Retardation. (2002). Mental Retardation: Definition, classification, and systems of supports (10th ed.). Washington, DC: AAMR.

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders.* (4th ed.). Washington, DC: American Psychiatric Association.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders – Text Revised.* (4th ed.). Washington, DC: American Psychiatric Association.

Asarnow, J. R. & Asarnow, R. F. (1996). Childhood onset schizophrenia. In E. Mash & R. Barkley (Eds.), *Child Psychopathology* (pp. 340-360). New York: Guilford Press.

Bailey, D. B. & Wolery, M. (1989). *Assessing infants and preschoolers with handicaps.* Columbus, OH: Merrill Publishing Co.

Ballabann-Gill, K., Rapin, I., Tuchman, R. & Shinnar, S. (1996). Longitudinal behavioral examination of the behavioral, language, and social changes in a population of adolescents and adults with autistic disorder. *Pediatric Neurology, 15,* 217-223.

Baranek, G. T. (1999). Autism in infancy: A retrospective video analysis of sensory motor and social behaviors at 9-12 months of age.
Journal of Autism and Developmental Disorders, 25, 355-379.

Baron-Cohen, S. (1987). Autism and symbolic play. *British Journal of Developmental Psychology, 5,* 139-148.

Baron-Cohen, S. (1988). An assessment of violence in a young man with Asperger syndrome. *Journal of Child Psychology and Psychiatry, 29,* 351-360.

Baron-Cohen, S. (1989). Do autistic children have obsessions and compulsions? *British Journal of Clinical Psychology, 28, 193*-200.

Baron-Cohen, S., Allen, J. & Gillberg, C. (1992). Can autism be detected at 18 months? *The needle, the haystack, and the CHAT. British Journal of Psychiatry, 161,* 839-843.

Belcher, H. M. (1996). Developmental screening. In A. J. Capute & P. J. Accardo (Eds.), *Developmental disabilities in infancy and childhood, Vol. 1* (2nd ed., pp. 323-340). Baltimore: Paul H. Brookes Publishing Co.

Berthier, M. L., Bayes, A. & Tolosa, E. S. (1993). Magnetic resonance imaging in patients with concurrent Tourette's disorder and Asperger's syndrome. *Journal of the American Academy of Child & Adolescent Psychiatry, 32,* 633-639.

Bettleheim, B. (1967). *The empty fortress.* New York: Free Press.

Bishop, D. V. M. (1994). Grammatical errors in specific language impairment: Competence or performance limitations? *Applied Psycholinguistics, 15,* 507-550.

Bishop, D.V.M. (2000). What's so special about Asperger syndrome? The need for further information on the borderlands of autism. In A. Klin & F. R. Volkmar (Eds.), *Asperger syndrome* (pp. 254-276). New York: The Guilford Press.

Bishop, D.V.M. & Rosenblum, L. (1987). Classification of childhood language disorders. In W. Yule & M. Rutter (Eds.), *Language development and disorders* (pp. 16-41). London: MacKeith Press.

Bristol, M. (1993). Maternal depressive symptoms in autism: Response to psychoeducational intervention. *Rehabilitation Psychology, 38,* 3-9.

Bristol, M. M., Gallagher, J. J. & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24,* 441-451.

Brook, S. L. & Bowler, D. M. (1992). Autism by another name? Semantic and pragmatic impairments in children. *Journal of Autism & Developmental Disorders, 22,* 61-81.

Bruininks, R., Woodcock, R., Weatherman, R. & Hill, B. (1984). *Scales of Independent Behavior*. Allen, TX: Teaching Resources/DLM.

Bruininks, R., Woodcock, R., Weatherman, R. & Hill, B. (1996). *Scales of Independent Behavior-Revised*. Chicago, IL: Riverside Publishing Co.

Buchsbaum, M. S., Siegel, B. V., Wu, J., Hazlett, E., Sicotte, N., Haier, R., et al. (1992). Brief report: Attention performance in autism and regional brain metabolic rate assessed by positron emission tomography. *Journal of autism and Developmental Disorders, 22,* 115-125.

Burd, L. & Kerbeshian, J. (1987). A North Dakota prevalence study of schizophrenia presenting in childhood. *Journal of the American Academy of child and Adolescent Psychiatry, 26,* 347-350.

California Department of Education, (1997). Best practices for designing and delivering effective programs for individuals with autistic spectrum disorders. Sacramento, CA.

Carpentieri, S. & Morgan, S. B. (1996). Adaptive and intellectual functioning in autistic and nonautistic retarded children. *Journal of Autism & Developmental Disorders, 26,* 611-620.

Carr, E. G., Dunlap, G., Horner, R. H., Koegel, R. L., Turnbull, A. P., Sailor, W., et al. (2002). Positive behavior support: Evolution of an applied science. *Journal of Positive Behavior Interventions, 4,* 4-16.

Carr, E.G. & Levin, L. (1994). Communication-based intervention for problem behavior:†A user's guide for producing positive change. Baltimore, MD: Paul H. Brookes Publishing.

Carter, A. S., Gillham, J. E., Sparrow, S. S. & Volkmar, F. R. (1996). Adaptive behavior in autism. *Child & Adolescent Psychiatric Clinics of North America, 5*, 945-961.

Cherry, K. E., Matson, J. L. & Paclawskyj, T. R. (1997). Psychopathology in older adults with severe and profound mental retardation. *American Journal on Mental Retardation, 101,* 445-458.

Cohen, D. J., Volkmar, F., Anderson, G. M. & Klin, A. (1993). Integrating biological and behavioral perspectives in the study and care of autistic individuals. *Israel Journal of Psychiatry and Related Sciences, 30,* 15-32.

Committee on Educational Interventions for Children with Autism, (2001). Educating Children with Autism. Washington, DC, National Academy Press.

Committee on Children with Disabilities. (1994). Screening infants and young children for developmental disabilities. *Pediatrics, 93,* 863-865.

Cox, A., Klein, K. & Charman, T. (1999). Autistic spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis. *Journal of Child Psychology and Psychiatry, 40,* 719-732.

Curry, C.J., Stevenson, R.E., Aughton, D., Byrne, J., Carey, J. C., Cassidy, S., Cunniff, C., Graham, J. M., Jr., Jones, M. C., Kaback, M. M., Moeschler, J., Schaefer, G. B., Schwartz, S., Tarleton, J., & Opitz, J. (1997). Evaluation of mental retardation: recommendations of a Consensus Conference: *American College of Medical Genetics. American Journal of Medical Genetics*, 72, 468-477.

Damasio, A. R. (1984). *Autism* [Editorial]. *Archives of Neurology, 41,* 481.

Dawson, G. & Osterling, J. (1997). Early Intervention in autism. In M. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 307-326). Baltimore, MD: Paul H. Brookes Publishing.

Deb, S. & Prasad, K. B. (1994). The prevalence of autistic disorder among children with a learning disability. *British Journal of Psychiatry, 165,* 395-399.

Delong, R. & Nohria, C. (1994). Psychiatric, family history and neurological disease in autistic spectrum disorders. *Developmental Medicine and Child Neurology, 36,* 441-448.

DeMyer, M. K., Barton, S., Alpern, G., Kimberlin, C., Allen, J., Yang, E., et al. (1974). The measured intelligence of autistic children. *Journal of Autism and Childhood Schizophrenia, 4,* 42-60.

Dunst, C., Trivette, C. & Deal. A. (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books.

Eaves, L. C. & Ho, H. H. (1996). Brief report: Stability and change in cognitive and behavioral characteristics of autism through childhood. *Journal of Autism & Developmental Disorders, 26,* 557-569.

Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Gould, J., Welham, M., et al. (1996). Comparison of clinical symptoms in autism and Asperger's disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 35,* 1523-1531.

Filipek, P. A. Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, E. H. Jr., Dawson, G., et al. (2000). Practice parameter: Screening and diagnosis of autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology, 55,* 468-479.

Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H. Jr., Dawson, G., Gordon, B., et al. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 29,* 439-494.

Fine, J., Bartolucci, G., Ginsberg, G. & Szatmari, P. (1991). The use of intonation to communicate in pervasive developmental disorders. *Journal of Child Psychology and Psychiatry, 32*, 771-782.

First Signs. (2000). Screening Tools Comparison Report, Merrimac, Mass, First Signs, Inc.

Fombonne, E., Simmons, H., Ford, T., Meltzer, H. & Goodman, R. (2001). Prevalence of pervasive developmental disorders in the British Nationwide Survey of Child Mental Health. *Journal of the American Academy of Child & Adolescent Psychiatry*, *40*, 820-827.

Freeman, B. J., Ritvo, E. R., Guthrie, D., Schroth, P. & Ball, J. (1978). The Behavior Observation Scale for Autism: Initial methodology, data analysis, and preliminary findings on 89 children. *Journal of the American Academy of Child Psychiatry, 17,* 576-588.

Freeman, B. J. & Cronin, P. (2002) Diagnosing autistic spectrum disorders in young children: an update. *Infant Young Children, 14 (3), 1-10.*

Frith, U. (1991). *Autism and Asperger's syndrome.* London: Cambridge University Press.

Gabriels, R. L., Hill, D. E., Pierce, R. A., Rogers, S. J. & Wehner, B. (2001). Predictors of treatment outcome in young children with autism. *Autism, 5,* 407-429.

Ghaziuddin, M., Tsai, L. & Ghaziuddin, N. (1991). Brief report: Violence in Asperger Syndrome, a critique. *Journal of Autism and Developmental Disorders, 21,* 349-354.

Ghazzudian, M., Tsai, L. Y. & Ghazzudian, N. (1992). Brief report: A comparison of the diagnostic criteria used for Asperger syndrome. *Journal of Autism and Developmental Disorders, 22,* 643-649.

Gill, M. J. & Harris, S. L. (1991). Hardiness and social support as predictors of psychological discomfort in mother of children with autism. *Journal of Autism and Developmental Disorders, 21,* 407-416.

Gillberg, C. (1990). Medical work-up in children with autism and Asperger's syndrome. *Brain Dysfunction, 3,* 249-260.

Gillberg, C. (1991). Outcome in autism and autistic-like conditions. *Journal of the American Academy of Child and Adolescent Psychiatry, 30,* 375-382.

Gillberg, C., Rasmussen, P., Carlstrom, G., Svenson, B. & Waldenstrom, E. (1982). Perceptual, motor , and attentional control in 6-year old children. *Journal of Child Psychology and Psychiatry, 23,* 131-144.

Gillberg, C., Terenius, L., Hagberg, B., Witt-Ingerstrom, I. & Eriksson, I. (1990). CSF b-endorphins in childhood neuropsychiatric disorders. *Brain and Development, 12,* 88-92.

Gillberg, I. C. & Gillberg, C. (1989). Asperger syndrome: Some epidemiological considerations. *Journal of Child Psychology and Psychiatry, 30,* 631-638.

Gilliam, J. E. (1995). *The Gilliam Autism Rating Scale*. Austin, TX: PRO-ED.

Glascoe, F. P. (1989). The importance of parents' concerns about their child's development. *American Journal of the Disabled child, 143,* 955-958.

Glascoe, F. P. (1991). The importance of parent's concerns about their child's behavior. *Clinical Pediatrics, 30,* 8-11.

