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Practice Parameters For The Assessment And Treatment Of Children, Adolescents, And Adults With Autism And Other Pervasive Developmental Disorders

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ABSTRACT

Autism and the related pervasive developmental disorders (PDDs) are characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills, which arise in the first years of life. Although frequently associated with mental retardation these conditions are distinctive in terms of their course and treatment. These conditions have a wide range of syndrome expression and their management presents particular challenges for clinicians. Individuals with these conditions can present for clinical care at any point in development. The multiple developmental and behavioral problems associated with these conditions often require the care of multiple providers; coordination of services and advocacy for individuals and their families is important. Early, sustained intervention is indicated as is the use of various treatment modalities (e.g., pharmacotherapy, special education, speech-communication therapy, and behavior modification). **Key Words:** autism, practice parameters,

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guidelines, developmental disorders, pervasive developmental disorders, children, adolescents, adults.

INTRODUCTION

Autism and the pervasive developmental disorders (PDDs) are neuropsychiatric disorders characterized by patterns of delay and deviance in the development of social, communicative, and cognitive skills. These conditions have their onset in the first years of life, disrupt diverse developmental processes, and are often associated with mental retardation. These conditions differ from primary mental retardation and from the language and other specific developmental disorders in that the behavioral features and patterns of development are observed in multiple areas, are highly distinctive, and are not simply a manifestation of developmental delay.

The diverse expression of autism and the other PDDs over the course of development presents some of the greatest challenges for clinicians. Individuals with these conditions may present for evaluation and treatment at any point during their development. For example, clinicians may be involved in the initial assessment of the toddler and subsequently in the treatment of that child as he or she matures through middle childhood and adolescence. In addition autism and PDDs 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. An awareness of the range of syndrome expression and an appreciation of the complexities of developmental change are important. Each child requires a unique, comprehensive program of services provided by professionals from diverse disciplines. One of these professionals must be responsible for service coordination and advocacy.

EXECUTIVE SUMMARY

Autism and other pervasive developmental disorders are conditions of onset in the first years of life, which disrupt various developmental processes. The diverse expression of these disorders both across and within individuals presents particular challenges for clinical assessment and treatment. Individuals with these conditions may present for evaluation and treatment at any point in the life cycle. Clinicians must be aware of the tremendous range in syndrome expression and the complexities of developmental change. The variety, intensity, and comprehensiveness of services needed by individuals with these conditions as well as the

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participation of professionals from various disciplines require the efforts of some professional to coordinate and advocate for the child. In this regard it is important that the clinician encourage and welcome the participation of the parents and, as appropriate, other family members in the assessment process; support of the parents and family as well as the affected child is an important goal for the clinician.

THE EVALUATION PROCESS

A complete psychiatric assessment is indicated. Aspects of the assessment will vary depending on the child's age, history, and previous evaluations.

Historical Information

In taking the history the clinician should be particularly aware of features important in differential diagnosis such as the nature of social relatedness in the first years of life, difficulties in the development of language and communication skills, and unusual environmental responses. In many cases parents may be asked to complete rating scales or symptom checklists specific to autism and related conditions:

- *Pregnancy, Neonatal, and Developmental History.* This includes a review of the pregnancy, labor, and delivery and early neonatal course. A developmental history should be taken and should include review of communicative and motor milestones. Aspects of the onset or recognition should be reviewed, e.g. when were parents first concerned about the child and why were they concerned, were any aspects of the child's early development unusual, and so forth.
- *Medical history.* Should include discussion of possible seizures, sensory deficits such as hearing or visual impairment, or other medical conditions including signs of specific syndromes such as the Fragile-X syndrome, and history of the use of behavior modifying medications. The family history should be reviewed for the presence of other developmental disorders or autism. The review of current and past psychotropic medications should include a discussion of dose and the child's behavioral response, along with adverse as well as positive effects of the agent. The impact of other medications on behavioral status should also be reviewed.
- *Family and psychosocial factors.* The interviewer should be sensitive to the family situation as well as to family supports and stresses. It is important that the efforts of

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various specialists and consultants be well coordinated and that at least one care provider assumes an overall role as coordinator and liaison with schools and other providers of intervention.

- *Intervention history.* Includes review of response to any educational program as well as response to any behavioral interventions. Materials that may be reviewed include reports of previous evaluations for educational and other services, information based on standard rating scales and symptom checklists, any narrative reports of teachers or care providers, and review of individual educational programs. The examiner should obtain an overall sense of the quality, intensity and appropriateness of the program and the child's response to it.

Psychiatric Examination of the Child

- *Observational settings.* Given the potentially adverse impact of new and/or unstructured environments on the child's behavior, the clinician should be prepared to observe the child in both more and less structured settings such as the home or school. The clinician should be alert to factors in the environment which impact positively or negatively on the child, e.g., an overstimulating school setting for a child who is overly sensitive to extraneous stimuli. Clarification about how representative the child's behavior is can be helpful. Observation of the child in interaction with parents and siblings can also provide important information on the child, on the levels of stress experienced by the family in response to the child's symptoms, and on the effectiveness of parental interventions. Several sessions are usually needed.

- *Overall developmental level.* Characteristic symptoms in the areas of social interaction, communication/play, restricted and unusual interests and behaviors, and any unusual features (e.g., hand-washing stereotypies) should be evaluated relative to overall developmental level. This should include observation of level of language and communication skills exhibited by the child and any unusual strengths, weaknesses, or special interests that may impact on programming.

- *Specific problem behaviors.* The clinician should note the presence of specific problem behaviors, which interfere with programming and require behavioral or pharmacological intervention, for example, aggression, self-injury, or stereotype.

Medical Assessment

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- *Goals of assessment.* Physical examination of the child is concerned with a search for treatable medical conditions, for conditions that sometimes produce symptoms suggestive of PDD, and for conditions with important implications for the family, e.g., inherited medical conditions such as Fragile X syndrome or tuberous sclerosis.
- *Initial and Subsequent Medical Assessment.* A medical history and physical examination should be obtained. The physician should be aware of medical conditions frequently associated with autism, e.g., relative to screening for inherited disorders such as Fragile X and tuberous sclerosis, which may guide the examination and laboratory studies. As part of routine medical care standard information (immunization history, history of allergies or unusual responses to medication) and routine laboratory studies should be obtained. The latter should include lead levels as the high rate of pica in this group of children increases the risk for lead intoxication.
- *Audiological and Visual Examinations.* Concerns about possible deafness are a typical initial presenting complaint. Frequent ear infections may be reported or, in some cases, chronic ear infections may be late in being recognized because of the child's language delay. Although behavioral audiometry is often initially attempted brain stem auditory evoked response auditory should be conducted if there is any question that prior audiological assessment has not been definitive. Similarly, concerns regarding vision should prompt thorough assessment.
- *Neurological Assessment.* Given the frequency of seizure disorders in this population, observation of the child for symptoms suggestive of seizures and careful review of neurological status with parents are indicated. Symptoms suggestive of seizure disorder should prompt EEG and/or neurological consultation.
- *Laboratory Studies.* There is no specific laboratory test for autism. Specific studies to search for associated conditions are indicated based on history and clinical presentation. Fragile X testing is typically indicated given the apparent association of this condition with autism as is Wood's lamp examination for tuberous sclerosis. A DNA test for Fragile X syndrome is now available. Depending on the history and examination additional tests may be indicated. The presence of dysmorphic features or other specific findings may suggest obtaining genetic screening for inherited metabolic disorders or chromosome analysis.
- *Consultative Services.* Evaluations from various other professionals may be indicated given the history and examination. These may include evaluations by geneticists,

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pediatric neurologists, and other medical professionals. For individuals with Rett's disorder, the services of orthopedists and respiratory therapists may be needed.

Psychological Assessment

- *Developmental/Intelligence Testing.* Assessments of the child's cognitive ability are indicated to establish overall levels of function and, in many states, eligibility for services from some agencies. Whenever possible, separate estimates of verbal and nonverbal (performance) IQ should be obtained.
- *Adaptive Skills.* Assessment of adaptive skills is essential to document the presence of any associated mental retardation and in helping to establish priorities for treatment planning.
- *Other assessments.* Neuropsychological and/or achievement testing may be needed, depending upon the clinical context.

Speech-Language-Communication Assessments

- *Vocabulary.* Measures of single word vocabulary (receptive and expressive) should be obtained whenever possible.
- *Language Skills.* Actual use of language (receptive and expressive) should be assessed, over and above the level of single word vocabulary.
- *Articulation and Oral-Motor skills.* Difficulties with articulation or specific oral-motor difficulties should be assessed as appropriate.
- *Pragmatic Skills.* The social use of language-communication skills is often an area of great difficulty for individuals with autism and related disorders. During the course of a formal assessment the clinician should evaluate the child's capacities for use of whatever level of communication skills he/she has in relation to the social context.

Occupational and Physical Therapy Assessments

Assessments may be indicated, particularly if there is some degree of sensory hyper or hyposensitivity or difficulties in motor development.

Family and Parental Support

To the extent possible it is important to involve parents and, as appropriate, other family members, in the process of assessment. This helps to set the stage for a long-term collaborative

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relationship and also helps parents become better informed advocates for their child. Various parent and family support groups may provide important sources of information and support to parents (see Appendix 1).

Differential Diagnosis

The differential diagnosis includes consideration of the various pervasive developmental disorders, mental retardation not associated with PDD, specific developmental disorders (e.g., of language), and early onset psychosis (e.g., schizophrenia) among others. Specific guidelines for diagnosis of the various pervasive developmental disorders are provided in DSM-IV: autistic disorder, childhood disintegrative disorder, Rett's disorder, Asperger's disorder, and PDD-NOS (atypical autism):

- In autistic disorder the apparent onset of the condition is almost always within the first years of life. Parents may initially be concerned that the child is deaf although they also report unusual sensitivities to the nonsocial environment. Language is typically significantly delayed or absent. Unusual behaviors, (e.g., stereotyped movements) are common, particularly after about age 3 years.
- In childhood disintegrative disorder, there is a prolonged period of normal development followed by a marked regression in multiple areas and the development of many autistic-like features.
- In Rett's disorder, very early growth and development is normal but is followed by a deceleration in head growth, development of marked mental retardation, and unusual hand washing stereotypies and other features.
- In Asperger's disorder, early development (including both cognition and language development) is apparently normal, the child often has unusual interests that are pursued with great intensity. Social deficits become more prominent as the child enters preschool and is exposed to peers.
- In PDD-NOS (atypical autism), criteria for one of the other PDDs are not met but the child has problems in social interaction and other areas consistent with a diagnosis of PDD.