Glascoe, F. P. (1999). A method for determining how to respond to parents' concerns about development and behavior. *Ambulatory Child Health, 5,* 197-208.

Glascoe, F. P. (2001). Can teachers' global ratings identify children with academic problems? *Journal of Developmental & Behavioral Pediatrics, 22,* 163-168.

Grandin, T. (1986). *Emergence: Labeled autistic.* Novato, CA: Arena.

Greenspan, S. I. (1997). *Developmentally based psychotherapy.* Madison, CT: International Universities Press, Inc.

Greenspan, S. I., Wieder, S. & Simons, R. (1998). *The child with special needs: Encouraging intellectual and emotional growth.* Reading, MA: Addison-Wesley/ Addison Wesley Longman, Inc.

Greer, S., Bauchner, H. & Zuckerman, B. (1989). The Denver Developmental Screening Test: How good is its predictive validity. *Developmental Medical Child Neurology, 31,* 774-781.

Gresham, F. M. & MacMillan, D. L. (1998). Early intervention project: Can its claims be substantiated and its effect replicated? *Journal of Autism and Developmental Disorders, 28,* 5-13.

Hagerman, R. J. (1999). *Neurodevelopmental disorders: Diagnosis and treatment.* New York : Oxford University Press.

Harris, S. (1994a). *Siblings of children with Autism*. Bethesda, MD: Woodbine.

Harris, S. (1994b). Treatment of family problems in autism. In E. Schopler & G. Mesibov, (Eds.) *Behavioral Issues in Autism* (pp. 161-175). New York, NY: Plenum Press.

Harris, S. L. & Delmolino, L. (2002). Applied behavior analysis: Its application in the treatment of autism and related disorders in young children. *Infants and Young Children, 14,* 11-17.

Hollis, C. (1995). Child and adolescent (juvenile onset) schizophrenia: A case control study of premorbid developmental impairments. *British Journal of Psychiatry, 166,* 489-495.

Hollis, C. (1996). Childhood antecedents of schizophrenia. *Schizophrenia Monitor, 6,* 1-5.

Howlin, P. (1998). *Children with Autism and Asperger's Syndrome: A guide for practitioners and carers.* New York: John Wiley & Sons.

Howlin, P. & Moore, A. (1998). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism: International Journal of Research and Practice, 1,* 135-162.

Institute of Medicine. (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Washington, DC: National Academy Press.

Jacobson, J. W., Mulick, J. A. & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism: General model and single state case. *Behavioral Interventions, 13,* 201-226.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child, 2,* 217-250.

Kerbeshian, J. & Burd, L. (1986). Asperger's syndrome and Tourette syndrome: The case of the pinball wizard. *British Journal of Psychiatry, 148,* 731-736.

Kim, A., Szatmari, P., Bryson, S., Streiner, D. & Wilson, F. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism, 4,* 117-132.

Klin, A., Lang, J., Cicchetti, D. V. & Volkmar, F. R. (2000). Brief report: Interrater reliability of clinical diagnosis and *DSM-IV* criteria for autistic disorder: Results of the *DSM-IV* autism field trial. *Journal of Autism & Developmental Disorders, 30,* 163-167.

Klin, A., Mayes, L. C. & Volkmar, F. R. (1995). Multiplex developmental disorder. *Journal of Developmental and Behavioral Pediatrics, 16,* 7-11.

Klin, A. & Shephard, B. (1994). Psychological assessment of autistic children. *Child and Adolescent Psychiatric Clinics of North America, 3,* 53-70.

Klin, A., Sparrow, S. S., Marans, W. D., Carter, A. & Volkmar, F. R. (2000). Assessment issues in children and adolescents with Asperger's syndrome. In A. Klin, F. R. Volkmar & S. S. Sparrow (Eds.), *Asperger's syndrome* (pp. 309-339). New York: The Guilford Press.

Klin, A. & Volkmar, F.R. (1995). Autism and the pervasive developmental disorders. *Child and Adolescent Psychiatric Clinics of North America, 4,* 617-630.

Klin, A., Volkmar, F. R., Sparrow, S. S. (1992). Autistic social dysfunction: Some limitations of the theory of mind hypothesis. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 33,* 861-876.

Klin, A., Volkmar, F. R. & Sparrow, S. S. (Eds.). (2000). *Asperger's syndrome.* New York: The Guilford Press.

Klin, A., Volkmar, F. R., Sparrow, S. S., Cicchetti, D. V. & Rourke, B. P. (1995). Validity and neuropsychological characterization of Asperger syndrome: Convergence with nonverbal learning disabilities syndrome. *Journal of Child Psychology and Psychiatry, 36,* 1127-1140.

Koegel, L., Koegel, R. & Dunlap, G. (1996). *Positive Behavioral Support: Including People with Difficult Behavior in the Community*. Baltimore, MD: Paul H. Brookes Publishing.

Koegel, R. L., Schreibman, L., Britten, K. R., Burke, J. C. & O'Neill, R. E. (1982). A comparison of parent-training to direct child treatment. In R. L. Koegel, A. Rincover & A. L. Egel (Eds.), *Educating and understanding autistic children* (pp.260-279). San Diego: College Hill Press.

Konstantareas, M. (1989). After diagnosis? Some of the possible problems around diagnostic assessments? *Canadian Journal of Psychiatry, 34,* 549-553.

Konstantareas, M. (1992). Assessing resources and stress in parents of severely dysfunctional children through the Clark modification of Holroyd's questionnaire on resources and stress. *Journal of Autism and Developmental Disorders, 22,* 217-234.

Kugler, B. (1998). The differentiation between autism and Asperger's syndrome. *Autism, 2,* 11-32.

Kumra, S., Jacobsen, L. K., Lenane, M., Zahn, T. P., Wiggs, E., Alaghband-Rad, J., et al. (1998). "Multidimensionally impaired disorder": Is it a variant of very early onset schizophrenia. *Journal of the American Academy of Child and Adolescent Psychiatry*, *37,* 91-99.

Lainhart, J. E. & Folstein, S. E. (1994). Affective disorders in people with autism: A review of published cases. *Journal of Autism & Developmental Disorders, 24,* 587-601.

Leekam, S., Libby, S. & Wing, L. (2000). Comparison of ICD-10 and Gillberg's criteria for Asperger syndrome. *Autism: International Journal of Research and Practice, 4,* 11-28.

Lewine, R. R. (1988). Gender in schizophrenia. In M. T. Tsuang & J. C. Simpson (Eds.), *Handbook of schizophrenia: Vol. 3. Nosology, epidemiology and genetics of schizophrenia* (pp. 379-397). Amsterdam: Elsevier.

Liss, M., Bullard, S., Robins, D. & Fein, D. (2000). Brief report: Cognitive estimation in individuals with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 30,* 613-618.

Liss, M., Harel, B., Fein, D., Allen, D., Dunn, M., Feinstein, C., et al. (2001). Predictors and correlates of adaptive functioning in children with developmental disorders. *Journal of Autism and Developmental Disorders, 31,* 219-230.

Littlejohns, C. S., Clarke, D. J. & Corbett, J. A. (1990). Tourette-like disorder in Asperger's syndrome. *British Journal of Psychiatry, 156,* 430-433.

Lord, C. (1993). The complexity of social behavior in autism. In S. Baron-Cohen, H. Tager-Flusterberg & D. Cohen (Eds.), *Understanding other Minds: Perspectives from Autism* (pp. 292-316). Oxford, England: Oxford University Press.

Lord, C. (1995). Follow-up of two-year olds referred for possible autism. *Journal of Child Psychology and Psychiatry, 36,* 1365-1382.

Lord, C. (2000). Diagnosis of autism spectrum disorders in young children. In A. Wetherby & B. Prizant (Eds.), *Autism, A Transactional, Developmental Perspective* (pp. 11-30). Baltimore: Paul H. Brookes.

Lord, C., Bristol, M. M. & Schopler, E. (1993). Early intervention for children with autism and related developmental disorders. In E. Schopler & M. E. Van Bourgondien (Eds.), *Preschool issues in autism* (pp. 199-221). New York: Plenum Press.

Lord, C., Pickles, A., McLennan, J., Rutter, M., Bregamn, J., Folstein, S., et al. (1994). Diagnosis of Autism: Analysis of data from the Autism Diagnostic Interviews. In American Psychiatric Association (Eds.), *DSM-IV sourcebook*. Washington, DC: American Psychiatric Association.

Lord, C., Pickles, A., McLennan, J., Rutter, M., Bregman, J., Folstein, S., et al. (1997). Diagnosing autism: Analyses of data from the Autism Diagnostic Interview. *Journal of Autism & Developmental Disorders*, *27,* 501-517.

Lord, C. & Rutter, M. (1994). Autism and pervasive developmental disorders. In M. Rutter, E. Taylor & L. Hersov (Eds.), *Child and adolescent psychiatry* (pp. 569-593). Boston, MA: Blackwell.

Lord, C., Rutter, M. & DiLavore, P. (1996). Autism Diagnostic Observation Schedule-Generic (ADOS-G). Unpublished manuscript, University of Chicago.

Lord, C., Rutter, M. & DiLavore, P. (1999). *Autism Diagnostic Observation Schedule-Generic (ADOS-G).* The Western Psychological Corporation.

Lord, C., Rutter, M. & LeCouteur, A. (1994). Autism diagnostic interview-revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorder. *Journal of Autism and Developmental Disorders, 24,* 659-685.

Lord, C. & Schopler, E. (1989). The role of age at assessment, developmental level, and test in the stability of intelligence scores in young autistic children form preschool years through early school age. *Journal of Autism and Developmental Disorders, 18,* 302-314.

Lord, C. & Venter, A. (1992). Outcome and individual studies of high-functioning autistic individuals. In E. Schopler and G. Mesibov (Eds.), *High functioning Individuals with Autism* (pp. 187-199). New York: Plenum Press.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Autism and Developmental Disorders, 9,* 315-323.

Mahoney, W. J., Szatmari, P., MacLean, J. E., Bryson, S. E., Bartolucci, G., Walter, S., et al. (1998). Reliability and accuracy of differentiating pervasive developmental disorder subtypes. *Journal of the American Academy of Child & Adolescent Psychiatry, 37,* 278-285.

Marans, W.D. (1997). Communication Assessment. In D.Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 427-447). New York: John Wiley & Sons, Inc.

Marriage, K., Miles, T., Stokes, D. & Davey, M. (1993). Clinical and research implications of the co-occurrence of Asperger's and Tourette syndrome. *Australian and New Zealander Journal of Psychiatry, 27,* 666-672.

Mash, E. J. & Dozois, D. A. J. (1996). Child psychopathology: A developmental systems perspective. In E. J. Mash & R. A. Barkley (Eds.), Child Psychopathology (pp.3-62). New York: Guilford Press.

Mayes, S. D., Calhoun, S. L. & Crites, D. L. (2001). Does *DSM-IV* Asperger's disorder exist? *Journal of Abnormal Child Psychology, 29,* 263-271.

Mazza, M., De Risio, A., Surian, L., Roncone, R. & Casacchia, M. (2001). Selective impairments of theory of mind in people with schizophrenia. *Schizophrenia Research, 47,* 299-308.