The differential diagnosis of autism and other pervasive developmental disorders also includes consideration of various other developmental and psychiatric conditions:

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- Mental retardation or borderline intelligence often coexists with pervasive developmental disorder. Usually in mental retardation, social and communicative skills are at levels expected given the child's overall development. Individuals with severe and profound mental retardation may exhibit various autistic-like features, particularly stereotyped movements. Mental retardation is not usually observed in association with Asperger's disorder.
- Specific developmental disorders, particularly language-related disorders, may sometimes mimic autism and related conditions. Usually in the language disorders, the primary deficits are in the area of language/communication, social skills are relatively preserved, and the unusual restricted interests and behaviors associated with autism are not present.
- Rarely schizophrenia has its onset in childhood. Usually there is a previous history of normal or near normal development with the onset of characteristic hallucinations and delusions typical of schizophrenia appearing later in development.
- Selective mutism sometimes is confused with autism and related conditions. In selective mutism the child's ability to speak in some situations is preserved, but the child is mute in other situations. The history and presentation are quite different from autism and related conditions. Although it is the case that children with autism are often mute, their mutism is not selective in nature.
- Social anxiety disorder may sometimes be confused with autism or other pervasive developmental disorder (particularly PDD-NOS) but with the exception of social anxiety the other criteria for autism would not be present.
- Stereotypic movement disorder is characterized by motor mannerisms (stereotypies) and the presence of mental retardation. A diagnosis of stereotypic movement disorder is not made if the child meets criteria for one of the pervasive developmental disorders.
- Occasionally a dementia has its onset in childhood. In some cases the child will fulfill criteria for childhood disintegrative disorder, in which case that diagnosis as well as the specific medical diagnosis causing the dementia would be made. The typical pattern in dementia of childhood onset is one of progressive deterioration in functioning.
- Some children with obsessive compulsive-disorder present with unusual interests and behaviors. Usually, however, social skills are preserved, as are language/communication skills.

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- In schizoid personality disorder, the child is relatively isolated but has the ability to relate normally in some contexts.
- Avoidant personality disorder is characterized by anxiety in dealing with social situations.
- In reactive attachment disorder, there usually is a history of a marked or very severe neglect. The social deficits of reactive attachment disorder tend to remit dramatically in response to a more appropriate environment.

A multi-axial, developmentally based approach to differential diagnosis is very useful. Specific behaviors can then be viewed in the context of intellectual, communicative, and other abilities. When standardized assessments, (e.g., of intelligence or language), are used it is important that they be selected to be appropriate to the individual. Measures of adaptive skills are readily obtained and help to guide intervention programs.

The developmental stage and level of the individual are important in assessment and treatment. For infants and very young children, there should be increased awareness of the complexities of diagnosis. For example, not all of the features of autism may be present before age 3. Asperger's disorder is rarely diagnosed before age 3. The clinician should also be aware that marked neglect could lead to problems in social interaction, which initially might suggest autism or PDD.

TREATMENT

THE TREATMENT PLAN

Planning for the individual's program of services is essential in insuring consistency and efficacy of intervention. This planning should include parents and family members as well as school staff and other professionals. In treatment planning some elements are always or almost always required (e.g., establishing goals for educational intervention for school age children) while others are relevant depending on the clinical context and available evidence regarding efficacy (e.g., in indications for and use of pharmacological interventions). Treatments proposed should be based on solid, empirical evidence. Treatment planning should include a realistic assessment of available resources as well as characteristics of the child, which may impact (positively or negatively) on the intervention program.

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The treatment plan should address:

- Establishing goals for educational intervention.
- Establishing target symptoms for intervention.
- Prioritizing target symptoms/co-morbid conditions.
- Monitoring multiple domains of functioning (including behavioral adjustment, adaptive skills, academic skills, social-communicative skills, and social interaction with family members and peers).
- Monitoring medication for efficacy and side effects, as appropriate.

PSYCHOSOCIAL TREATMENTS

- Educational services (including special education, some forms of behavior modification, and other services) are the central and integral aspect of the treatment of autism in children and adolescents. Federal law 94-142 mandates the provision of an appropriate educational plan for all children in the U.S. and provides specific rights to parents. As part of this educational program, ancillary services are often required. These include speech-language therapy, occupational therapy and physical therapy. Sustained and continuous programming is more effective than episodic programming. The option for summer programming may be needed since children with these conditions often regress in the absence of such services. Professionals should be prepared to consult and collaborate with teachers and other school personnel.
- Psychosocial interventions include parent training (e.g., in behavior modification techniques) and referral to parent/sibling support groups. In some cases parental counseling may be appropriate or, for the affected individual, social skills training and/or highly structured individual counseling or psychotherapy may be indicated particularly for older and higher functioning individuals.
- In some cases parents will seek additional ancillary treatments outside the school setting. It is important that providers of such services coordinate their work with that of the other providers.

PHARMACOLOGICAL AND RELATED INTERVENTIONS

- Medications may be useful for symptoms that interfere with participation in educational interventions or are a source of impairment or distress to the individual. The medications are not specific to autism and do not treat core symptoms of the disorder and

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their potential side effects should be carefully considered. The neuroleptics, selective serotonin reuptake inhibitors, tricyclic antidepressants, lithium and mood stabilizers, and anxiolytics have been used in these patients with varying degrees of success.

- Dietary and other alternative treatments are not clearly established as being efficacious. Families should be helped to make informed decisions about their use of alternative treatments. Treatments that pose some risk to the child and family should be actively discouraged.

FOLLOW-UP ASSESSMENTS AND ONGOING TREATMENT

- Usually services are needed at different points in the child's development for various lengths of time. Coordination of services and family support are important aspects of ongoing care. The nature and intensity of such contact depend on the clinical situation and needs of the individual. More frequent contact is needed for individuals who receive psychotropic medication or who exhibit behaviors which pose a danger to the individual or others or which interfere with the provision of an appropriate educational intervention program.

DEVELOPMENTAL ISSUES IN ASSESSMENT AND TREATMENT

Educational services are less frequently available for infants and young children, less than three years, but should be utilized whenever possible. While early intervention undoubtedly is very helpful, important questions remain to be addressed, e.g., what features of the treatment are most important and what characteristics of the child are associated with greatest improvement. If medications are used in this age group, considerable caution should be exercised and the child monitored very closely.

For school-aged children the eligibility for supportive services such as respite care may be important. This may depend upon establishing eligibility for services through state departments of mental retardation.

For adolescents with autism and related conditions, there should be more emphasis on vocational and prevocational skills as well as on adaptive skills. The latter are prerequisites for independent and semi-independent living. The clinician should help to identify areas of strength for vocational planning. It is important to note that during adolescence some children make major gains while slightly more exhibit significant developmental losses. Emerging sexuality may present other issues. The adolescent may also be more capable of participating directly in

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treatment and treatment planning. Co-morbid conditions, such as depression in individuals with Asperger's disorder, may first be seen in adolescence.

Among adults with autism and related conditions, the identification of community resources and support in planning for long-term care is critical. In many states individuals with PDD as adults are not eligible for services unless they are also eligible on the basis of associated mental retardation. These services may include provision of supported employment and supported residential living arrangements. Individuals without eligibility for state-supported services are often most in need of care. Services provided may depend upon having eligibility established for Department of Mental Retardation support. The latter may include provision of supported employment and supported residential living arrangements.

LITERATURE REVIEW

Multiple comprehensive literature searches were conducted using Medline and Psychological Abstracts. Although the focus was on papers published in the past decade older sources were, of necessity, included as relevant. Over 20 recent books were consulted. A bibliography of over 3,500 references was developed for this review. The review process was facilitated by the various reviews of the literature and data reanalysis developed for DSM-IV and published in the DSM-IV source books (Tsai, 1997; Szatmari, 1997; Volkmar, 1997). In addition, the recent National Institute of Health State of the Science Conference on Autism and the associated research reports (see Bristol, Cohen, Costello, Denkla, Eckberg, et al., 1996) provided an extremely helpful overview of research findings. For purposes of the present review, an emphasis was placed, when possible, on recent scientifically rigorous studies, rather than single case reports or uncontrolled research. In some instances, review articles and chapters were particularly helpful in providing either meta-analyses of available data or summaries of current knowledge (Klin et al., 1997; Rutter, 1996; van Acker, 1997; Volkmar, Klin, Marans & Cohen, 1997b). As noted subsequently, in some areas it is clear that research is lacking.

BRIEF HISTORY

Although autism was formally identified in 1943 by Leo Kanner, cases probably had been observed previously, e.g., in reports of "wild" or "feral" children or "idiot savants" (Treffert, 1989). There was much confusion, both before and after Kanner's (1943) description,

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regarding the continuity of autism with schizophrenia and other then recognized forms of psychosis. In his report Kanner described 11 children who exhibited an apparently congenital inability to relate to other people, which was in marked contrast to their ability to relate to objects. Kanner noted that this was the reverse of the pattern typically observed, i.e. infants typically were much more interested in the social, as opposed to nonsocial, environment. He also observed that when language developed in these children it was remarkable for echolalia, pronoun reversal, and concreteness. The children also exhibited unusual, repetitive, and apparently purposeless activities (stereotypies). In his choice for the name of the disorder “early infantile autism” he emphasized the distinctiveness of the condition.

For many years confusion centered around the possibility that autism was the earliest manifestation of schizophrenia. However, various lines of research (notably that of Kolvin, 1971, and Rutter, 1972) made it clear that autism and childhood schizophrenia differed in many respects, e.g., in clinical features, course, and family history. Autism was first included in DSM-III where it was placed in a new category of disorder, the Pervasive Developmental Disorders (PDD). The original DSM-III definition lacked a developmental emphasis and in DSM-III-R the name of the disorder and criteria were changed to reflect a greater developmental awareness. The definition of autism in DSM-IV was based on the results of a large, international, multi-site study. One of the advantages of this data-based definition is that it is conceptually identical to the one employed in ICD-10 (World Health Organization, 1994, see Volkmar, et al., 1994 for discussion).

Rett’s disorder was first described by Andreas Rett in 1966. There was initial confusion over whether or not these cases exhibited a form of autism. As cases were followed it became clear that the course of this condition was distinctive (van Acker, 1997). The condition now known as childhood disintegrative disorder (CDD) was first described by Heller in 1908 and known as either dementia infantilis or disintegrative psychosis. In DSM-III and III-R it was presumed that this relatively rare condition was always associated with a demonstrable neuropathological process but review of published cases indicates that this is not correct and that, although the condition resembles autism once it has developed, the course as well as onset are highly distinctive (see Volkmar, Klin, Marans, & Cohen, 1997).

Of the conditions now included in DSM-IV, Asperger’s disorder has been the most controversial. Originally described in 1944, the condition was largely unrecognized in the English language literature until the 1980’s. The term has come to be used in very different, and inconsistent, ways, (e.g., to refer to adults with autism, sub threshold autism, verbal or higher

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functioning autism, or, as in DSM-IV, to refer to a condition which differs from autism). As presently defined the onset of the condition is somewhat later than in autism and verbal skills are relatively preserved. Although not required for the diagnosis highly circumscribed and all encompassing interests are typical (see Klin & Volkmar 1997).

The term PDD-NOS is used to refer to sub threshold conditions in which the individual has problems suggestive of PDD but does not meet full criteria for one of the explicitly defined conditions. Although undoubtedly the most common PDD, this condition has been the focus of very little systematic study (see Towbin, 1997).

CLINICAL PRESENTATION

AUTISTIC DISORDER

The diagnosis of autism requires disturbances in each of three domains: 1) social relatedness, 2) communication and play, and 3) restricted interests and activities. By definition the onset is by age 3 (Volkmar, Klin, Siegel, Szatmari, et al., 1994). Areas of social disturbance include marked impairment in nonverbal behaviors in social interaction, failure to develop peer relations as appropriate to developmental level, lack of seeking to share enjoyment or interests, and a lack of social or emotional reciprocity. Impairments in communication include either a delay or total lack of spoken language (without an attempt to compensate through other means) or, for verbal individuals, a marked difficulty in the ability to sustain or initiate conversation; stereotyped and repetitive (or idiosyncratic) language; and lack of appropriate make-believe or social play as appropriate to developmental level. The category of restricted repetitive and stereotyped behavior, interests, and activities includes encompassing preoccupations and interest, adherence to nonfunctional routines or rituals, stereotypies and motor mannerisms (e.g., hand or finger flapping or body rocking), and persistent preoccupation with parts of objects. The onset before age 3 years is determined by whether or not the individual had abnormal or delayed functioning in the areas of social interaction, social use of language, or symbolic or imaginative play by that time. Delay or abnormality in any one area is typical and sufficient for diagnosis. If a child meets the behavioral criteria for autism but does not meet the onset criteria a diagnosis of atypical autism is made. The diagnosis of autistic disorder is not made if the disorder is better accounted for by Rett's disorder or childhood disintegrative disorder.

The most classic picture of autism is often presented by preschool children who may exhibit marked lack of interest in others, failure in empathy, absent or severely delayed speech

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and communication (Stone, 1997). However, the marked resistance to change, restricted interests, and stereotyped movements may develop or become more noticeable after age 3 years (Lord, 1996). Younger children with autism may exhibit attachments to specific objects, but, unlike typical transitional objects in normally developing children, the attachment objects of children with autism are more likely to be hard rather than soft, and the actual object may be less critical than the class of object. For example, a child may be attached to a specific type of magazine and carry this around, but the child may not care about a particular issue of the magazine as long as it is that particular kind of magazine.

Although awareness of the importance of early diagnosis has increased the sensitivity of pediatricians and primary care providers, delays in case detection of autism remain relatively common (Stone, 1997). There is a potential for misdiagnosis in both directions. Sometimes parents are concerned about the child's development early in life but are reassured by care providers that the child will "grow out of it." In other cases parental denial or lack of experience may delay diagnosis. Common presenting complaints at two years include concern about the child's lack of language, inconsistencies in responsiveness, or concern that the child might be deaf. There is variability in the age at which children present all features essential for the diagnosis (Lord, 1996). Predictors of ultimate outcome include the presence of communicative speech by age 5 and overall cognitive ability (IQ) (Stone, 1997).

By school age greater differential social responsiveness usually develops and communication skills increase. Problems in dealing with change and transitions and with various self-stimulatory behaviors (sometimes including self abuse) may also become more prominent (Loveland and Tunali-Kotoski, 1997). Disruptive or compulsive behaviors may prompt requests for pharmacological intervention.

In adolescence a small number of autistic individuals make marked developmental gains, while another subgroup will behaviorally deteriorate. An increased risk for the development of seizures is noted in adolescence (Mesibov & Handlan, 1997).

There is evidence that with earlier detection and with the better provision of services that the prognosis for autism has improved (Howlin, 1998). Early studies suggested that only 1-2% of individuals with autism were able to attain personal independence and independent employment with approximately two thirds needing intensive care as adults. In a recent study of outcome (Goode, Rutter, and Howlin, 1994) 75 adults were followed up. Fifteen had a good or very good outcome (were working independently and had friends), 18 had a fair outcome (did not live independently and had no friends), and with the remainder of the cases receiving

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relatively intensive care. Of the entire group, two-thirds were in day or residential treatment programs. Adults with autism who attain the capacity for independent living and sustained employment usually have the highest levels of cognitive and communicative skills but have persistent problems in social interaction.

OTHER PERVASIVE DEVELOPMENTAL DISORDERS

The definition and validity of other disorders in the PDD class has been more controversial (Rutter, 1996). This reflects the fact that although some of these disorders were first described many decades ago research efforts have, until recently, been focused almost exclusively on autism. The advent of formal definitions in DSM-IV and ICD-10 has already begun to stimulate additional research. It is likely that the definitions of these conditions will be further improved and refined. Two of the disorders now included as PDDs in DSM-IV are associated with a significant degree of developmental deterioration.

Rett's Disorder

In this condition a brief period of normal development precedes decelerated head growth, loss of purposeful hand movements, and development of severe psychomotor retardation (Tsai, 1997). The child's prenatal and perinatal development is apparently normal to at least age 6 months and the child has a normal head circumference at birth. Subsequently (and before age 4 years) the head growth decelerates; purposeful hand movements are lost and characteristic stereotyped hand movements (hand wringing or hand washing) develop (van Acker, 1997).

This condition usually has an onset in the later half of the first year of life. Although a few males with some features suggestive of Rett's have been reported, the diagnosis of these cases is questionable and to date this condition has been unequivocally observed only in females (van Acker, 1997). Early prenatal and perinatal development of the child is normal. A period of developmental stagnation may herald the onset of the condition (van Acker, 1997). A gradual and insidious onset is often reported as delays in development, decelerated head and body growth, and lack of interest in the environment develop. Developmental deterioration progresses and previously acquired skills, including purposeful hand movements, are lost (van Acker, 1997). The potential for confusion with autism is greatest in the preschool years because of the stereotyped hand movements, limited or deteriorating language, social, and motor skills (Olsson & Rett, 1987).

The course in Rett's syndrome is very characteristic and the prognosis poor. By the time the child reaches school age autistic-like features are less prominent. A developmental plateau

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or pseudostationary phase is then observed. Severe mental retardation, seizures and motor problems are major areas of concern and breathing difficulties (hyperventilation, breath holding spells, air swallowing), bruxism, motor problems, and early scoliosis are observed (Hagberg and Witt-Engerstrom, 1986). Apnea may alternate with hyperventilation. Subsequently an even more marked period of developmental deterioration occurs (Hagberg and Witt-Engerstrom, 1986). Although motor problems are pronounced, most children remain ambulatory until the final period of late motor deterioration (Hagberg, 1989). Seizures commonly develop. In the final phase of the disorder motor problems and scoliosis increasingly limit mobility and patients may become nonambulatory. There is an increased risk of sudden death (Hagberg, 1989) and there is some suggestion of decreased life expectancy (van Acker, 1997). Adults with the condition require very high levels of support and supervision.

Childhood Disintegrative Disorder

In this condition (CDD) a period of at least two years of normal development occurs (there must be age appropriate communication, social relatedness, play and adaptive behaviors). This is followed by a marked deterioration and clinically significant loss of at least two skills in the areas of receptive or expressive language, social skills, toileting skills, play, or motor skills (Volkmar et al., 1997b). The child also develops abnormal functioning in at least two of the areas of behavioral disturbance observed in autism (i.e., social relatedness, language-communication, or restricted interests and activities). Thus a child who previously had appeared perfectly normal typically loses language, self-help, and other skills and comes to exhibit behaviors suggestive of autism. By definition the condition is not better accounted for by another specific pervasive developmental disorder or by schizophrenia (see Volkmar & Rutter, 1995 for a critique of current criteria).

The onset of CDD is highly distinctive and a central diagnostic feature. The condition develops after a prolonged period (several years) of normal development, (e.g. the child has developed the ability to speak in sentences by age two years). The length of the period of normal development before the onset of CDD is defined in DSM-IV to be at least 2 years although in some cases there may have been very mild developmental difficulties (Kurita, 1988). Onset is typically between 3 and 4 years of age. Onset can be gradual (over a period of some weeks or months) or more abrupt (days to weeks). Sometimes parents report that the child had become agitated, anxious, or dysphoric in the days/weeks prior to the developmental deterioration (Heller, 1930).

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Once established CDD clearly resembles autism and clinical features include markedly impaired social skills (Kanner, 1973; Kurita, 1988; Volkmar et al., 1997b). Either mutism or marked deterioration in verbal communication skills is usual, and communication problems are similar to those observed in autism. Resistance to change, stereotyped movements, and other unusual behaviors of the type seen in autism also develop. Unusual affective responses are observed, e.g., general dysphoria and agitation. Deterioration in self-help and motor skills is often marked and previously acquired bowel and bladder control may be lost.

Three patterns of clinical course have been reported (Volkmar et al., 1997b). In most (about 75%) of cases the child's development and behavior deteriorate to a much lower level of functioning and plateaus, i.e., no further deterioration occurs but developmental gains are minimal (Volkmar & Cohen, 1989). Less frequently the developmental regression is followed by limited recovery, such that a child who had become totally mute may regain an ability to speak in single words, or, occasionally, in phrases or sentences (Volkmar & Cohen, 1989). In a handful of cases the child has been noted to have a noteworthy recovery. Sometimes the developmental regression is progressive, particularly if a progressive neurological process can be identified. Death may then be the eventual outcome (Corbett, 1987). Life expectancy otherwise is apparently normal. EEG abnormalities and seizure disorders are frequently observed (Volkmar et al., 1997b). In contrast to acquired epileptic aphasia (Landau-Kleffner syndrome), severe deficits in social interaction are observed in CDD.

At one time there was a presumption that the kind of deterioration associated with CDD was invariably a manifestation of some identifiable underlying neuropathological process or general medical condition but review of these cases suggests that while such conditions are sometimes observed, this is the exception rather than the rule.

Asperger's Disorder

Individuals with Asperger's disorder (AspD) usually do not present with delays in language acquisition nor with unusual behaviors and environmental responsiveness as is the case in autism nor do parents usually have serious concerns about the child's development in the first years of life (Klin & Volkmar, 1997). In Asperger's original (1944) description, the child was precocious in learning to talk and often talked in a pedantic way about a topic of particular, circumscribed interest. There may be early fascination with letters and numbers and the child may even be able to read (decode) words though sometimes with little or no understanding (hyperlexia). Approaches to peers and novel adults may be unusual or idiosyncratic but

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attachment patterns to family members are established. Referral for assessment is usually later than that in autism.

Of the various disorders newly included in the PDD class in DSM-IV, the most controversy has focused on Asperger's disorder. Given the absence of consensus definitions until quite recently, the concept has been used in markedly different ways. It has been used to refer to adults with autism or higher cognitively functioning individuals with autism, or to PDD-NOS (pervasive developmental disorder not otherwise specified), or to a condition that differs from autism in important ways (Gillberg, 1986; Klin, Volkmar, Sparrow, Cicchetti & Rourke, 1995; Szatmari, 1991; Wing, 1981). The limited data available do suggest potential differences between AspD and higher functioning autism (HFA) (Klin & Volkmar, 1997). However, the validity of AspD remains controversial.

The DSM-IV definition defines AspD on the basis of the presence of qualitative impairments in social interaction of the same kind observed in autism, but there is a lack of any clinically significant general delay in language or cognitive or adaptive behavior early in life. While early language skills are relatively normal it is possible that subsequent pragmatic skills may be impaired. By definition, the individual does not meet the criteria for another specific PDD.