McDougle, C. J., Price, L. H. & Volkmar, F. R. (1994). Recent advances in the pharmocotherapy of autism and related conditions. *Child and Adolescent Psychiatry clinics of North America, 3,* 71-90.

Mesibov, G. & Handlan, S. (1997). Adolescents and adults with autism. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 309-324). New York: Wiley.

Miller, J. N. & Ozonoff, S. (1997). Did Asperger's cases have Asperger Disorder: A research note. *Journal of Child Psychology and Psychiatry, 38*, 247-251.

Minshew, N. J. & Goldstein, G. (1998). Autism as a disorder of complex information processing. *Mental Retardation & Developmental Disabilities Research Reviews, 4,* 129-136.

Minshew, N., Goldstein, G. & Siegel, D. J. (1995). Speech and language in high functioning autistic individuals. *Neuropsychology, 9,* 255-261.

Minshew, N. J., Sweeney, J. A. & Bauman, M. L. (1997). Neurological aspects of autism. In D. D. Cohen, & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 344-369). New York: Wiley.

Mundy, P., Sigman, M. & Kasari, C. (1994). Joint attention, developmental level, and symptom presentation in autism. *Development and Psychology, 6,* 389-401.

Mundy, P. & Stella, J. (2000). Joint attention, social orienting, and nonverbal communication in autism. In A. Wetherby and B. Prizant (Eds.), *Autism, A Transactional, Developmental Perspective* (pp. 55-77). Baltimore: Paul H. Brookes.

O'Neill, R. E., Horner, R. H., Albin, R. W., Sprague, J. R., Storey, K. & Newton, J. S. (1997). *Functional Assessment and Program Development for Problem Behavior*. Pacific Grove, CA.: Brooks Cole.

Ornitz, E. M. (1989). Autism as the interface between sensory and information processing. In G. Dawson (Ed.), *Autism: Nature, diagnosis, and treatment (pp. 174-207)*. New York: Guilford Press.

Osterling, J. & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disorders, 24*, 247-258.

Ozonoff, S. (1997). Components of executive function in autism and other disorders. In J. Russell (Ed.), *Autism as an executive disorder* (pp. 179-211). New York: Oxford University Press.

Ozonoff, S. (1998). Assessment and remediation of executive dysfunction in autism and Asperger syndrome. In E. Schopler, G. Mesibov & L. Kunce (Eds.), *Asperger syndrome or high functioning autism? (*pp. 263-289). New York: Plenum.

Ozonoff, S. & Cathcart, K. (1998). Effectiveness of a home-program intervention for young children with autism. *Journal of Autism and Developmental Disorders, 28*, 25-32.

Ozonoff, S., Pennington, B.F. & Rogers, S. J. (1991). Executive function deficits in high functioning autistic individuals: Relationship to theory of mind. *Journal of Child Psychology and Psychiatry, 3,* 1081-1105.

Ozonoff, S., South, M. & Miller, J. N. (2000). *DSM-IV*-defined Asperger's syndrome: Cognitive, behavioral and early history differentiation from high-functioning autism. *Autism, 4,* 29-46.

Pickup, G. J.& Frith, C. D. (1996). 'Theory of mind' and executive function in schizophrenia. *Schizophrenia Research,18,* 206.

Pilowsky, T., Yirmiya, N., Arbelle, S. & Mozes, T. (2000). Theory of mind abilities of children with schizophrenia, children with autism, and normally developing children. *Schizophrenia Research, 42,* 145-155.

Plienis, A. J., Robbins, F. R. & Dunlap, G. (1988). Parent adjustment and family stress as factors in behavioral parent training for young autistic children. *Journal of the Multihandicapped Person, 1,* 31-52.

Prizant, B. M. & Wetherby, A. M. (1993). Communication assessment of young children. *Infants and Young Children, 5*, 20-34.

Pulver, A. E., Brown, C. H. & Wolyntec, P. (1990). Schizophrenia: Age of onset, gender and familial risk. *Acta Psychiatria Scandinavia, 82,* 344-351.

Rapin, I. (1991). Autistic children: Diagnosis and clinical features. *Pediatrics, 87,* 751-760.

Rapin, I. (1996a). Practitioner review: Developmental language disorders: A clinical update. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 37,* 643-655.

Rapin, I. (1996b). Preschool children with inadequate communication: Developmental language disorder. *Clinics in developmental medicine, 139*.

Rapin, I. & Allen, D. (1983). Developmental language disorders: Nosologic considerations. In U. Kirk (Ed.), *Neuropsychology of language, reading and spelling* (pp. 155-184). New York: Academic Press.

Robins, D. L., Fein, D., Barton, M. L. & Green, D. A. (2001). The modified checklist for autism in toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31,* 131-144.

Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology, 27,* 167-178.

Rokusek, C. (1995). An introduction to the concept of interdisciplinary practice. In Bruce Thyer & Nancy Kropf (Eds.), *Developmental disabilities: A handbook for interdisciplinary practice* (pp. 1-12). Cambridge, MA: Brookline Books.

Rourke, B. P. (1989). *Nonverbal learning disabilities: The syndrome and the model*. New York, NY: Guilford Press.

Rutter, M. (1970). Autistic children: Infancy to adulthood. *Seminars in Psychiatry, 2,* 2-22.

Rutter, M. (1995). Relationships between mental disorders in childhood and adulthood. *Acta Psychiatrica Scandinavica, 91,* 73-85.

Rutter, M. & Schopler, E. (1992). Classification of pervasive developmental disorders: Some concepts and practical considerations. *Journal of Autism and Developmental Disorders, 22,* 459-482.

Sasso, G. M. (2001). The retreat from inquiry and knowledge in special education. *Journal of Special Education, 34,* 178-193.

Schopler, E. (1998). Premature popularization of Asperger syndrome. In E. Schopler, G. Mesibov & L. Kunce (Eds.), *Asperger syndrome or high functioning autism* (pp.385-397). New York: Plenum Press.

Schopler, E., Reichler, R., DeVellis, R. & Daly, K. (1980). Toward objective classification of childhood autism: The Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders, 10,* 91-103.

Scheeringa, M. S. (2001). The differential diagnosis of impaired reciprocal social interaction in children: A review of disorders. *Child Psychiatry & Human Development, 32,* 71-89.

Schreibman, L., Koegel, R., Mills, D. & Burke, J. (1984). Training parent-child interactions. In E. Schopler & G. Mesibov (Eds.), *The effects of autism on the family* (pp. 187-205). New York: Plenum.

Scragg, P. & Shah, A. (1994). Prevalence of Asperger syndrome in a secure hospital. *British Journal of Psychiatry, 165,* 679-682.

Seligman, M., Darling, R. B. (1997). *Ordinary families, special children: A systems approach to childhood disability* (2nd ed.). New York: The Guilford Press.

Sheinkopf, S. & Siegel, B. (1998). Home-based treatment of young children with autism. *Journal of Autism and Developmental Disorders, 28,* 15-23.

Siegel, B. (1991a). Play diagnosis of autism: the ETHOS play session. In C. Schaefer, K. Gitlin & A. Sandgrund (Eds.), *Play Diagnosis and Assessment*. New York: John Wiley & Sons.

Siegel, B. (1991b). Towards *DSM-IV*: A developmental approach to autistic disorder. *Psychiatric Clinics of North America, 14,* 53-68.

Siegel, B. (1996). *The world of the autistic child: Understanding and treating autistic spectrum disorders.* New York: Oxford University Press.

Siegel, B. (2001). *The Pervasive Developmental Disorders Screening Test*. Paper presented at the Society for Research and Child Development.

Siegel, B., Pliner, C., Eschler, J. & Elliott, G. R. (1988). How children with autism are diagnosed: Difficulties in identification of children with multiple developmental delays. *Developmental and Behavioral Pediatrics, 9,* 190-204.

Siegel, B., Vukicevic, J., Elliott, G. R. & Kramer, H. C. (1989). The use of signal detection theory to assess *DSM-III-R* criteria for autistic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 28,* 542-548.

Smith, T. (1999). Outcome of early intervention for children with autism. *Clinical Psychology: Science and Practice, 6,* 33-49.

Sparrow, S. S., Balla, D. & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales (expanded form).* Circle Pines, MN: American Guidance Service.

Stone, W. L. & Caro-Martinez, L. M. (1990). Naturalistic observations of spontaneous communication in autistic children. *Journal of Autism and Developmental Disorders, 20,* 437-453.

Stone, W., Hoffman, E., Lewis, S. & Ousley, O. (1994). Early recognition of autism: Parental reports versus clinical observation. *Archives of Pediatrics and Adolescent Medicine, 148,* 174-179.

Stone, W. L. & Hogan, K. L. (1993). A structured parent interview for identifying young children with autism. *Journal of Autism and Developmental Disorders, 23,* 639-652.

Stone, W. L., Lee, E. B., Ashford, L., Brissie, J., Hepburn, S., Coonrod, E., et al. (1999). Can autism be diagnosed accurately in children under 3 years? *Journal of Child Psychiatry and Psychology, 40,* 219-226.

Szatmari, P. (1992). The validity of autistic spectrum disorders: A literature review. *Journal of Autism and Developmental Disorders, 22,* 583-600.

Szatmari, P., Archer, L., Fisman, S., Streiner, D. L. & Wilson, F. (1995). Asperger's syndrome and autism: Differences in behavior, cognition, and adaptive functioning. *Journal of the American Academy of Child and Adolescent Psychiatry, 34,* 1662-1671.

Szatmari, P., Bremner, R. & Nagy, J. (1989). Asperger's syndrome: A review of clinical features. *Canadian Journal of Psychiatry, 34,* 554-560.

Szatmari, P., Tuff, L., Finlayson, M. A. J. & Bartolucci, G. (1990). Asperger's syndrome and autism: Neurocognitive aspects. *Journal of the American Academy of Child and Adolescent Psychiatry, 29,* 130-136.

Tanguay, P. E. (2000). Pervasive developmental disorders: A 10-year review. *Journal of the American Academy of Child & Adolescent Psychiatry, 39,* 1079-1095.

Tantam, D. (2000). Adolescence and adulthood of individuals with Asperger's syndrome. In A. Klin, F. R. Volkmar & S. S. Sparrow (Eds.), *Asperger's syndrome* (pp. 367-399). New York: The Guilford Press.

Towbin, K. E., Dykens, E. M., Pearson, G. S. & Cohen, D. J. (1993). Conceptualizing "borderline syndrome of childhood" and "childhood schizophrenia" as a developmental disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 32,* 775-782.

Van der Gaag, R. J., Buitelaar, J., Van den Ban, E. & Bezemer, M., Njio, L. & Van Engeland, H. (1995). A controlled multivariate chart review of multiple complex developmental disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 34,* 1096-1106.

Vig, S. & Jedrysek, E. (1999). Autistic features in young children with significant cognitive impairment: Autism or mental retardation. *Journal of Autism and Developmental Disorders, 29*, 235-248.

Volkmar, F., Burak, J. & Cohen, D. (1990). Deviance and developmental approaches in the study of autism. In R. Hodapp, J. Burack & E. Zigler (Eds.), *Issues in the Developmental Approach to Mental Retardation* (pp. 246-271). New York: Cambridge University Press.

Volkmar, F. R., Carter, A., Sparrow, S. S. & Cicchetti, D. V. (1993). Quantifying social development in autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 32,* 627-632.

Volkmar, F. R. & Cohen, D. J. (1991a). Debate and argument: The utility of the term Pervasive Developmental Disorder. *Journal of Child Psychology and Psychiatry, 32,* 1171-1172.

Volkmar, F. R. & Cohen, D. J. (1991b). Nonautistic pervasive developmental disorders. In *Child Psychiatry* (pp. 1-6). Philadelphia: J.B. Lippincott.

Volkmar, F., Cook, E. H. Jr., Pomeroy, J., Realmuto, G. & Tanguay, P. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*(Suppl), 32S-54S.

Volkmar, F. R. & Klin, A. (1998). Asperger syndrome and nonverbal learning disabilities. Diagnostic issues in Asperger syndrome. In E. Schopler, G. Mesibov & L. Kunce (Eds.), *Asperger syndrome or high functioning autism* (pp.107-119). New York: Plenum Press.

Volkmar, F. R. & Klin, A. (2000). Diagnostic issues in Asperger syndrome. In A. Klin, F. Volkmar & S. Sparrow (Eds.), *Asperger syndrome* (pp. 25-71). New York: Guilford Press.

Volkmar, F. R., Klin, A. & Cohen, D. J. (1997). Diagnosis and classification of autism and related conditions: Consensus and issues. In D. H. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 5-40). New York: Wiley.

Volkmar, F. R., Klin, A., Marans, W. & Cohen, D. J. (1996). The pervasive developmental disorders: Diagnosis and assessment. *Child and Adolescent Psychiatry Clinics of North America, 5,* 963-978.

Volkmar, F. R., Klin, A., Siegel, B., Szatmari, P., Lord, C., Campbell, M., et al. (1994). Field trial for autistic disorder in *DSM-IV*. *American Journal of Psychiatry, 151,* 1361-1367.

Volkmar, F. R., Sparrow, S. A., Goudreau, D., Cicchetti, D. V., Paul, R. & Cohen, D. J. (1987). Social deficits in autism: An operational approach using the Vineland Adaptive Behavior Scales. *Journal of the American Academy of Child and Adolescent Psychiatry, 26,* 156-161.

Waterhouse, L., Wing, L. & Fein, D. (1989). Re-evaluating the syndrome of autism in the light of empirical research. In G. Dawson (Ed.), *Autism: Nature, diagnosis, and treatment* (pp. 263-281). New York, NY: The Guilford Press.

Watkins, J. M., Asarnow, R. F. & Tanguay, P. (1988). Symptom development in childhood onset schizophrenia. *Journal of Child Psychology and Psychiatry*, *29,* 865-878.

Werry, J. S. (1992). Child and early adolescent schizophrenia: A review in the light of *DSM-III-R. Journal of Autism and Developmental Disorders, 22,* 610-614.

Wetherby, A. M., Prizant, B. M. & Schuler, A. L. (2000). Understanding the nature of communication and language impairments. In A. M. Wetherby & B. M. Prizant (Eds.), *Autism spectrum disorders: A transactional developmental perspective* (pp. 109-141). Baltimore: Paul H. Brookes.

Wetherby, A. M., Schuler, A. L. & Prizant, B. M. (1997). Enhancing language and communication development: Theoretical foundations. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of Autism and pervasive developmental disorders* (2nd ed., pp. 513-538). New York: Wiley.

Wimpory, D., Hobson, P. R., Williams, M. G. & Nash, S. (2000). Are infants with autism socially engaged? A study of recent retrospective parent reports. *Journal of Autism and Developmental Disorders, 30,* 525-536.

Wing, L. (1981). Asperger syndrome: A clinical account. *Psychological Medicine, 11,* 115-129.

Wing, L. (1983). "The syndrome of autism: A medical model": Comment. *Integrative Psychiatry, 1,* 115-116.

Wing, L. (1988). The continuum of autistic characteristics. In, E. Schopler & G. Mesibov (Eds.), *Diagnosis and Assessment in Autism* (pp. 1-10). New York, NY: Plenum Press.

Wing, L. (1991). The relationship between Asperger's syndrome and Kanner's autism. In U. Frith (Ed.), *Autism and Asperger's Syndrome* (pp. *93-121)*. Cambridge, England: Cambridge University Press.

Wing, L. (1998). The history of Asperger syndrome. In E. Schopler, G. Mesibov & L. Kunce (Eds.), *Asperger Syndrome or High Functioning Autism?* (pp. 11-28). New York: Plenum Press.

Wing, L. & Attwood, A. (1987). Syndromes of autism and atypical development. In D. Cohen, A. Donellan & R. Paul (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 3-19). New York: John Wiley & Sons.

Wing. L. & Gould J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*, 11-29.

Wolff, S. (2000). Schizoid personality in childhood and Asperger syndrome. In A. Klin & F. R. Volkmar (Eds.), *Asperger syndrome* (pp. 278-305). The Guilford Press: New York.

Wolff, S. & Barlow, A. (1980). Schizoid personality in childhood: A comparative study of schizoid, autistic and normal children. In S. Chess & A. Thomas (Eds.), *Annual Progress in Child Psychiatry & Child Development* (pp. 396-417). New York: Brunner-Routledge.

World Health Organization. (1992a). *Manual of the international statistical classification of diseases, and related health problems, Vol. 1* (10th ed.). Geneva: World Health Organization.

World Health Organization. (1992b). *The ICD-10 classification of mental and behavioral disorders. Clinical descriptions and diagnostic guidelines.* Geneva: World Health Organization.

World Health Organization. (1993). *International classification of diseases* (10th ed.). Geneva, Switzerland: WHO.

Yeung-Courchesne, R. & Courchesne, E. (1997). From impasse to insight in autism research: From behavioral symptoms to biological explanations. *Development and Psychopathology*, 9, 389-419.

Zero to Three, Diagnostic Classification Task Force. (1994). Diagnostic classification of mental health and developmental disorders of infancy and early childhood (DC:0-3). Arlington, VA: Zero to Three, National Center for Infants, Toddlers and Families.

"AUTISTIC SPECTRUM DISORDER" AND "PERVASIVE DEVELOPMENTAL DISORDER"

Early in the development of these *Guidelines*, the choice of the term "pervasive developmental disorder" or "autistic spectrum disorder" became the subject of much discussion. Both are overarching terms linked to the same specific pervasive developmental disorders listed in *DSM-IV* (American Psychiatric Association, 1994), and according to the literature, each has advantages and disadvantages.

In the 1970s, Lorna Wing and Judith Gould developed the concept of a range of disorders with a triad of impairments in common—social interaction, communication and imagination (Wing & Gould, 1979). This range of impairments became the foundation of the autistic spectrum concept. Although Allen (1988) coined the term "autistic spectrum disorder," Wing and Gould were using the terms "autistic spectrum" and "autistic continuum" interchangeably at the same time (Wing, 1988); they eventually settled on "autistic spectrum". There is still controversy surrounding the "spectrum" concept, primarily due to the questions remaining as to whether disorders within the autistic spectrum are, in fact, continuous. Volkmar (1991) pointed out that the assumption that all of the conditions on the so-called "spectrum" represent some variant of autism remains a hypothesis and is not an established fact. Wing was also careful to suggest that phenotypic profiles along the "autistic spectrum" vary widely and cannot be construed as continuous (Wing, 1988).

One of the first published references to use the term "autistic spectrum" occurred in 1984 (Damasio, 1984). Lorna Wing and Tony Attwood (1987) were the first to describe the concept of an autistic spectrum in detail. Earlier, the *DSM-III* (1980) introduced the term "pervasive developmental disorder" as a descriptor for a class of disorders that included autism. *The DSM-III,* Revised (American Psychiatric Association, 1987) preserved the term "pervasive developmental disorder," as did the International Classification of Diseases, 10th edition (World Health Organization, 1993). In 1991, Volkmar et al. published a debate concerning the relative appropriateness of the two terms, "pervasive developmental disorder" and "autistic spectrum disorder."

The arguments for using "autistic spectrum disorder" instead of "pervasive developmental disorder" as the official term included several important ideas. Clinicians in favor of using "autistic spectrum disorder" (Wing, 1991; Gillberg, 1991) pointed out that the word "pervasive" was unclear at best, and in the worst case, misleading. The word "pervasive" implied that autism and the other related disorders affected all aspects of development. In questioning the use of "pervasive," several authors were quick to point out that unevenness of development is the hallmark of autism and related disorders, and that some persons with autism have typical ability in selected areas. Therefore, the term "pervasive" appeared to be appropriate only in those cases of autism where severe to profound mental retardation was

present. Because some individuals with autism function with significantly higher intellectual and adaptive competence, the term "pervasive" appeared to be a misleading descriptor, i.e., impairment was not pervasive in all aspects of their condition.

The advocates for maintaining "pervasive developmental disorder" as the descriptive label argued that the term "pervasive" was intended "to imply the scope of disturbance as it applies to functioning domains in contrast to the global impairment which characterizes other developmental disorders and the centrality of cognitive problems in 'primary' mental retardation" (Volkmar, 1991). For example, an individual with autistic disorder with an IQ in the normal range may have significant difficulty with the application of skills to everyday situations, which culminates in significant adaptive impairment across domains. Volkmar (1991) argued that use of the term "pervasive" fully appreciates the fact that "disturbances within autism and associated conditions are felt throughout the individual's life and these difficulties pervade and affect virtually every area of activity and development." Advocates for use of "pervasive developmental disorder" pointed out that terms like "autistic spectrum disorder" encourage the assumption that there is an underlying continuity among the variations of autism. However, use of the term "pervasive" implies that all abilities are affected to a similar degree. There may be confusion regarding the terms "pervasive" and "global," which are not synonymous, that may be difficult to circumvent. Nevertheless, the hallmark of autism is the relative discrepancy between abilities and skills, regardless of the degree of impairment.

As a result, "autistic spectrum disorder" (ASD) has become the clinical term that most closely captures the relationships among autistic disorder and other closely related disabilities that share many of the core characteristics. Use of the term "autistic spectrum disorder" or "ASD" in these *Guidelines* is limited to exactly the same conditions specified under pervasive developmental disorder in the

DSM-IV. Those conditions include the following diagnoses and classifications: (1) autistic disorder, (2) Asperger's disorder, (3) Rett's disorder[1], (4) childhood disintegrative disorder[2] and (5) PDD-NOS. The final category is reserved for individuals who do not meet full criteria for autistic disorder and/or demonstrate equivocal symptomatology that may not be impaired to the same degree as that found in autistic disorder.

[1] Rett's disorder is a genetic disorder that primarily affects girls and is characterized by hard neurological signs including seizures and distinctive hand mannerisms. Girls with Rett's syndrome almost always function within the severely impaired range of cognitive functioning.

[2] Childhood disintegrative disorder is a rare condition characterized by seemingly normal development for at least the first two years of life and followed by marked regression in previously acquired skills, including communication, motor functioning (at times) and loss of adaptive skills.

"RED FLAG" INDICATORS FOR DEVELOPMENTAL CHANGES

Certain noteworthy clinical signs, or "red flags," exist that can help identify children at risk for developmental delay and/or autistic spectrum disorder within a routine office or other health facility visit. These indicators typically are tracked through routine developmental surveillance procedures, which should occur at all well-child visits.