The DSM-IV definition for AspD has been criticized (Miller & Ozonoff, 1997). It is likely that some modifications will be made in light of recent research. The theoretical notion underlying the definition does, however, have historical continuity with Asperger's original description and subsequent research. Asperger emphasized that while social deficits were a major problem the child's language and cognitive abilities were largely preserved and the apparent onset of the condition was usually after age 3. It should also be noted that if a child's language is relatively normal at age 3 this is no guarantee that subsequent language, particularly social language, will be normal. Asperger (1944) emphasized the importance of restricted, intense, and highly circumscribed interests, which interfered with the acquisition of basic skills in his original report. Such interests are indeed commonly encountered clinically, but are not absolutely required for a diagnosis of AspD in DSM-IV. Similarly, early motor clumsiness and awkwardness is commonly reported by parents of children with AspD (in contrast to autism where motor skills tend to be preserved early in life) but such deficits are not required for the diagnosis to be made.

Asperger originally (1944) predicted a positive outcome since he assumed that the children could gainfully use their special interests and since similar traits were seen in family

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members, particularly fathers. Over time this optimism was somewhat tempered (Asperger, 1979) but Asperger continued to feel that the better outcome of the condition was a feature central in differentiating it from Kanner's autism. Substantive empirical data regarding outcome in AspD are lacking although it appears that individuals with the condition have generally a better outcome than those with high-functioning autism (i.e., are more likely to have gainful employment, live independently, and may establish a family). The ability to marry and have a family appears to be a major point of differentiation from autism. However, the social difficulties of AspD are apparently lifelong (Tantam, 1988). Individuals with AspD have been reported to be at increased risk for psychosis and violence but this impression is based almost entirely on case reports, rather than controlled studies (Mawson, Grounds & Tantam, 1985). The association of AspD with depression has also been noted (Klin & Volkmar, 1997). Such symptoms may be the cause for initial psychiatric referral.

Pervasive Developmental Disorder Not Otherwise Specified/Atypical Autism

The term pervasive developmental disorder-not otherwise specified (PDD-NOS) (also sometimes termed atypical PDD or atypical autism) encompasses subthreshold cases. For example, where there is marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest but where full features for autism in each of these domains or another explicitly defined PDD are not met. Thus this category is defined implicitly based on the judgement of the clinician.

Relative to the other PDDs the natural history of PDD-NOS has been rarely studied. The limited data suggest that individuals with PDD-NOS have a better prognosis than persons with autism but social, communicative or adaptive and behavioral problems may be prominent during the school years. In adolescence and adulthood there appears to be increased risk for anxiety and mood disorders (Towbin, 1997).

While deficits in social and other skills are noted these problems usually are less severe than in classical autism (Towbin, 1997). The issues of whether meaningful subtypes might be defined within the broad PDD category and the nature of the spectrum of these conditions remains the topic of debate (van der Gaag et al., 1995; Rapin, 1991). Recent family and twin studies have suggested the possible importance of a broader conceptualization (Rutter et al., 1997).

DIFFERENTIAL DIAGNOSIS

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Autism and the other PDDs must be differentiated from each other as well as from the specific developmental disorders, e.g., language disorders, and from sensory impairments, e.g., deafness. A comprehensive developmental history is the most useful tool in this effort and usually will be obtained from parents but occasionally collateral sources, e.g., teachers and other therapists. Difficulties in diagnosis can arise in several situations. The diagnosis of autism in infants and very young children can be difficult (Lord, 1996; Stone, 1997) since assessment is more challenging and some features (e.g., stereotyped movements) may develop after other features. The incorrect assignment of a diagnosis of autism is more likely in children with significant sensory impairments and with very severe degrees of developmental retardation. It is sometimes necessary to follow children over time since some children who did not meet full criteria for autism do so between ages 3 and 4 (Lord, 1996). Similarly, issues of diagnosis can be complex in older individuals if an informant about the person's early development is not available or is not reliable. The uses of collateral sources of information as well as past records may be helpful in such cases. Diagnostic impressions of autism among individuals with severe or profound mental handicap may be incorrectly influenced by the prominence of stereotyped movements/mannerisms in the absence of social or communicative criteria for autism. The judgement of whether social or communicative criteria are deviant relative to the persons overall level of ability is helpful.

Diagnostic difficulties also arise among higher functioning individuals with autism and related disorders. Several recent attempts have been made to differentiate AspD and higher functioning autism on the basis of specific neuropsychological tests and abilities (Klin et al., 1995; Ozonoff, Rogers & Pennington, 1991; Pomeroy, Friedman & Stephens, 1991; Szatmari, Archer, Fisman, Streiner & Wilson, 1995). With the advent of more consensual definitions of the syndrome it appears that differences from autism are more likely to be observed. In general (again consistent with Asperger's original report), the preservation of verbal abilities is a striking feature and one that differentiates AspD from higher functioning autism.

The Role of Historical Information

Adequate and reliable historical information facilitates the process of evaluation and differential diagnosis. In autism it is more typical for parents to report that either the child was "too good" or undemanding or was little interested in others or was unusually sensitive to the nonsocial environment. In a minority of cases a period of normal or near normal development is reported. This is typical in Rett's syndrome (where the period of normal development is short)

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and in CDD (where the period of normal development is relatively much longer). Sometimes in autism parents will report a developmental regression or stagnation (e.g., the child had the ability to say single words but language development did not then blossom as expected). In taking a history, questions about specific developmental skills may be helpful.

If there is a history of some period of reasonably normal development possible diagnoses include elective mutism, Rett's disorder, childhood disintegrative disorder, developmental language disorder, schizophrenia, and degenerative CNS disorder. Children with reactive attachment disorder may exhibit deficits in attachment but these usually significantly improve if adequate care taking is provided (Richters & Volkmar, 1994). In CDD the pattern of onset is highly distinctive. It appears that in Asperger's disorder language skills are relatively more preserved, parents are worried rather later, and motor delays may be more common than in autism. Unusual features, (e.g., rapid deterioration in a previously normally developing child), suggest the need for thorough medical evaluation (see laboratory studies). Children with PDD-NOS and Asperger's disorder often come to professional attention rather later than is the case with autistic children (see Klin and Volkmar, 1997 for a discussion). Given the recency of the official definition it is likely that this definition will be refined in subsequent editions of the Diagnostic and Statistical Manual. At present clinicians diagnosing AspD should pay careful attention to both the criteria **and** text of DSM-IV (APA, 1994) and the emerging literature on this topic.

General Medical Conditions

In general the proportion of cases of autism attributable to specific medical conditions is relatively low. The relationship, particularly a causal relationship, of other medical conditions to autism is complex. Often initial reports of such associations are based on case reports and not controlled studies or epidemiologically based samples. For example, the impression of a strong relationship between autism and congenital rubella had to be modified as it became apparent that such cases tended to become less "autistic-like" over time and that at least some of the resemblance to autism related to the sensory impairment and severe mental handicap exhibited. For studies of associated medical conditions in autism, the critical question is not whether associations are ever observed but whether the association is greater than would be expected given the rate of the disorder in the general population. Rates of reported medical conditions, which might causally relate to autism have varied widely depending on various factors. Gillberg and Coleman (1996) have reported rates of such medical conditions approaching 25% while

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Rutter and colleagues (Rutter, Bailey, Bolton & Le Couter, 1994) suggest that 10% is more representative. The data do not seem to suggest more than chance associations of autism with Down syndrome, congenital rubella, cerebral palsy, PKU, and neurofibromatosis. On the other hand, both Fragile X syndrome and tuberous sclerosis occur in persons with autism at higher rates than would be expected on a chance basis. Approximately 1 in 100 persons with autism exhibits the Fragile X anomaly (Rutter et al., 1994). The rate of autism in tuberous sclerosis is also elevated (Smalley, Tanguay, Smith & Gutierrez, 1992). Infants with congenital sensory handicaps, (e.g., blindness or deafness), may present with a question of possible autism because of unusual movements or language difficulties but usually full criteria for autism are not met.

Comorbid Psychiatric Disorders

Autism has been reported to co-occur with various other developmental and behavioral conditions. Some of these associations seem relatively frequent, others much less so. The critical issues are: 1) whether such associations occur at levels greater than would be expected by chance alone; and 2) are the symptoms and behavioral manifestations observed best viewed as part of autism or as the manifestation of some other condition (Tsai, 1996). These problems become particularly complex for individuals who are largely or entirely mute or who function in the severely or profoundly mentally retarded range.

With the exception of Asperger's disorder, mental retardation frequently co-occurs with autism and other PDDs, and the frequency of symptoms suggestive of autism increases with the degree of mental retardation (Wing & Gould, 1979). Individuals with very low (and very high) intelligence scores present the most challenging diagnostic problems. The task of diagnosis is often most complex when clinicians evaluate younger and more impaired individuals (Lord, 1996; Rutter, 1996). It is sometimes the case that the nature of the disorder becomes clear only over the course of development (Volkmar, Klin & Cohen, 1997a). It is appropriate to share, within reason, diagnostic uncertainties with parents.

Focusing on symptoms rather than disorder makes it clear that individuals with the PDDs exhibit many behavioral difficulties including hyperactivity, attentional problems, obsessive compulsive-like phenomena, self-injury and stereotype, tics, and affective symptoms (Poustka & Lisch, 1993; Jaselskis, Cook & Fletcher, 1992; Quintana et al., 1995; Ghaziuddin, Tsai & Ghaziuddin, 1992; Ghaziuddin, Alessi & Greden, 1995; Realmuto & Main, 1982; Nelson & Pribor, 1993; Brasic, Barnett, Kaplan, Sheitman et al., 1994; McDougle, Kresch, Goodman, Naylor et al., 1995b). While such behaviors can be very appropriate targets for intervention

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there currently is disagreement about whether such symptoms justify an additional diagnosis. For example, since stereotyped behaviors are very frequent in autism and are included in diagnostic criteria an additional diagnosis of stereotypic movement disorder cannot be made for persons with autism. Similarly, many features such as unusual affective responses or problems in language or communication problems may be present in autism and the question then arises as to when an additional diagnosis, (e.g., of anxiety disorder or articulation problem), is justified. Mental retardation is frequently associated with autism. On the other hand some conditions, such as Tourette's disorder, and schizophrenia, are only occasionally observed.

Schizophrenia. Early investigators assumed a continuity between autism and schizophrenia based largely on the severity of the conditions. Subsequent work has shown that the conditions are not fundamentally related. While individuals with autism sometimes develop schizophrenia (Petty, Ornitz, Michelman & Zimmerman, 1985) they do not seem to do so at rates higher than expected (Volkmar & Cohen, 1991). Similarly, reports of association of psychosis with Asperger's disorder are based almost entirely on case reports and it is unclear if rates of schizophrenia or psychosis are increased. Histories of premorbid oddity, sometimes consistent with a diagnosis of PDD-NOS, are sometimes reported in early onset childhood schizophrenia.