- No babbling by 12 months of age,
- No back and forth gestures such as pointing, showing, reaching or waving by 12 months of age,
- No words by 16 months of age,
- No two-word meaningful phrases (does not include imitation or repetition) by 24 months of age,
- ANY loss of speech, babbling or social skills at ANY age.

APPENDIX C

MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (MCHAT)

Please fill out the following about how your child **usually** is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2. Does your child take an interest in other children?	Yes	No
3. Does your child like climbing on things, such as up stairs?	Yes	No
4. Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5. Does your child ever pretend, for example, to talk on the phone or take care of dolls, or pretend other things?	Yes	No
6. Does your child ever use his/her index finger to point, to ask for something?	Yes	No
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8. Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling, or dropping them?	Yes	No
9. Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10. Does your child look you in the eye for more than a second or two?	Yes	No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No
12. Does your child smile in response to your face or your smile?	Yes	No
13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes	No
14. Does your child respond to his/her name when you call?	Yes	No
15. If you point at a toy across the room, does your child look at it?	Yes	No
16. Does your child walk?	Yes	No
17. Does your child look at things you are looking at?	Yes	No
18. Does your child make unusual finger movements near his/her face?	Yes	No
19. Does your child try to attract your attention to his/her own activity?	Yes	No
20. Have you ever wondered if your child is deaf?	Yes	No
21. Does your child understand what people say?	Yes	No
22. Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23. Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT), SPANISH*

Evaluación del desarollo de niños en edad de caminar

Por favor conteste acerca de como su niño (a) es **usualmente**. Por favor trata de contestar cada pregunta. Si el comportamiento de su niño no ocurre con frecuencia, conteste como si no lo hiciera.

1. ¿Disfruta su niño (a) cuando lo balancean o hacen saltar sobre su rodilla?	SÌ	No
2. ¿Se interesa su niño (a) en otros niños?	SÌ	No
3. ¿Le gusta a su niño (a) subirse a las cosas, por ejemplo subir las escaleras?	SÌ	No
4. ¿Disfruta su niño (a) jugando “peek-a-boo” o “hide and seek” (a las escondidas)?	SÌ	No
5. ¿Le gusta a su niño (a) jugar a pretendar, como por ejemplo, pretende que habla por telÈfono, que cuida sus muñecas, o pretende otras cosas?	SÌ	No
6. ¿Utiliza su niño (a) su dedo Ìndice para señalar algo, o para preguntar alguna cosa?	SÌ	No
7. ¿Usa su niño (a) su dedo Ìndice para señalar o indicar interÈs en algo?	SÌ	No
8. ¿Puede su niño (a) jugar bien con jugetes pequeños (como carros o cubos) sin llevárselos a la boca, manipularlos o dejarlos caer)?	SÌ	No
9. ¿Le trae su niño (a) a usted (padre o madre) objetos o cosas, con el propósito de mostrarle algo alguna vez?	SÌ	No
10. ¿Lo mira su niño (a) directamente a los ojos por mas de uno o dos segundos?	SÌ	No
11. ¿Parece su niño (a) ser demasiado sensitivo al ruido? (por ejemplo, se tapa los oidos)?	SÌ	No
12. ¿Sonrie su niño (a) en respuesta a su cara o a su sonrisa?	SÌ	No
13. ¿Lo imita su niño (a)? Por ejemplo, si usted le hace una mueca, su niño (a) trata de imitarlo?	SÌ	No
14. ¿Responde su niño (a) a su nombre cuando lo(a) llaman?	SÌ	No
15. ¿Si usted señala a un juguete que está al otro lado de la habitación a su niño (a), lo mira?	SÌ	No
16. ¿Camina su niño (a)?	SÌ	No
17. ¿Presta su niño (a) atención a las cosas que usted está mirando?	SÌ	No
18. ¿Hace su niño (a) movimientos raros con los dedos cerca de su cara?	SÌ	No
19. ¿Trata su niño (a) de llamar su atención (de sus padres) a las actividades que estada llevando a cabo?	SÌ	No
20. ¿Se ha preguntado alguna vez si su niño (a) es sordo (a)?	SÌ	No
21. ¿Comprende su niño (a) lo que otras dicen?	SÌ	No
22. ¿Fija su niño (a) su mirada en nada o camina sin sentido algunas veces?	SÌ	No
23. ¿Su niño le mira a su cara para chequear su reacción cuando esta en una situación diferente?	SÌ	No

*The Spanish version of the M-CHAT is a direct translation of the English M-CHAT. The reliability and validity of the Spanish version has not been independently determined.

APPENDIX E

PERVASIVE DEVELOPMENTAL DISORDER SCREENING TEST-II

PDDST-II Stage Two-Developmental Disorders Clinic Screener

Directions: Fill in answers to show any difficulty you may have experienced with your child up to now. Answer the questions to show what is most often true about your child, not 'best' or 'worst'.

Name of child _____ Today's date _____

Age in months _____ Sex M / F _____

	Usually True YES	Usually False NO
Had your baby not yet developed little games or routines designed to get you to look at him, laugh at him, or admire him?	❑	❑
Had your toddler not yet begun to show what he wanted, either by using words or by pointing?	❑	❑
Did your toddler seem uninterested in learning to talk?	❑	❑
Did your toddler often seem bored or uninterested in conversations around him?	❑	❑
Did your toddler usually enjoy being tickled or being chased, but did not usually enjoy playing patty-cake or peek-a-boo?	❑	❑
Did your toddler either ignore toys most of the time, or play almost all the time with one or two things?	❑	❑
Did your toddler cry when you left, but seemed not to notice when you returned?	❑	❑
At times, did you feel that your toddler didn't care if you were there or not?	❑	❑
Had you noticed that your toddler could be very alert to some sounds but ignore other sounds that were just as loud?	❑	❑
Did your toddler only rarely or never babble?	❑	❑
Did your toddler babble mostly to himself rather than babbling to 'talk' to others?	❑	❑

PDDST-II Stage Two-Developmental Disorders Clinic Screener (cont.)

	Usually True YES	Usually False NO
Did your toddler seem to babble in his own "language", rather than making the usual "ma-ma-ma" or "ba-ba-ba" sounds?	❑	❑
Did your toddler seem to babble in his own "language", rather than making the usual "ma-ma-ma" or "ba-ba-ba" sounds?	❑	❑
Did your child often seem to understand only part of what was said to him? (For example, was it hard to tell if he was disobeying, or just not understanding you?)	❑	❑
Were there words you had heard your child say, but that he usually wouldn't repeat, even if strongly encouraged?	❑	❑
Did your child sometimes say a word by its "melody" rather than by sounding it out?	❑	❑
Did your child ever seem to forget old words when he learned new words? (Write N/A if no speech at this age).	❑	❑
Did your toddler ever do one thing, over and over, for so long, that you were surprised someone this age could concentrate so well?	❑	❑
Did your child like things he could play with the same way, over and over, such as a "See n' Say" (a pull-string toy) or toys with push-buttons (such as a toy telephone)?	❑	❑
Did your child seem unusually interested in mechanical things, such as light switches, door latches, locks, fans, vacuums or clocks?	❑	❑
Did your child play with some toys in ways that aren't the main ways such toys were meant to be used?	❑	❑
Did your child not yet imagine make-believe people and actions when he played?	❑	❑
Did your child seem unable to learn by copying others?	❑	❑

Appendix F

Instruments for Diagnostic Evaluation and Assessment for Intervention Planning—Birth through Age 5

Diagnostic Interviews for ASD

Parent Interview

The Autism Diagnostic Interview, Revised (ADI-R)

The Parent Interview for Autism

Behavioral Observations

The Autism Diagnostic Observation Schedule (ADOS)

The Behavior Observation Schedule

The Ethological Observation Schedule

The Childhood Autism Rating Scale (CARS)

Cognitive Testing

Formal Procedures and Tools

Bayley Scales of Infant Development–II

Wechsler Preschool and Primary Scales of Intelligence, Revised

Stanford-Binet, 4th edition

Mullen Scales of Early Learning

Kaufman Assessment Battery for Children

Leiter International Performance Scale, Revised

Merrill-Palmer Scales of Mental Tests

Informal Procedures

Brigance (see "Screening Instruments—General Developmental Assessment")

Developmental Profile II (see "Screening Instruments—General Developmental Assessment")

The Early Learning Accomplishment Profile for Developmentally YoungChildren (Revised Edition) Birth to 36 Months

Language Testing

Parent-Interview/Observation

Rosetti Infant Toddler Language Scale

Communication and Symbolic Behavior Scales

Autism Diagnostic Observation Schedule—Generic

Early Social and Emotional Scales

Direct Child Assessment

- Receptive One-Word Picture Vocabulary Test
- Expressive One-Word Picture Vocabulary Tests (EOWPVT)
- Sequenced Inventory of Communicative Development, Revised
- Pre-Clinical Evaluation Language Fundamentals (Pre-CELF)
- Preschool Language Scales
- Reynell Developmental Language Scales (RDLS)
- Peabody Picture Vocabulary Test, 3rd edition

Adaptive Scales

- Vineland Adaptive Behavior Scales
- Scales of Independent Behavior – Revised

Domain Specific Measures

- Ages & Stages Questionnaires: Social-Emotional (ASQ: SE)
- Vineland Social Emotional Scales

Motor

- Peabody Developmental Motor Scales, 2nd Edition
- Beery-Buktenica Developmental Test of Visual-Motor Integration
- MAND

Sensory

- Sensory Profile – Ages 3–10
- Infant Toddler Sensory Profile
- Analysis of Sensory Behavior

Behavioral

- Behavior Assessment Guide
- Functional Assessment Interview
- Functional Assessment Observation Form

Family Measures

- Family Environment Scale
- Questionnaire on Resources and Stress
- Parenting Stress Index

Appendix G

Instruments for Diagnostic Evaluation and Assessment—Age 6 and Older

Cognitive Testing

Standardized Tests

- Wechsler Preschool and Primary Scales of Intelligence, Revised
- Wechsler Preschool and Primary Scales of Intelligence, 3rd edition (Available Fall 2002)
- Wechsler Intelligence Scale for Children, 3rd edition
- Wechsler Adult Intelligence Scale, 3rd edition
- Stanford-Binet, 4th edition
- Kaufman Assessment Battery for Children
- McCarthy Scales of Children's Abilities

Nonverbal Tests

- Leiter International Performance Scale
- Merrill-Palmer Scales of Mental Tests[1]

Standardized Tests with Minimal Verbal Requirements

- Kaufman Assessment Battery for Children

Tests for Younger Children

- Bayley Scales of Infant Development-II
- Mullen Scales of Early Learning
- Merrill-Palmer Scales of Mental Tests

Adaptive Scales

- The Vineland Adaptive Behavior Scales (VABS)
- Alpern-Boll Scales
- AAMD Adaptive Behavior Scales
- Scales of Independent Behavior – Revised

Motor

- Peabody Developmental Motor Scales, 2nd edition
- Beery-Buktenica Developmental Test of Visual-Motor Integration
- Bruinsky-Oseretsky (motor for 5 through 15)

Sensory

- Sensory Profile Ages 3–10
- Adolescent and Adult Sensory Profile Ages 11 and Older

[1] Norms for this instrument are significantly out of date. It is included due to its utility in estimating nonverbal functioning in children at lower levels of ability and its minimal reliance on verbal comprehension. A useful measure for identifying significant strengths and weakness but tends to overestimate IQ

Clinical Measures

Structured Interviews

Semi-Structured Clinical Interview for Children and Adolescents Aged 6–18 (SCICA)

Semi-Structured Clinical Interview for Children Aged 6–11

Diagnostic Interview Schedule for Children (DISC)

Diagnostic Interview for Children and Adolescents, Revised (DICA-R)

Schedule for Affective Disorders and Schizophrenia for School-Age Children (K-SADS)

Interview Schedule for Children (ISC)

Self-Report Measures

Minnesota Multiphasic Personality Inventory—Adolescence (MMPI-A)

Millon Clinical Multiaxial Inventory—Adolescence (MCMI-A)

Piers Harris Self-Esteem Scale

Achenbach Child Behavior Checklist—Youth Self-Report

Communication and Language

Traditional Language Assessment.

Clinical Evaluation of Language Fundamentals, Third Edition

Test of Auditory Comprehension of Language, Revised

Peabody Picture Vocabulary Test, 3rd edition

Assessment of Pragmatics

Test of Language Competence, Expanded Edition

Test of Problem Solving—Elementary

Test of Problem Solving—Adolescents

Test of Pragmatic Language

Nonverbal/Preverbal Communication

Communication and Symbolic Behavior Scales

Autism Diagnostic Observation Schedule (ADOS)

Achievement Testing

Wide Range Achievement Test 3 (WRAT3) (1993)

APPENDIX H

ASPERGER'S DISORDER

Background

Since Hans Asperger originally described a clinical entity termed "autistic psychopathy" in 1944, considerable confusion and debate has occurred as to the precise definition of this disorder and its relationship to those on the autistic spectrum. Furthermore, contemporary classification systems bear little resemblance to Asperger's original description. Research and interest in Asperger's disorder began with Wing's 1981 introduction of the term to the literature and the translation of Asperger's original writings in 1991 (Frith, 1991).

Description of the Disorder

The description of Asperger's disorder has evolved somewhat since Asperger's original descriptions. Differing sets of diagnostic criteria have emerged. As can be seen in the following proposed classification systems, there is some intent to reflect Asperger's original writings and other attempts to strike a balance between early descriptions and contemporary classification systems.

Hans Asperger

Asperger (1944) first described a phenomena observed in children as "autistic psychopathy." His writings, however, were largely unknown until the early 1980s. Although he did not identify specific diagnostic criteria, he highlighted certain key features observed in this group.

A. Socially odd, naïve and detached from others

B. Egocentric and sensitive to perceived criticism, while oblivious to other's feelings

C. Good grammar and extensive vocabularies. Pedantic speech not used for reciprocal conversation

D. Poor nonverbal communication and atypical vocal intonation

E. Circumscribed interests

F. Difficulty with academics despite average to above-average intelligence; ability to produce original ideas and possessed of skills linked with interests

G. Poor motor coordination and organization of movement

H. Lack of common sense

Asperger described other features of note, which included stereotyped movements and play, sensory abnormalities, destructiveness and aggression. He summarized the children's problems by stating that they failed to assimilate the automatic routines of every day life and followed their own spontaneous agendas regardless of

environmental constraints. He also postulated that these traits were lifelong with a certain number of more able individuals achieving success in adult life through compensation of their differences, such as employment and life-style with fewer social demands (Wing, 1998).

Lorna Wing

Lorna Wing (1981) was the first to suggest that Asperger's disorder was a subgroup of the autistic spectrum. Her descriptions were based on classifications of 35 individuals based upon Asperger's original description and modified based upon current clinical presentation. For example, she noted that the syndrome could be observed in girls and be associated with mild retardation and language impairment. Wing also suggested that patterns of genetic transmission were more complex than those put forth by Asperger. Her description of the disorder is as follows:

A. Difficulty with empathy

B. A social style characterized by naïve, inappropriate, one-sided interaction, with consequential social isolation

C. Pedantic and monotonic speech

D. Poor nonverbal communication

E. Intense absorption in circumscribed topics learned in a rote fashion

F. Poor motor coordination with clumsiness and odd posture

Gillberg and Gillberg (1989)

A. Social impairment—extreme egocentricity (at least two of the following):

   a. Inability to interact with peers

   b. Lack of desire to interact with peers

   c. Lack of appreciation of social cues

   d. Socially and emotionally inappropriate behavior

B. Narrow interest (at least one of the following):

   a. Exclusion of other activities

   b. Repetitive adherence

   c. More rote than meaning

C. Repetitive routines (at least one of the following):

   a. On self, in aspects of life

   b. On others

D. Speech and language peculiarities (at least three of the following):

a. Delayed development

b. Superficially perfect expressive language

c. Formal pedantic language

d. Odd prosody, peculiar voice characteristics

e. Impairments of comprehension, including misinterpretations of literal/applied meanings

E. Nonverbal communication problems (at least one of the following):

a. Limited use of gestures

b. Clumsy/gauche body language

c. Limited facial expression

d. Inappropriate expression

e. Peculiar, stiff gaze

F. Motor clumsiness

a. Poor performance on neurodevelopmental examination

Szatmari (1989)

A. Solitary (two of the following):

a. No close friends

b. Avoids others

c. No interest in making friends

d. A loner

B. Impaired social interaction (one of the following):

a. Approaches others only to have own needs met

b. A clumsy social approach

c. One-sided responses to peers

d. Difficulty sensing feelings of others

e. Detached from feelings of others

C. Impaired nonverbal communication (one of the following):

a. Limited facial expression

b. Unable to read emotion from facial expression of child

c. Unable to give messages with eyes

d. Does not look at others

e. Does not use hands to express oneself

f. Gestures too large and clumsy

g. Comes too close to others

D. Odd speech (two of the following):

a. Abnormalities in inflection

b. Talks too much

c. Talks too little

d. Lack of cohesion to conversation

e. Idiosyncratic use of words

f. Repetitive patterns of speech

E. Does not meet *DSM-III-R* criteria for autistic disorder

DSM-IV Criteria

The diagnostic criteria for Asperger and autistic disorders in the *Diagnostic and Statistical Manual, 4th edition* (American Psychiatric Association, 1994) share the common features of impairments in social interactions and behavior, but Asperger's disorder differs in the following ways:

- An absence of cognitive impairment and clinically significant language delay.
- Presence of age-appropriate self-help and adaptive skills (with the exception of social)
- Curiosity regarding the environment.

Criteria for Asperger's disorder include the following:

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye-gaze, facial expression, body postures and gestures to regulate social interaction

2. Failure to develop peer relationships appropriate to developmental level

3. A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., lack of showing, bringing or pointing out objects of interest to other people)

4. Lack of social-emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interest and activities, as manifested by at least one of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal in either intensity or focus

2. Apparently inflexible adherence to specific nonfunctional routines or rituals

3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)

4. Persistent preoccupation with parts of objects

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

D. There is no clinically significant general delay in language (e.g., single words by age 2 years, communicative phrases used by age 3 years)

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction) and curiosity about the environment in childhood.

F. Criteria are not met for another pervasive developmental disorder or schizophrenia.

ICD-10 Research Criteria (1993)

A. There is no clinically significant delay in spoken or receptive language or cognitive development. Under ICD 10 criteria, a diagnosis requires that single words be developed by 2 years of age or earlier and that communicative phrases be used by 3 years of age or earlier. Self-help skills, adaptive behavior and curiosity about the environment during the first three years of life should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not a necessary diagnostic feature). Isolated special skills, often related to abnormal preoccupations, are common, but are not required for diagnosis.

B. There are qualitative abnormalities in reciprocal social interaction in at least two of the following areas (criteria as for autism):

a. Failure adequately to use eye-to eye gaze, facial expression, body posture and gesture to regulate social interaction

b. Failure to develop (in a manner appropriate to mental age and despite ample opportunities) peer relationships that involve a mutual sharing of interest, activities and emotions

c. Lack of social-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behavior according to social context; or a weak integration of social, emotional and communicative behaviors

d. Lack of spontaneous seeking to share enjoyment, interest or achievements with other people (e.g., a lack of showing, bringing or pointing out to other people objects of interest to the individual)

C. The individual exhibits an unusually intense, circumscribed interest or restricted, repetitive or stereotyped patterns of behavior, interest and activities in at least one of the following areas (criteria as for autism; however, it would be less usual for these to include either motor mannerisms or preoccupations with parts of objects or non-functional elements of play materials):

a. An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in their intensity and circumscribed nature though not in their content or focus

b. Apparently compulsive adherence to specific nonfunctional routines or rituals

c. Stereotyped and repetitive motor mannerism that involve either hand or finger flapping or twisting or complex whole body movements

d. Preoccupations with part-objects or nonfunctional elements of play materials (such as the odor or feel of the play material's surface or the noise or vibration the play material generates)

B. The disorder is not attributable to the other variants of pervasive developmental disorder: simple schizophrenia; schizotypal disorder; obsessive compulsive disorder; anankastic personality disorder; reactive and disinhibited attachment disorders of childhood

The preceding interpretations of Asperger's original work clearly illustrate the difficulties created for clinicians in the diagnosis of Asperger disorder. Note that while all systems share similarities and overlapping features, there are differences that may suggest descriptions of very different individuals. These differences are pertinent, as all research on Asperger's disorder before its inclusion in *DSM-IV* derives from these differing conceptualizations and must be interpreted accordingly.

A number of authors and clinicians have reported difficulty diagnosing Asperger's disorder using *DSM-IV* criteria. These issues center mainly on distinguishing Asperger's disorder from "high functioning" autism, which will be discussed in the next paragraph. Furthermore, whereas PDD-NOS serves as a diagnosis for cases that do not meet fully the criteria for autism or Asperger's disorder, Asperger's may be used when a child evidences impairment that is not to the same degree as autism and does not have significant mental retardation, technically, PDD-NOS (Siegel, 1996).

Autistic Disorder vs. Asperger's Disorder

Difficulties diagnosing Asperger's disorder using current *DSM-IV* criteria revolve mainly around the differentiation from autistic disorder. Conceptually, it is difficult to identify individuals with significant impairment in social and behavioral domains that are similar to those seen in autistic disorder who do not have accompanying communication deficits. Thus, it is possible that those who do meet *DSM-IV* criteria for Asperger's disorder also meet criteria for autistic disorder. Szatmari et al. (1995) identified only one of sixty-eight preschool children previously identified as higher functioning pervasive developmental disorder. Of the twenty-one who were given a "clinical" diagnosis of Asperger's disorder, 86 percent met communication criteria for autism, 81 percent met both reciprocal social impairment and restricted interest thresholds, and all twenty-one met onset criterion. Overall, 57 percent also qualified for a diagnosis of autistic disorder. Another study examined the use of modified *DSM-IV* criteria to ascertain the accuracy of expert clinicians in the identification of Asperger's disorder (Mahoney et al, 1998). A child was classified as having Asperger's disorder if he/she used spontaneous verbal phrases before age 3 and had an IQ above seventy. Overall, agreement was 94 percent indicating that these modifications may be useful *when used by experts*.