Obsessive-Compulsive Disorder. A possible association of this condition with autism has been the focus of much interest given the availability of effective pharmacological treatments for OCD. Features suggesting OCD are frequently observed in adults with autism and Asperger's Disorder, (e.g. ordering and reordering of objects is frequent) (Rumsey, Rapoport & Sceery, 1985). Rates of such behaviors vary between studies (Brasic et al., 1994; McDougle et al., 1995b; Fombonne, 1997) but such symptoms may respond to SSRIs (Gordon, State, Nelson, Hamburger et al., 1993; McDougle et al., 1996). The meaning of drug responsiveness remains complex since many factors are involved and various disorders can sometimes be treated with the same agent. Thus even though certain behavioral features are suggestive the question of whether an additional diagnosis of OCD is justified in autism remains controversial (Baron-Cohen, 1989).

Other features and conditions. Unusual motor mannerisms and stereotypies are common in autism. These behaviors change in intensity, type, and frequency over time and as a function of variables such as adequacy of educational programming. Verbal stereotypies and preservation may also be observed. As noted previously, the stereotyped movements of autism do not justify an additional diagnosis of stereotypic movement disorder. On the other hand, several case reports and a few series have suggested possible associations between autism and Asperger's

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disorder with Tourette's disorder (Kerbeshian & Burd, 1986; Realmuto & Main, 1982; Nelson & Pribor, 1993). Unfortunately differentiating tics from stereotyped movements and other motor problems can be difficult. Catatonia has also been associated with autism (Realmuto & August, 1991). Occasionally children who have been severely and chronically neglected and/or abused may present with deficits in social interaction or communication suggestive of a PDD. In such cases of reactive attachment disorder, the social and other deficits tend to improve markedly following provision of appropriate care.

High levels of anxiety, inappropriate affective responses, and occasionally overt depression or bipolar disorders can be observed in autism (Ghaziuddin & Tsai, 1991). Depression may be more likely in higher functioning individuals with autism, Asperger's disorder, or PDD-NOS. This may reflect higher levels of communicative and cognitive ability.

Attentional problems are often noted in the PDDs. In DSM-III-R the diagnoses of autistic disorder and attention-deficit hyperactivity disorder (ADHD) could not both be given. This restriction has been removed in DSM-IV although it is clear that a diagnosis of ADHD should not be given if the attentional problems are the result of autism. Some reports suggest that ADHD should be considered an additional diagnosis and target of treatment in persons with autism but solid empirical data on this question are lacking. The additional co-morbid diagnosis of ADHD may more easily be made in individuals with Asperger's disorder or PDD-NOS (Barkely, 1990).

The Landau-Kleffner syndrome (of acquired aphasia with epilepsy) is not presently recognized in DSM-IV but is included in ICD-10 as a language disorder since the available data suggest that social skills are generally preserved and the clinical presentation is generally more consistent with aphasia. In this condition a highly distinctive EEG abnormality is present and associated with development of a marked aphasia (see Tuchman, 1994; Rapin, 1991). Recent interest has centered on the possibility that less specific EEG abnormalities (which are very common in autism and related conditions) might suggest Landau Kleffner syndrome or other conditions that might merit anticonvulsant treatment. While reports of such treatment have appeared the results are limited in several respects and controlled studies are needed; the risks associated with treatment with anticonvulsants or high dose steroids should be carefully considered.

EPIDEMIOLOGY

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PREVALENCE

A number of studies, mostly conducted outside the U.S., have examined the prevalence of autism (Bryson, 1997; Wing, 1993). Epidemiological data on the other PDDs is much more limited. Of the approximately 20 studies of autism available the median prevalence is 4.8/10,000 cases (Fombonne, 1998). However, these estimates include studies conducted at various points in time and using various methods for case ascertainment and diagnostic criteria. Changes in the definition of autism complicate the interpretation of previous research. The most recent studies suggest that the prevalence of autism may be on the order of 1 in 1,000 (Bryson, 1997). It remains unclear whether this represents a true secular increase or is simply a function of differences in method such as better case ascertainment.

It appears that PDD-NOS is much more common than more strictly defined autism, with a prevalence of perhaps as many as 1 in several hundred school-age children (Towbin, 1997). With the possible exception of Asperger's disorder, the other PDDs are apparently less common than autism (Fombonne, 1998). Prevalence estimates of Asperger's syndrome have varied widely depending on the stringency of the definition used (Klin & Volkmar, 1997). With the exception of Rett's disorder, for which there is an increased risk of early death, life expectancy in the other PDDs is normal.

GENDER, IQ AND SOCIAL CLASS DIFFERENCES

Epidemiological studies have confirmed the male predominance in autism that has also been observed in clinic-based samples (Fombonne, 1997; Lord, Schopler & Revicki, 1982). Autism is approximately 3 to 4 times more common in males than in females, but when females have autism, they tend to be more severely retarded. Except for Rett's disorder (which has been unequivocally observed only in females), male predominance has been noted in the other specifically defined PDDs. In most epidemiologically based samples of autism approximately 50% of cases exhibit severe or profound mental retardation, 30% mild to moderate mental retardation, and the remaining 20% of cases have IQs in the normal range (Fombonne, 1997).

In his original report, Kanner noted that almost all of his cases came from families of high educational level or accomplishment, which led to the notion that autism could only be seen in such families. It also contributed to the unfortunate movement towards blaming parents for the child's disorder based on the presumption that deviant childcare caused the condition. It is now clear that children with autism and other PDDs are observed in families of all levels of educational and occupational achievement and earlier impressions to the contrary were the result

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of selection bias (Wing, 1980), as parents with higher levels of education and professional status were more likely to seek referral.

ASSESSMENT

The term PDD implies that multiple areas of development are affected, making assessments of various aspects of behavior and development essential for diagnosis. The task of viewing behavioral features in the context of developmental level becomes easier when valid measures of cognitive, communicative, or adaptive skills are available (Sparrow, et al., 1997). Issues in assessment vary depending on the age of the individual and the context of the evaluation. Thus, different approaches will have to be used for initial diagnosis in the preschool child, management of behavior problems in the school age child, and evaluation of behavior change in an adolescent. Physicians have a special role in this process as they integrate medical and developmental perspectives into the task of providing and coordinating services and serving as advocates for the child and family.

The certainty of diagnosis is ultimately based on clinical judgments about the reliability and quality of data obtained from various sources (i.e., direct observation, assessment of the child by other professionals, and historical information provided by parents). Major discrepancies between history and direct observation should be carefully and thoughtfully considered while keeping in mind that the child's behavior may indeed be highly variable. Conflicting or insufficient data may be supplemented by multiple opportunities for direct observation. Also, if problem behaviors or other difficulties significantly interfere with the assessment, the clinician should be prepared to take appropriate steps to ensure that results obtained are representative and valid, such as videotaping the child on multiple occasions, in multiple settings, or utilizing appropriate observational techniques. (Volkmar, Klin, Marans & Cohen, 1996). This is not always practical or easy to do, and very young and lower functioning individuals often present assessment problems (Klin et al., 1997). The child with autism who does well in a highly structured setting in a minimally stimulating environment may behave very differently in a rather unstructured and overly stimulating classroom designed for children without disabilities (Olley & Reeve, 1997). The clinician should appreciate the strengths,

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competencies, and skills presented as well as areas of difficulty. Appropriate socio-cultural issues should be encompassed in treatment planning.

Since all the PDDs share as the central, defining feature serious problems in socialization, it is important that evaluators pay close attention to the child's social skills and the relationship between social emotional functioning and other aspects of behavior and development. As part of the assessment attention must be paid to both developmental delay as well as to deviance. Intellectual functioning or adaptive behavior can be measured using normed instruments, whereas information concerning deviant behaviors needs to be obtained through clinical observation and, in some cases, the use of diagnostic instruments (Lord, 1997; Volkmar et al., 1996).

ASPECTS OF INTERDISCIPLINARY ASSESSMENT AND REFERRAL

When multiple service providers are involved it is essential that one professional assume a coordination function for the child and family. A shared commitment to a developmental approach to intervention simplifies the task of collaboration. Interdisciplinary collaboration and consultation with child and adolescent psychiatrists, psychologists, neurologists, speech pathologists, pediatricians, occupational and physical therapists, and other primary care providers, is often needed depending on the clinical context. For example, pediatric neurologists are very likely to be involved in the evaluation of a child with possible CDD or seizures and respiratory and occupational therapists in the assessment or management of a child with Rett's disorder.

In conducting assessments, areas of deficit and need as well as strengths and important resources should be noted (Sparrow et al., 1997). The results of such assessment can be used to help organize specific services, to measure the efficacy of interventions and to provide prognostic guidance. Areas of functioning that should typically be assessed include intellectual and communicative skills, behavioral presentation, and functional adjustment of the child (Sparrow, 1997). The impact of specific problem behaviors such as over activity, self-stimulation, self-injury, and preservation should be documented.

Since many (but not all) individuals with PDD function in the mentally retarded IQ range, tests of intellectual functioning are important. The choice of specific psychological and other tests requires clinical judgement and skills since many standard tests (e.g., of intelligence or language) require degrees of language or attentional skills which may be just the skills frequently lacking in children with PDD. Various approaches are available to deal with these

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clinical dilemmas (see Sparrow et al., 1997). For some very low functioning individuals, tests designed for very young children may be administered to help clarify areas of strengths and weaknesses. For a diagnosis of mental retardation (with or without a PDD), deficits in both intellectual development (IQ) and adaptive behavior must be documented.

In many jurisdictions the diagnosis of MR also determines eligibility for other services, particularly adult services. When referring individuals with the PDDs for evaluation, it is important that the examiner be fully informed about the purpose and nature of the assessment, i.e., the testing is primarily for purposes of planning intervention in which case the psychologist or other examiner may decide to modify usual administration procedures or for purposes of eligibility for services in which case standard administration procedures should be strictly adhered to. While the use of any single score or test to describe the abilities of a child with PDD is clearly limited, the overall intellectual level (IQ score) does help to establish a framework against which specific diagnostic criteria can be judged and within which other aspects of behavior can best be evaluated. In this regard it is also important to note that, given the usual scatter in skills of these children, a major goal of any formal testing is to obtain a profile of strengths and weaknesses, which can help in designing intervention programs. When an individual has marked scatter in his or her abilities it is also important that the presence of specific, isolated (splinter) skills not mislead educators or other professionals about the child's more typical capacities for learning.

Similar issues arise with regard to assessment of speech/communication skills. Except for Asperger's disorder and PDD-NOS, it is common for individuals with autism and the other PDDs to be either largely mute or to have major difficulties in communication. Even with Asperger's disorder, higher functioning autism, and PDD-NOS, problems in the social uses of language may be marked. Speech-language-communication assessment can be requested even if the child is nonverbal. Such assessments should provide relevant information regarding communication skills and the likelihood of developing augmentative or nonverbal communicative abilities. Therefore, assessment should not be restricted to assessment of articulation and oral-motor capacities or to single word vocabulary. For nonverbal individuals, broader issues of communication such as communicative intent, the capacity for protest, early turn taking, joint attention, etc. can be assessed. With older individuals assessments should include pragmatic skills, the use of prosody, and other higher order language abilities.

ASSESSMENT INSTRUMENTS SPECIFIC TO AUTISM AND THE PDDs

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Various checklists, rating scales, or other dimensional assessments have been developed to help in the task of screening for and evaluating individuals with autism (see Lord, 1997 and Parks, 1983 for summaries of available instruments). Similar instruments remain to be developed for the other PDDs. Generally, instruments developed for autism rate the presence and/or severity of behaviors often seen in autism and usually rely either on direct observation of current functioning or parental or teacher report of past and present functioning.