Tanguay (2000) discussed research demonstrating that cognitively, children with Asperger's have better verbal relative to performance scores than children with "high-functioning" autism (HFA) on standardized IQ tests. Others (Eisenmajer et al., 1996) suggested that few clinical differences exist between "high-functioning" individuals with autism and individuals with Asperger's as categorized by clinicians. Ozonoff, South and Miller (2000) concluded that Asperger's disorder and "high-functioning" autism evidence the same symptoms but differ in severity of those symptoms.

Researchers continue to question the distinction between Asperger's and autism (Kugler, 1998) and suggest that approaching the disorders, as part of a continuum of one disorder may be more appropriate (Eisenmajer et al., 1996; Leekam et al., 2000; Mayes, Calhoun & Crites (2001). Wing, who first introduced the term "Asperger syndrome" to the English-language literature in 1981, suggests that "in-depth examination of specific aspects of autistic spectrum disorders (ASD) is likely to be more productive than pursuing differences between autism and Asperger

syndrome," (Wing, 2000, p. 425) and argues "strongly against its existence as a separate entity," (Wing, 2000, p. 430). Furthermore, it is less clear that the differentiation from other ASD is clinically useful in that there is no consensus that Asperger's disorder has a distinct etiology, outcome or response to intervention different from "higher-functioning" individuals on the autistic spectrum. It is not clear whether it is as important to distinguish Asperger's from other ASD, as it is to differentiate it from other disorders outside of the autistic spectrum.

While a number of authors and clinicians have noted difficulties with establishing a diagnosis based upon *DSM-IV* criteria, it remains the current standard for diagnostic classification for Asperger's disorder and must be adhered to when making the diagnosis.

APPENDIX I

MEDICAL CENTERS IN CALIFORNIA WITH SPECIALIZATION IN AUTISTIC SPECTRUM DISORDERS

Children's Hospital Oakland
Child Development Center
Division of Developmental and Behavioral Pediatrics/
Communication Clinic
(510) 428-3351
http://www.childrenshospitaloakland.org

Specialty: Diagnosis, assessment for intervention planning
Population: Children (birth–18)

Children's Hospital and Health Center, San Diego
Autism Intervention Center
3020 Children's Way, MC 5042
San Diego, CA 92123
(858) 966-7453
(877) 64AUTISM
e-mail: lhickey@chsd.org
http://www.chsd.org/body.cfm?id=35&action=detail&ref=55

Specialty: Diagnostic evaluation, assessment for intervention planning, intervention, educational consultation
Population: Children (birth–18)

The M.I.N.D. Institute
UC Davis Medical Center
4860 Y Street, Room 3020
Sacramento, CA 95817
Toll-Free Phone: (888) 883-0961
Local Phone: (916) 734-5153
http://mindinstitute.ucdmc.ucdavis.edu/

Specialty: Medical evaluation, Genetic testing, Neuropsychological testing
Social work services including recommendations for school and treatment referrals
Behavioral evaluations (Child Development Section)
Pediatric Neurological Assessments (Child Neurology Section)
Full services of UCDMC including neurophysiological testing, imaging (MRI, etc.)
referral to other pediatric specialty services
laboratory services
Autism evaluation
Fragile X evaluation and treatment program

Stanford University
Neuropsychiatry/Pervasive Developmental Disorders Clinic
Department of Psychiatry and Behavioral Sciences
401 Quarry Road
Palo Alto, Ca.
(650)-498-9111
http://www-cap.stanford.edu/services/outpatient/autism_main.html

Specialty: Diagnosis, assessment for intervention planning, educational consultation
Population: Children (birth–18)

University of California, Irvine/For OC Kids
1915 West Orangewood Ave., Suite 200
Orange, CA
(888) 9-OC-KIDS
e-mail: forockids@uci.edu
www.forockids.com.
Specialty: Diagnosis, assessment for intervention planning, educational consultation
Population: Children (birth–18), special emphasis in children under 5

University of California, Los Angeles
Neuropsychiatric Institute
Department of Psychiatry & Biobehavioral Sciences
300 Medical Plaza, Suite 2406
Los Angeles, CA
http://www.mentalhealth.ucla.edu

University of California, San Diego
UCSD Autism Research Laboratory
Phone: (858) 534-6144
Fax: (858) 822-1746
http://psy.ucsd.edu/~cwhalen/lab.html

Specialty: Intervention, parent training, educational consultation

University of California, San Francisco
Pervasive Developmental Disorders Clinic
Child and Adolescent Psychiatry
(415) 476-7385
http://www.ucsf.edu/psych/folp.htm

Specialty: Diagnosis, assessment for intervention planning, educational consultation
Population: Children (birth–18)

University of California, Santa Barbara
Autism Research Center
1163A Phelps Hall
Information: (805) 893-2176
Fax: (805) 893-7264
http://www.education.ucsb.edu/autism/
Specialty: Intervention

CALIFORNIA REGIONAL CENTERS

Regional Center	Areas Served
Alta California Regional Center http://www.altaregional.org/ (916) 978-6400	Alpine, Colusa, El Dorado, Nevada,Placer, Sacramento, Sierra, Sutter, Yolo and Yuba Counties
Central Valley Regional Center http://www.cvrc.org/ (559) 276-4300	Fresno, Kings, Madera, Mariposa,Merced and Tulare Counties
Eastern Los Angeles Regional Center http://www.elarc.org/ (626) 299-4700	Eastern Los Angeles County, including the communities of Alhambra and Whittier
Far Northern Regional Center http://www.farnorthernrc.org (530) 222-4791	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama and Trinity Counties
Frank D. Lanterman Regional Center http://www.lanterman.org (213) 383-1300	Central Los Angeles County, including Burbank, Glendale and Pasadena
Golden Gate Regional Center http://www.ggrc.org (415) 546-9222	Marin, San Francisco and San Mateo Counties
Harbor Regional Center http://www.harborrc.org (310) 540-1711	Southern Los Angeles County, including Bellflower, Harbor, Long Beach and Torrance Counties
Inland Regional Center http://www.inlandrc.org (909) 890-3000	Riverside and San Bernardino Counties
Kern Regional Center http://www.kernrc.org (661) 327-8531	Inyo, Kern and Mono Counties
North Bay Regional Center http://www.nbrc.net (707) 256-1100	Napa, Solano and Sonoma Counties
North Los Angeles County Regional Center http://www.nlacrc.com/ (818) 778-1900	Northern Los Angeles county, including San Fernando and Antelope Valleys

CALIFORNIA REGIONAL CENTERS, CONT.

Regional Center	Areas Served
Redwood Coast Regional Center http://www.redwoodcoastrc.org (707) 445-0893	Del Norte, Humboldt, Mendocino and Lake Counties
Regional Center of the East Bay http://www.rceb.org (510) 383-1200	Alameda and Contra Costa Counties
Regional Center of Orange County http://www.rcocdd.com/ (714) 796-5100	Orange County
San Andreas Regional Center http://sarc.org (408) 374-9960	Monterey, San Benito, Santa Clara and Santa Cruz Counties
San Diego Regional Center http://www.sdrc.org (858) 576-2996	Imperial and San Diego Counties
San Gabriel/Pomona Regional Center http://www.sgprc.org (909) 620-7722	Eastern Los Angeles County, including El Monte, Monrovia, Pomona and Glendora
South Central Los Angeles Regional Center http://www.sclarc.org (213) 763-7800	Southern Los Angeles County, including the communities of Compton and Gardena
Tri-Counties Regional Center http://www.tri-counties.org (805) 962-7881	San Luis Obispo, Santa Barbara and Ventura Counties
Valley Mountain Regional Center http://www.vmrc.net (209) 473-0951	Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne Counties
Westside Regional Center http://www.westsiderc.org (310) 258-4000	Western Los Angeles County, including the communities of Culver City, Inglewood and Santa Monica

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APPENDIX L

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APPENDIX N

LIST OF BEST PRACTICE RECOMMEMDATIONS

BEST PRACTICE RECOMMENDATION		
Age	**Screening for Autistic Spectrum Disorders**	**PG #**
0 to 5	All professionals responsible for the care of children perform routine developmental surveillance to identify children with atypical development.	12
0 to 5	All professionals involved in the care of young children are aware of developmental indicators of ASD.	14
0 to 5	Specific screening for ASD occurs for all children at 18 and/or 24 months of age.	14
0 to 5	Parents' concerns about their child' s development and behaviors are elicited at every health care provider contact, including well- and ill-child visits.	15
0 to 5	A regional interagency training and information sharing process is in place to assure early identification of persons with ASD.	17
0 to 5	Healthcare professionals stay up-to-date on best practice guidelines and related research.	29
0 to 5	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.	22
0 to 5	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.	22
0 to 5	Within the constraints of confidentiality, efficient sharing of information among clinicians assures timely referral and more complete evaluation of children for concerns regarding ASD.	24
Age	**Diagnostic Evaluation**	**PG #**
0 to 5	The diagnosis of ASD should be made as soon as possible to facilitate intervention and initiate family counseling.	25
0 to 5	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.	26
0 to 5	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.	26
0 to 5	To enable intervention as soon as possible, the diagnostic evaluation is efficiently organized and coordinated.	27

LIST OF BEST PRACTICE RECOMMEMDATIONS, CONT.

0 to 5	The diagnostic evaluation includes examination of multiple domains of functioning to: differentiate ASD from other conditions, and provide a complete profile of the individual to allow for comprehensive intervention planning and service initiation.	27
0 to 5	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.	27
0 to 5	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.	28
0 to 5	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.	29
0 to 5	Informed clinical judgment is maintained through periodic training that includes case review, peer review of individual cases, and discussion of published literature.	29
0 to 5	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.	31
0 to 5	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.	32
0 to 5	Diagnostic accuracy improves when the diagnostic team uses formal diagnostic tools, clinical experience and clinical judgment in diagnosing children suspected of ASD.	38
0 to 5	A comprehensive medical assessment including health history, physical examination and developmental/neurological examination is performed as part of the diagnostic evaluation.	42
0 to 5	All children as part of their developmental assessment are screened for vision and hearing with referral to specialists as appropriate.	43
0 to 5	Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of ASD.	46
0 to 5	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.	51
0 to 5	Domains of adaptive function are evaluated for all children, as they are pivotal in diagnosing ASD and/or coexisting mental retardation.	53

LIST OF BEST PRACTICE RECOMMEMDATIONS, CONT.

Age	Assessment for Intervention Planning	PG #
0 to 5	Ongoing assessment of a child' s behavior and developmental profile is maintained in order to reformulate assessment conclusions and plan appropriate intervention.	56
0 to 5	The involvement of parents is essential in the assessment process as they are most knowledgeable regarding the child.	57
0 to 5	Cultural and family values are considered throughout the assessment process, as they will guide team recommendations and intervention planning.	58
0 to 5	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.	59
0 to 5	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.	68
Age	**Formulation, Presentation and Documentation of Findings**	**PG #**
0 to 5	The final diagnostic formulation derives from using clinical judgment to integrate clinical data with DSM-IV/ICD-9 diagnostic criteria.	71
0 to 5	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.	74
0 to 5	Written reports document diagnostic conclusions keyed to specific DSM-IV criteria. Evaluation and assessment reports are comprehensible to parents and providers and contain practical recommendations for the next phase in the process.	75
Age	**Issues and Concepts in Referral, Diagnostic Evaluation and Assessment**	**PG #**
6 +	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.	78
6 +	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.	79
6 +	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.	80
6 +	Accurate identification and description of coexisting psychiatric conditions and consequent symptoms establishes the basis for quality intervention planning.	80

LIST OF BEST PRACTICE RECOMMEMDATIONS, CONT.