As a practical matter all of these instruments vary in their usefulness for usual clinical practice. Some require specific training in administration and use. Such training is required to establish and maintain reliability. Some instruments provide information about diagnosis and others provide a general measure of severity of autism.

Commonly used instruments include:

- Autism Behavior Checklist (Krug, Arick, and Almond, 1980) - a screening instrument completed by teachers,
- Childhood Autism Rating Scales (CARS) (Schopler, et al., 1988) - an instrument in which individuals of different ages are rated, some training is required,
- Autism Diagnostic Interview - Revised (ADI-R) (Lord, Rutter & Le Couteur, 1994), a semistructured interview for parents,
- Autism Diagnostic Observation Scale (ADOS) (DiLavore, Lord & Rutter, 1995) an observational scale for children and adults.

Both the ADI-R and ADOS require considerable training to insure reliability. Information on reliability and validity of these instruments is available (Lord, 1997). With the exception of a few instruments (notably the ADOS and ADI-R) most have little or no explicit relationship to categorical diagnostic criteria. This reflects the fact that categorical diagnostic systems have a conceptual approach as opposed to the somewhat more empirical approach usually employed in developing rating scales and checklists, (i.e., where the concern relates to sampling a large number of possibly relevant behaviors or developmental features). The latter features may, of course, make such instruments more useful for other purposes, (e.g., as global measures of severity or dependent measures in intervention studies). Some of the instruments may be of use to the general clinician but, at best, are intended to approximate good clinical judgement and do not replace thoughtful clinical assessment.

PSYCHIATRIC ASSESSMENT PROCEDURES

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History

Historical information is central in the task of differential diagnosis of autism and the PDDs and also helps to clarify the need for additional laboratory or other studies and for the services of other professionals. The clinician should take care to obtain a detailed and relevant history of the child with special attention to information about the pregnancy and neonatal period, early development of the child including developmental milestones, unusual features of early development, medical and pharmacological history, family history, previous assessments, and current educational program. The major concerns of the parents and their reasons for seeking the evaluation should be carefully explored. Occasionally, parents will arrive with copious information about the results of previous assessments. Such information may be helpful but does not substitute for a detailed and thoughtful review of the child's history. Taking a careful history also conveys to the parents the importance of the information they provide and helps build the possibility of a longer-term, collaborative relationship.

Systematic attention to the areas relevant to differential diagnosis is indicated. Information on the type and age of onset of the condition should be collected, such as when were the parents first worried about the child? What was the nature of their early concern? Did they think they child might be deaf? For parents of older individuals or when parents have difficulty remembering, it can help if parents are asked to recall a specific, well remembered time (such as the child's first birthday or first Christmas). Photograph albums, baby books, videotapes may help parents in this regard. Information on the onset should include a focus on early social skills and communication as well as discussion of more deviant behaviors such as gaze aversion, idiosyncratic interests, attachments to unusual objects, and so forth.

The patterns of onset in Rett's disorder and CDD are highly distinctive. In contrast to higher functioning autism, a child with Asperger's disorder may have an apparent onset of their condition rather later in development (often after age 3) since early development is essentially normal and social problems become more striking when the child moves into novel settings or is exposed to peers, such as in preschool (Klin and Volkmar, 1997).

Information on the nature of changes over the course of development (e.g., in response to intervention) should be obtained. For example, another clinician may have avoided giving a diagnosis of autism in a young child who appeared to exhibit autism but for the relative absence of stereotyped motor mannerisms or other restricted interest and activities criteria. Not uncommonly, such features appear somewhat later in development and a diagnosis of autism can

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then be made. Similarly, a report of recent developmental change in association with some unusual behavior on the child's part may suggest the onset of a seizure disorder.

Mental Status Examination

It is helpful if the child can be observed in both more and less structured settings since this will give a better sense of the child's performance and may have practical importance in helping to design an intervention program. Attention should be paid to the three broad areas of behavioral disturbance relevant to the diagnosis of autism and PDD: social interaction, communication/imaginative play, and unusual responses to the environment. The child's age and developmental levels may dictate some modification in assessment procedures.

Social Interaction. Evaluate the relationship of the individual to familiar and nonfamiliar adults. Is the child interested in social interaction or aloof from it? Does the child passively accept social interaction but not generally seek it out? Is the child interested in social interaction but limited in her/his abilities because of marked eccentricity and oddness? Can the child make and sustain eye contact and can she/he use it to help regulate the interaction? Does the child use other nonverbal behaviors to help regulate the interaction? What is the nature of the child's attachment to the parents? Will the child or adolescent share enjoyment or relate empathically to others? Does the child have friends? Are peer relations appropriate to developmental level?

Communication Skills. Is the child verbal or mute? If the child is largely or entirely mute is there some attempt to use nonverbal means to compensate? Will the child point to desired food or will the child lead the parent/examiner by the hand to gain a desired object without making eye contact? If the child is verbal and has adequate speech can he/she begin and maintain a conversation? If the child is verbal are there unusual features of language, such as stereotyped language, echolalia, pronoun reversal, overly literal (pedantic) use of language, monotonic voice quality, and so forth? Does the person pursue one topic regardless of the conversational partner's interest? Can the individual make inferences, understand humor, respond appropriately to indirect requests, and take into account the perspective of the conversational partner? If there is any suggestion of disturbance in thought process or content the clinician should be alert to the possibility of schizophrenia or other psychotic conditions. However, the unusual preoccupations of individuals with autism or the tendency of patients with AspD to verbalize their thoughts or discuss their particular circumscribed interest should not be confused with thought process disorder.

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Play. Can the child use play materials for truly imaginative play? Does the child become preoccupied by unusual aspects of play materials (feel or smell)? Is the play repetitive and stereotyped in nature? Some suggestion of cognitive abilities can also be obtained by observation of the child's play, i.e., is it sensorimotor in nature or does it involve symbolic activities?

Restricted Interests and Unusual Behaviors. Does the child have a particular preoccupation or special interest? If such an interest or preoccupation is present does it interfere with functioning and is it abnormal in terms of intensity or focus (e.g., an interest in snakes which pervades essentially all the child's waking time including conversations with others) or is the person preoccupied with some unusual topic (e.g., the models and specifications of deep fat fryers). Does the individual have difficulties with change? Does he/she have difficulty with transitions or adhere to nonproductive routines? Are stereotyped movements present? If they are present do they occur when the child is excited or aroused or are they preferred activities? Can the child be interrupted while engaging in such activities? Is the child preoccupied with parts of objects (e.g., a toy truck is of interest only because the wheels can be spun)? Does the child exhibit the unusual "hand washing" or "hand wringing" stereotypies associated with Rett's Disorder?

In addition note should be made of any behaviors or features, which could interfere with programming (for example is the child is readily distracted by extraneous stimuli). Similarly, unusual affective responses may impact on program implementation. The effects of the observational setting should be taken into account, e.g., are new situations the source of anxiety? Parents or caregivers can provide information on how representative (or not) the child's behavior is on a given day.

Self-injurious behavior, when present, is often of low frequency but may be a clinically important focus of treatment (Bregman, 1997). If such behaviors are present the frequency, intensity, relationship to the ongoing context should be noted e.g., do they occur only during times of frustration?

The child's reaction to environmental change should be observed. How does the child cope with transitions? Is the child readily disorganized by extraneous stimuli? Are there particular stimuli or materials to which the child is either very sensitive or very interested? In this context it is usually most helpful if assessments can be conducted in locations where the impact of extraneous environmental stimuli is minimized.

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Areas of potential strength should be noted as well as areas of difficulty. For example, what activities motivate the individual? Does the person have a capacity for humor or self-awareness? Does the person have any strengths or splinter skills which might be used in intervention? For individuals with Asperger's syndrome, the better verbal abilities may be a strength for programming.

Motor abilities may, in some cases, also present an area of strength for the child and provide opportunities for structured interaction. It is important to note that what appear to be maladaptive behaviors may, in fact, have potential adaptive and developmentally understandable functions. For example, echolalia may serve to prolong interaction and may have adaptive functions such as in turn taking, indicating affirmation, and so on.

Indications for Additional Laboratory or Medical Studies

At the present time reasonable medical practice in terms of the medical evaluation of persons with autism is for the clinician to be guided by history and examination in ordering laboratory and other medical tests. Thus a family history of mental retardation or specific physical findings may suggest the need for chromosome analysis, including Fragile X testing or genetic consultation. A history of staring spells or of developmental regression suggests the need for EEG and/or neurological consultation. The observation that many individuals with autism develop seizures in adolescence is a reminder that repeat examination may be needed even if earlier EEGs were normal (Minshew, Sweeney, & Bauman, 1997). MRI is not presently indicated as part of a routine or initial evaluation of children with PDD. It may be indicated as part of the evaluation of possible seizure disorder or other condition.

As noted previously, one of the most common presenting concerns at the time of initial assessment is that regarding hearing. This concern should prompt rapid and thorough audiological assessment (Lacamera & Lacamera, 1997). Definitive audiological assessment should be obtained whenever there is any question of possible hearing impairment, such as when the child is language delayed or has little or no speech or has a history of recurrent ear infections. In some cases children with autism can exhibit hearing loss, in other cases the child with hearing loss may present with behaviors suggestive of autism. Parent report or simple behavioral testing or observation is often not enough to establish normal hearing levels and brain stem auditory evoked response audiometry (Klin, 1993) may be needed.

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The child who has a tendency to mouth materials may be at increased risk for lead intoxication (Shannon & Graef, 1996) and may require blood lead screening. Observation of unusual dysmorphic features (e.g., unusual facial appearance) also suggests the need for more extensive genetic assessment (Rutter et al., 1997).

The unusual pattern of a marked developmental regression following several years of normal development seen in CDD suggests the need for very careful neurological consultation.

Occasionally general medical disorders present behaviorally, particularly in younger or lower functioning individuals. For example, a preschool child may begin to head bang in association with an unrecognized early infection or a lower functioning adolescent may engage in face slapping as the result of a previously unrecognized dental problem (Lacamera & Lacamera, 1997).

TREATMENT

Because many disciplines are involved in aspects of the evaluation and treatment, it is important that one clinician be primarily involved with the parents to develop a plan of care for the child. This clinician should help to coordinate services and work with parents to obtain appropriate educational programs, advocate for services such as respite care, support the family, and provide consultation regarding behavior management and psychopharmacology (Marcus, Kuncie & Schopler, 1997). Over time clinical involvement with individuals with PDD and their families may be sustained or may be episodic with periods of greater involvement alternating with longer intervals between visits. Even when contact is episodic it often continues over many years.

At the present time a growing body of research suggests the importance of intensive, sustained treatment in improving the long-term outcome in autism and related conditions. Treatment planning should be related to assessment of the individual's current levels of functioning and his or her strengths and weaknesses. While grounded in the present reality it should focus on the long-term vision for the person's potential. Planning entails attention to educational interventions, group living situations, and community based day and vocational programs (Gerhardt & Holmes, 1997; Harris & Handleman, 1997; Marcus et al., 1997). A well functioning intervention program will also include appropriate involvement and collaboration with the individual's family (Siegel, 1997). Intervention should be focused and individualized and must be broadly enough gauged to relate to the full range of impairments.

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Regardless of the individual's age treatment planning should include provision for structured opportunities for learning and for generalization of what is learned. Individuals with autism and related conditions require high-level general medical and psychiatric care, which includes provision for routine preventive health measures as well as for the special needs of the disabled person.

PSYCHOSOCIAL INTERVENTIONS

Educational and Vocational Interventions

At the present time the best available evidence suggests the importance of appropriate and intensive educational interventions to foster acquisition of basic social, communicative, and cognitive skills related to ultimate outcome (Le Couteur, 1990). Behavioral interventions and special education may facilitate the child's learning. The educational setting should be chosen to be appropriate to the child's needs. For example, many children with autism have difficulty sustaining attention and learning in overstimulating classroom settings and work best in smaller, highly structured settings. Other children may be able to learn in a more traditional classroom environment if appropriate supports, such as, trained aides, are provided.

With the passage of Public Law 94-142 schools have been mandated as providers of these services for persons from 3 to 21 years of age. The importance of this law in guaranteeing the right of handicapped individuals to a free and appropriate education cannot be overemphasized (Berkman, 1997); at the same time the law has been implemented with varying degrees of success. It mandates that services be provided in as normative a setting as possible (Harris & Handleman, 1997). This has led to controversy about the role of special education and segregated educational settings. In some instances, honest disagreements occur between individuals who argue, on a philosophical basis, that every child must be educated in the mainstream vs. those who argue, on an empirical basis, that the child's needs should determine what setting is most appropriate (Burack, Root & Zigler, 1997). Dearth of realistic supports in mainstream settings often poses a major challenge (Harris & Handleman, 1997) and in many areas of the country there are few other resources, in the form of special schools, regional cooperative schools, statewide programs for autism and so forth. Potential advantages and disadvantages of alternative educational placements should be carefully considered (Campbell et al., 1996; Schopler, 1997). For example, educational interventions are best provided on a year round basis as the usual pattern of summer school vacations is not typically well tolerated and

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increases the potential for the child to regression. Advocates for individuals with autism should be aware of the basic requirements of legal entitlements and resources for parents

Vocational and prevocational training is important for adolescents with autism and other PDDs. Such training may aim toward independent or supported employment and provides important opportunities for continued social development as well as helping to maximize capacities for independent living (Gerhardt & Holmes, 1997). In some cases short or longer-term residential care (e.g., for purposes of respite or in community based group homes or supervised apartments) may provide important training and preparation for more independent living (Van Bourgondien & Reichle, 1997). Residential and respite services are often scarce and may be available only if the child is eligible on the basis of associated mental retardation.

Behavioral Interventions

Early and sustained intervention appears to be particularly important, regardless of the particular philosophy of the program, so long as a high degree of structure is provided (Rogers, 1996). Such programs have typically incorporated behavior modification procedures and applied behavior analysis (i.e., careful behavioral assessment of the child and conditions in the environment which can be used to help the child acquire higher levels of skills through behavioral procedures). These methods build on a large body of research on the application of learning principles to the education of children with autism and related conditions (Bregman, 1997; Powers, 1997). Procedures that strengthen desired behaviors and/or decrease undesired maladaptive behaviors are utilized in the context of a careful and individualized plan of intervention based on observation of the individual (Campbell et al., 1996). It is clear that behavioral interventions can significantly facilitate acquisition of language, social, and other skills (Koegel, Koegel, Hurley & Frea, 1992a; Koegel, Koegel & Surratt, 1992b) and that behavioral improvement is helpful in reducing levels of parental stress (Koegel, Schreibman, Loos, Dirlich-Wilhelm & et al., 1992c; Moes, Koegel, Schreibman & Loos, 1992; Schreibman, Kaneko & Koegel, 1991).

Social skills training can be used to enhance social competence and build social skills (Lord, 1995). This may be more behaviorally or developmentally based and might emphasize the importance of generalization by teaching social skills in real life settings (Grey & Garand, 1993).

Sustained improvement or actual claims for cure have been made following intensive early behavioral intervention (Lovaas & Smith, 1989) or other treatment programs (Greenspan &

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Wieder, 1997). Unfortunately, various methodological issues complicate the interpretation of such claims. For example, claims for gains in IQ are made based on dubious proxies for usual IQ scores or where original diagnostic status is unclear. Behavioral intervention has, historically, not been as strongly concerned with issues of diagnosis and some claims for success may have been made for children who may not have exhibited autism or, for that matter, PDD of any variety. Considerable time (and money) is required for implementation of such programs, and older and more intellectually handicapped individuals are apparently less likely to respond (Campbell et al., 1996; Mesibov, 1993; Mundy, 1993; Smith, McEachin & Lovaas, 1993). While there is now little question that early and sustained intervention is indicated, important questions regarding the duration and intensity of the intervention and characteristics of children who respond remain to be addressed.

Family Interventions

Support of the parents and siblings of children with autism and other PDDs is an integral part of the treatment process. Parents are the natural advocates for their child. They, and other family members, should be encouraged to be involved in the assessment and treatment process (Morgan, 1988). This helps to demystify assessment and treatment procedures and provides a set of shared observations for subsequent discussion. In addition to their unique ability to provide historical information and a truly developmental perspective, parents have an awareness of specific problem behaviors that helps the clinician keep in mind the interplay between assessment and intervention.

The presentation of the initial diagnostic assessment and the interpretation of results to parents is important (Shea, 1993). This should include enough time to provide a reasonable discussion of parental concerns and counseling about the needs of the child and family as well as of possible interventions. The generally life-long nature of autism implies that professionals should be available for the long term; this usually will take the form of periodic involvement, which will be more or less intensive depending on the situation. A continuity of care helps to establish the context for a longer term partnership in which the professional plays a central role in coordinating efforts of various evaluators and serves as an advocate for the child, couple, and family as a whole.

It is important in this regard to note that parents and siblings may have special needs (Marcus et al., 1997). Parents may be at increased risk for depression or stress related illness as a result of the unique problems inherent in living with a child with a serious disability (Marcus et

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al., 1997). Siblings are also at increased for other developmental problems as well as for autism and related conditions (Rutter, et al., 1997). Such problems add to the parents' burden of care.

It is important that the positive attempts at coping be encouraged. Professionals should be knowledgeable about local and national resources and opportunities for parent support (such as is provided by parent support and sibling support groups and provision of respite care). The efforts of advocacy groups at the national, state, and local autism societies, and other organizations such as the Rett's syndrome association and similar groups may be very helpful. Books written specifically for parents and/or siblings are also available (see Appendix 1).

Psychotherapy

At one time psychodynamic psychotherapy was thought to be the treatment of choice for autism. It now appears that the usefulness of psychotherapy in autism is very limited (Riddle, 1987). This is even more true for Rett's disorder and childhood disintegrative disorder. The core symptoms of autism do not respond to psychotherapy. Individuals with autism who are high functioning, or for those with Asperger's disorder or PDD-NOS may benefit from psychotherapy (individual, group, family) if some co-morbid condition/symptom is present, such as depression or marked obsessive-compulsive symptomatology (Wing, 1983). For Asperger's disorder in particular the use of a highly structured and directive psychotherapeutic approach may be helpful and can rely on verbal skills and on use of learned routines. The acquisition of adaptive skills and generalization of such skills is important. For more verbal individuals, particularly those with Asperger's disorder, the use of explicit verbal strategies, which can be applied in problematic situations, is important. Although unstructured psychotherapy is not usually helpful some individuals, particularly the more able ones, may benefit from psychotherapy if specific indications for it are present. The use of more supportive therapy or more structured therapeutic procedures may be indicated and procedures for explicit teaching of social problem solving may be useful (Gray and Garand, 1993). When psychotherapy is undertaken it should be done after very careful consideration of the particular strengths/weaknesses of the individual and in the presence of specific indications that the individual has problems that can benefit from it (Wing, 1983).

PHARMACOTHERAPY

Although not curative, pharmacological intervention may increase the ability of persons with PDD to profit from educational and other intervention (McDougle, 1997). Such

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interventions should be focused on the target symptom without losing sight of the larger clinical picture, i.e., results may be statistically but not clinically significant. The clinician should be judicious in her/his use of medications for individuals in younger age groups. Furthermore, with the major exception of the work of Campbell and colleagues (e.g., Campbell, et al., 1988; 1990), much of the information available for use of psychotropic medications in this population has been collected in adults and sometimes little information is available regarding the use of these agents in children. When such information is available it may be based on single case reports or open studies rather than double-blind, placebo-controlled studies. It remains unclear whether results obtained with adults readily generalize to children and adolescents and the safety and efficacy of many agents has yet to be adequately established in children.

As with the use of any psychopharmacological agent care should be taken in the selection and administration of medications. The profile of side effects and risk as well as potential benefits will, of course, vary depending on the agent used and the target symptoms. Since individuals with autism/PDD are often nonverbal, reliance typically is made on reports and observation of specific behaviors. This can be an advantage in many ways in helping to document the efficacy of the selected medication. However, it is important not to lose sight of the overall goal of facilitating the child's adjustment and engagement with educational intervention. For example, sedation might be misinterpreted as a positive therapeutic response. Issues of informed consent should be carefully considered particularly as many agents have yet to be FDA approved for use in children and close follow-up is required.

Neuroleptics

These agents, dopamine receptor antagonists, have been intensively investigated in individuals with autism (Campbell et al., 1996). Although these agents differ in several respects, their fundamental mode of action appears to be dopamine receptor blockade. Of this group, haloperidol has been the most extensively studied (McDougle, 1997). The results of numerous controlled clinical trials in children with autism suggest the potential for significant benefit in terms of reduced stereotype and withdrawal thus facilitating learning (Campbell, Anderson & Small, 1990a). The most frequent side effects include sedation and irritability but in general are dose related (Campbell et al., 1996). Longer-term administration can be associated with other side effects such as drug related dyskinesias including tardive dyskinesia. Campbell, et al. (1988) reported dyskinesias were relatively common and although all dyskinesias were reversible this sometimes took months.

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Systematic controlled trials on other neuroleptics have been less common. Considerable interest centers on the atypical neuroleptics, e.g., risperidone. Single case reports have been positive (McDougle et al., 1995a; Purdon, Lit, Labelle & Jones, 1994). Controlled studies, including studies with children, of this and other atypical neuroleptics are now emerging.

Selective Serotonin Reuptake Inhibitors.

The selective serotonin reuptake inhibitors (SSRIs), like clomipramine, are potent inhibitors of the serotonin transporter and were initially of interest in autism given the observation of high peripheral serotonin levels in autism. Although peripheral levels of serotonin do not seem to be related to clinical response to these agents several studies have suggested clinical utility in this population.