6 +	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.	81
6 +	The collation and integration of multiple sources of information strengthens the reliability of the diagnosis; conclusions are weighted with respect to all evidence.	81
6 +	The developmental disability and mental health service systems collaborate and cooperate to be effective in addressing the unique service needs of children with ASD.	82
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.	83
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.	83
Age	**Referral Process**	**PG #**
6 +	Referring parties clearly identify the reason for referral, select the most appropriate evaluation resource, and share relevant information in a timely manner.	89
Age	**Components of a Diagnostic Evaluation/Assessment Process**	**PG #**
6 +	Accuracy of assessment of older children and adolescents with adequate language skills requires a face-to-face interview.	98
6 +	When the evaluation and assessment requires differential diagnosis of psychiatric disorders, the clinician seeks further referral and/or consultation when indicated.	104
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.	109
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.	113

Glossary

Age-related peers. Individuals who share the same age range.

Algorithm. A set of instructions or rules for performing a calculation or process to determine whether a score on a diagnostic test or set of observations meets specific criteria necessary to assign a diagnosis.

Assessment. See **Assessment for intervention planning**.

Assessment for intervention planning. Careful examination of an individual's strengths and challenges across several domains of functioning with the express objective of directing treatment planning and intervention based upon the person's individual profile. An assessment for intervention planning expands upon the diagnostic evaluation, capturing the child's heterogeneity and individuality within the diagnostic category. The desired outcome of the assessment process is an individualized profile that is incorporated into an intervention plan. The intervention plan is designed to maximize child development and functional skills within the context of the family and community environment. (Often referred to as "assessment" or "interdisciplinary assessment.")

Care coordinator. The person who manages a caseload and who is responsible for ensuring that services written in the Individual Family Service Plan and/or Individual Education Plan for an individual with a developmental disability are provided.

Circumstantiality. A pattern of speech that is indirect and delayed in reaching its goal because of excessive or irrelevant detail or parenthetical remarks. The speaker does not lose the point, but to the listener it seems that the end will never be reached.

Comorbid disorder. A disorder that coexists with another diagnosis so that both share a primary focus of clinical attention. Comorbidity may affect the ability of affected individuals to function and survive in a given environment; it may be used as a prognostic indicator for treatment effectiveness and outcome.

Developmental disability. A severe and chronic impairment that is attributable to one of the following conditions: mental retardation, cerebral palsy, epilepsy, autism or a disabling condition closely related to mental retardation or requiring similar treatment. To establish eligibility for services within the regional center system, a disability is further defined as having begun before the eighteenth birthday, as being expected to continue indefinitely and as presenting a substantial adaptive impairment.

Developmental surveillance. An ongoing process of routine monitoring and tracking of children's specific developmental milestones during regular well child visits. The practice of developmental surveillance by health care providers ensures early detection of developmental problems.

Diagnostic evaluation. The process of gathering information via interview, observation and specific testing in order to arrive at categorical conclusions.

Differential diagnosis. Based on analysis of clinical data, the determination of which of two or more disorders with similar symptoms is the disorder that is the primary focus of clinical attention.

Early identification. The prompt detection of developmental delays through medical and developmental screening and at the youngest age possible. Such screening is provided to children school age or younger and to their families who have or who are at risk of having a handicapping condition or other special need that may affect their development. Early identification increases the chances for improving developmental skills.

Cholalia. A disorder of language that results in repetitions of words or phrases previously heard. Echolalic responses can be immediate or delayed.

Ecological factor. The influence of interactions among people and their environments including the social/emotional and physical environment. Ecological factors are studied in behavior settings, such as a family and the environment within which it operates, in order to predict the effect a specific factor may have on a particular individual.

Ecological validity. Skills or abilities authenticated and evidenced in natural and informal procedures, such as a familiar setting at home or a casual conversation, that may not be similarly expressed in structured assessment measures and tests.

Eye gaze. An individual's eye contact with another individual or with an object. Eye contact is a nonverbal form of communication and means of regulating social interaction. Observance of patterns of avoidance or initiation of eye gaze is important in detecting a child's capacity for sharing of attention and affect.

Family-centered. The procedure of assessing the child's and family's needs as a whole, i.e., allowing the assessment to be family directed and designed to determine the resources, priorities and concerns of the family. The outcome of a family-centered assessment is the identification of supports and services needed to enhance the family's capacity to meet the needs of the child.

High-functioning. A non-clinical description of a person with a diagnosis of autistic disorder who has average or near-average intellectual ability. "High functioning" individuals with autism tend to achieve higher levels of adaptive and communication skills. Also termed, "high functioning autism," or "HFA," it is not a distinct diagnostic category.

Individuals with Disabilities Education Act (IDEA). Public Law 105-17, amended in 1997, that ensures that all children with disabilities have a free appropriate public education and related services that prepare them for employment and independent living.

Interdisciplinary. The descriptor for the process of gathering information from a variety of disciplines having unique knowledge of a particular aspect of the child and family, which stresses a highly coordinated effort among the disciplines to complement (rather than duplicate) efforts and to forge information into a cohesive plan for diagnostic conclusions and/or intervention.

Joint attention. The ability to share with another person the experience of an object of interest. Joint attention generally emerges between 8 and 12 months of age. A moving toy, for example, typically elicits a pointing behavior by the child, who looks alternately at the caregiver and the object.

Lead clinician. The professional who takes responsibility during an interdisciplinary team evaluation for ensuring that all relevant evaluations are performed, documented and reported. The lead clinician is responsible for assuring the integration of separate findings to formulate a diagnosis and/or assessment conclusions to communicate the findings to the family and other team members.

Longitudinal assessment. Measurement across time of developmental progress, behavior and/or specific symptomatology following treatment and/or intervention.

Longitudinal study. Research in which variables relating to an individual or group of individuals are assessed over a period of time, such as a study of child development drawn from research data compiled from the same group of children at different points in their lives.

Multidisciplinary. In contrast to an interdisciplinary process, a process that proceeds as separate evaluations by various professionals who often are affiliated with different entities (i.e., a university or hospital), are rarely in close proximity and often operate without benefit of collaboration with other evaluating professionals, consequently often drawing separate conclusions based upon their particular experience. A multidisciplinary process can take one to two days, with the child and family participating in numerous sessions, or it can take place over the course of several months.

Nonverbal IQ. A measure of intelligence that requires little or no language. Nonverbal tests of IQ measure intellectual ability by requiring the examinee to manipulate objects, copy or draw. Examples of nonverbal intelligence tests are the performance subtests of the Columbia Mental Maturity Scale, 3rd edition, Merrill-Palmer Scale of Mental Tests, Leiter International Performance Scale and the Test of Nonverbal Intelligence, 3rd edition.

Non verbal communication. Facial expressions, tone of voice, gesture, eye contact, spatial arrangements, patterns of touch, expressive movement, cultural differences and other acts of expression involving no or minimal use of spoken language. Research suggests that nonverbal communication is more important in understanding human behavior than words alone and critical to social development and comprehension.

Norm-referenced assessment. Test scores, derived during the administration of a standardized test in its developmental stage to a large sample of individuals within the same age range, which form the yardstick for comparing a given individual's score to a group average.

Phenotype. The visible properties of an organism that are produced by the interaction of the genotype and the environment. In other words, the "phenotypic" expression of a disorder refers to the outward, behavioral expression of symptoms that may or may not share a similar etiology, course or response to treatment.

Pragmatics. The analysis of language in terms of the situational context within which utterances are made, including the knowledge and beliefs of the speaker and the relation between speaker and listener; the ability and desire to communicate in an appropriate way for one's age and culture.

Preverbal communication. Eye contact, gaze shifts, vocalizations and gestures that form the basis of expression prior to spoken language development. Eye contact, gaze shifts, vocalizations and gestures are examples of preverbal forms of communication.

Prosody. Prosody refers to the use of vocal stress and intonation to convey a meaning. For example, the only difference between the noun 'object and the verb ob'ject is that of stress placement. Intonation determines whether the sentence "Mary's eating cake" will be perceived as a statement (pitch falls on the last word) or a question (pitch rises on the last word).

Psychometrics. The measurement of human characteristics such as intelligence, personality, etc. through the administration of tests that are validated by objective and standardized scientific methods.

Receptive language. The act of understanding that which is said, written or signed.

Regional center. A statewide system of twenty-one locally based, state-funded, private nonprofit agencies that provide diagnostic, case management and other services to individuals with developmental disabilities and that help individuals and their families find and access those services.

Ritualistic behavior. Rigid routines, such as insistence on eating particular foods or driving to the store via only one specific route when many options exist, or repetitive acts, such as hand flapping or finger mannerisms (e.g., twisting, flicking movements of hands and fingers carried out near the face).

Screening. The use of a specific test or instrument to identify those children in the population most likely to be at risk for a specified clinical disorder. The application of specific screening instruments for a particular disorder may occur at a specific age for the general population or when concerns and/or results of routine developmental surveillance indicate that a child is at risk for developmental difficulties. Screening instruments are not intended to provide definitive diagnoses but rather, to suggest a need for further diagnostic evaluation and assessment for intervention planning.

Social reciprocity. Mutual responsiveness in the context of interpersonal contact, such as awareness of and ability to respond appropriately to other people. Social reciprocity is synonymous with intersubjectivity.

Social referencing. An aspect of early social development whereby the infant or toddler uses the nonverbal social cues (i.e., eye gaze, facial expression, tone of voice) of another to express or share excitement or pleasure, or checks to see if a behavior will be affirmed or disapproved. The child with autism rarely, if ever, gains social feedback through another's tone of voice or facial expression.

Splinter skills. An isolated ability that often does not generalize across learning environments. These abilities are often widely discrepant from other areas of functioning.

Stereotypic behavior. Repetitive movement of objects or repetitive and complex motor mannerisms including hand or whole body movement such as clapping, finger flapping, whole-body rocking, dipping, swaying, finger flicking, etc.)

Structured interview. An interview that follows a fixed protocol for gathering information in which the interviewer asks standard questions and codes the answers in accordance with predefined criteria.

Syndrome. A set of clinical signs or a series of behaviors occurring together that often point to a single disorder or condition as the cause. In autistic disorder, a number of symptoms belong to the disorder, but a variable subset of all the symptoms qualifies an individual for the disorder.

Tangentiality. Replying to a question in an oblique or irrelevant way.

Temperament. Characteristic behaviors, habitual inclinations or modes of emotional response in infants and toddlers, which may persist and contribute to the development of personality in adulthood. Temperamental behaviors are biologically rooted, commonly recognized as individual differences that appear early in development and stable as observable behavior. Core temperamental characteristics are attentional persistence, positive affectivity to people or objects, fearfulness, distress and irritability to novelty and frustration.

Index

P

Q

R

S

T

U

V

W