Fluvoxamine is a potent and selective 5-HT uptake inhibitor, which has been shown to be effective in the treatment of both OCD, refractory depression and social phobia (McDougle 1997). Single case reports with adults with autism (McDougle, Price & Goodman, 1990) have suggested that this agent may be effective in reducing levels of obsessive-compulsive-like behaviors. The results of double-blind, placebo-controlled study in adults with autism suggest that about half of this group responds positively (McDougle, 1997). Occasional worsening of hyperactivity may occur (Fatemi, Realmuto, Khan, and Thuras, in press).

The selective 5-HT uptake inhibitor fluoxetine has been evaluated in open label studies and case reports and may be useful in the treatment of some individuals with autism (Cook, Rowlett, Jaselskis & Leventhal, 1992; Ghaziuddin et al., 1991). These data have been derived from older adolescents and adults and suggest reduced levels of ritualistic behaviors and improved mood. Ghaziuddin et al. (1991) reported that fluoxetine (20-40 mg/day) reduced levels of some depressive symptoms in adolescents with autism. In a larger open label study of children, adolescents and adults, Cook et al. (1992) found that fluoxetine (in doses ranging from 20 mg every other day to 80 mg daily) was associated with improved levels of functioning in individuals with autism and with mental retardation without autism. Dose-related side effects included insomnia, hyperactivity, restlessness, agitation, and decreased appetite.

Clomipramine, a non-selective tricyclic, has been reported to reduce some forms of self injury (Lipinski, 1991). Gordon et al. (1993) reported that this agent was superior to desipramine in a randomized, crossover study of children with autism. Improvement was noted in the areas of over activity and obsessive-compulsive symptomatology. Adverse effects of the agent ECG changes and seizures. Side effects observed in relation to desipramine included

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irritability and aggression. McDougle, Price, Volkmar, Goodman & et al. (1992) obtained similar results in a study of 5 adults; exacerbation of seizure disorder was noted to be a side effect. While clomipramine may be effective for older individuals with autism, data on its efficacy in children are limited and its potential for exacerbating seizure disorder suggests the need for some caution.

Antidepressants

Affective symptoms are frequently observed in persons with autism. These include affective lability, inappropriate affective responses, anxiety, and depression. For higher functioning autistic persons, an awareness of their difficulties may result in overt clinical depression (Ghaziuddin & Tsai, 1991). Persons with Asperger's disorder may be at particular risk for depression (Rourke, Young & Leenaars, 1987).

Imipramine has been used in the treatment of autistic children. Campbell et al. (Campbell, Fish, Shapiro & Floyd, 1971) noted a variable clinical response. Although the agent decreased affective blunting it was associated with various negative side effects and an increase in disorganization of speech. Information on the use of these agents in Asperger's disorder is more limited. It does appear to be the case that the depression sometimes observed in association with this condition may respond to antidepressants (Klin & Volkmar, 1997). The use of these agents requires special considerations, such as appropriate medical evaluations such as ECG, blood levels of medication, and careful education of parents regarding issues of drug safety.

Mood Stabilizers

In general the response of individuals with autism to lithium have not suggested major therapeutic benefit (Campbell et al., 1990a). This agent may be useful if there is a strong family history of bipolar disorder or if clinical features suggest that an additional diagnosis of bipolar disorder is justified (Kereshian, Burd & Fisher, 1987; Steingard & Biederman, 1987). Epperson and colleagues (Epperson et al., 1994) have described the augmentation of fluvoxamine with lithium in an adult with autism. There is even less information on the use of other mood stabilizers in autism.

Other Agents

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Anxiolytics. Various anxiolytic agents have been used in the treatment of autism and related conditions. The use of these agents is sometimes associated with an increase in behavioral disorganization, which is thought to reflect a behavioral disinhibition syndrome. Realmuto and colleagues (1989) used buspirone in a very small sample of children with autism and noted that 2 of the 4 cases appeared to have reduced levels of over activity and one a reduction in stereotypies. Others have reported similar results (Ratey, Mikkelsen & Chmielinski, 1989). Placebo-controlled studies using this agent in children are needed.

Beta-blockers. These agents have also been used with some success in small samples of patients (Ratey et al., 1987) but it is difficult to draw firm conclusions based on the limited data available from controlled studies. Clonidine, an alpha-2 noradrenergic receptor agonist, has been used in the treatment of Tourette's syndrome as well as attention deficit disorder. In a double-blind, placebo-controlled crossover study this agent was felt to be of limited benefit in treating the over activity associated with autism (Jaselskis et al., 1992). Several studies have evaluated the efficacy of naltrexone in autism; the data have suggested some effect on over activity but not on the core social deficit associated with autism. This agent increased the frequency of stereotypies in double-blind, placebo-controlled studies (Willemsen-Swinkels, Buitelaar, Nijhof & van England, 1995).

Stimulants. Few studies have systematically evaluated the role of stimulant medications in autism (Campbell, et al., 1996). In animals stimulants induce stereotyped behaviors and the indirect DA receptor agonist amphetamine often exacerbate stereotypies and increases agitation and activity in children with autism. The limited data available suggest that the children with autism can respond adversely to stimulants although some positive responders have also been reported (Quintan, et al., 1995). While the response of children with Asperger's disorder and PDD-NOS to stimulants has been little studied it appears that positive responses are more likely in these groups (McDougle, 1997).

Contraindicated Medications

Fenfluramine releases 5-HT presynaptically and blocks its reuptake. Although the acute effect is an increase in 5-HT chronic administration is associated with a reduction. Initial reports of a small study of this agent (Geller, Ritvo, Freeman & Yuwiler, 1982) generated considerable interest that has not, unfortunately, been supported by subsequent research. In a careful placebo controlled study, Campbell et al. (1988) noted that the use of this agent had a negative impact on discrimination learning. Various side effects including sedation have been observed. This agent

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has the potential for producing nonreversible changes in the brain of animals and that it has long term effects on other neurochemical systems (Anderson & Hoshiono, 1997). Leventhal, Cook, Morford, Ravitz, et al. (1993) suggest considerable caution in its use. At the present time this agent does not appear to be useful in the treatment of autism or related conditions.

NONESTABLISHED TREATMENTS

Given the relatively poor prognosis and severity of the PDDs it should not be surprising that essentially every conceivable treatment has been used. Treatments proposed have included various pharmacological agents, somatic treatments (such as ECT, holding therapy, auditory training and patterning), psychotherapy, vitamins, dietary change, steroid treatments, immunoglobulins, as well as others (Campbell, Schopler, Cueva & Hallin, 1996; DeMyer et al., 1981; Gillberg, 1990; Le Couteur, 1990). Unfortunately most putative treatments have not been systematically assessed. There is a bias for single case reports to be published if results are positive. Short term change may be nonspecific and unsustainable.

Given the severity and chronicity of autism and related conditions and the lack of knowledge regarding specific causal factors, much less a cure, it is not surprising that putative cures surface quite frequently. Often these attract considerable attention from the news media but substantive data are lacking. Not uncommonly the initial report in the lay media relate to an individual child or a handful of cases. Unfortunately such reports are difficult to interpret, as the diagnosis may be ambiguous or highly dubious. Secondly, even for autism, we know that a small number of cases had a good outcome even in the years before specific, effective treatments were available. Finally, such reports usually are not followed by more rigorous, controlled studies in the peer reviewed scientific literature.

Essentially the alternative treatments fall into a number of different groups. One group has little or questionable scientific basis but the treatment proposed bears relatively little risk to the child and family. For example, considerable interest has centered on the effect of megavitamins and nutritional supplements (Rimland & Baker, 1996) but the studies available suffer from various methodological problems. In any case, low doses of vitamin supplements pose little threat of harm to the child and do not drain familial resources. However, higher doses can be associated with toxicity.

Other alternative treatments pose a danger to the child and family in that a cure is essentially promised to the family, usually after the expenditure of a significant sum of money.

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Such treatments may actually pose a risk to the child in terms of disruption of ongoing programs which have demonstrated efficacy, have the risk of depleting family resources, and, when they fail to work, may be associated with some degree of blame directed to the parents. Clinicians experienced in work with this population can report many examples of such approaches (e.g. attempts to cure autism through “realignment” of brain and nerves, elimination diets, and so forth).

Another group of alternative treatments has the potential for direct serious harm to the affected child or family. As an example, the recent fad of facilitated communication had no empirical basis (Mesibov, 1995) but was used, in some cases, as a rationale for removing a child from the family’s care because of reports, via the alleged facilitation, of physical or sexual abuse. Other potentially harmful treatments may involve somatic therapies, such as injection of foreign substances such as sheep brain extract.

Treatments such as auditory training, patterning, hugging/ holding, sensory integration, the use of secretin, and the Options method have little or no empirical evidence, to date. In a few instances some research has been conducted, e.g., relative to auditory training (Rimland & Edelson, 1995) but the research is difficult to interpret or limited because of the small numbers of subjects involved or other problems in design. In other cases when research has been conducted, it has failed to support the usefulness of the approach, e.g., a study of patterning found this treatment to be without benefit (Sparrow and Zigler, 1978). Families should be helped to make informed decisions about their use of alternative treatments. Treatments, which pose some risk to the child and family, should be actively discouraged.

CONFLICT OF INTEREST

As a matter of policy, some of the authors to these practice parameters are in active clinical practice and may have received income related to treatments discussed in these parameters. Some authors may be involved primarily in research or other academic endeavors and also may have received income related to treatments discussed in these parameters. To minimize the potential for these parameters to contain biased recommendations due to conflict of interest, the parameters were reviewed extensively by Work Group members, consultants, and Academy members; authors and reviewers were asked to base their recommendations on an objective evaluation of the available evidence; and authors and reviewers who believed that they

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might have a conflict of interest that would bias, or appear to bias, their work on these parameters were asked to notify the Academy.

SCIENTIFIC DATA AND CLINICAL CONSENSUS

Practice parameters are strategies for patient management, developed to assist clinicians in psychiatric decision-making. These parameters, based on evaluation of the scientific literature and relevant clinical consensus, describe generally accepted approaches to assess and treat specific disorders, or to perform specific medical procedures. The validity of scientific findings was judged by design, sample selection and size, inclusion of comparison groups, generalizability, and agreement with other studies. Clinical consensus was determined through extensive review by the members of the Work Group on Quality Issues, child and adolescent psychiatry consultants with expertise in the content area, the entire Academy membership, and the Academy Assembly and Council.

These parameters are not intended to define the standard of care; nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results. The ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all the circumstances presented by the patient and his or her family, the diagnostic and treatment options available, and available resources. Given inevitable changes in scientific information and technology, these parameters will be reviewed periodically and updated when appropriate.

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APPENDIX 1

Parent Support Groups

Aspen of America, Inc. (Asperger's Syndrome)
POB 2577
Jacksonville, FL 32203-2577
904-745-6741

Autism Society of America
8601 Georgia Ave.
Suite 503
Silver Spring, MD 20910
301-565-0433

Childhood Disintegrative Disorder Network
c/o Madeline Catalano
1172 Four Mile Rd.
Allegany, NY 14706

International Rett Syndrome Association
8511 Rose Marie Dr.
Fort Washington, MD 20744
301-248-7031

National Alliance for Autism Research
2 Center Plaza, Suite 420
Boston, MA 02108
908-359-9957

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