

Best Practice Guidelines for the Diagnosis of Pervasive Developmental Disorders 2009

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Copies of this document may be found at http://www.ddas.vermont.gov/ddas-programs-programs-autism-default-page#publications or requested from the Department of Disabilities, Aging and Independent Living at 241-2614.

Best Practice Guidelines for the Diagnosis of Pervasive Developmental Disorders Vermont

Introduction

The Diagnostic and Statistical Manual of Mental Disorders, fourth edition, Text Revision (American Psychiatric Association, 2000) identifies five Pervasive Developmental Disorders: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder and Childhood Disintegrative Disorder. Consistent with national trends, the number of individuals in Vermont being identified with a Pervasive Developmental Disorder (PDD) has been increasing steadily over the past 15 years (State of Vermont, 2008). In response to this increase, the Vermont legislature directed the Agency of Human Services and the Department of Education to develop a plan for providing services across the lifespan for individuals with an autism spectrum disorder (ASD) and their families. (The terms PDD and ASD are often used interchangeably in the field, although ASD generally refers to Autistic Disorder, Asperger's and PDD-NOS.) An interagency autism plan was developed in 2008. One of the goals of the plan is to increase timely identification and diagnosis to enable access to appropriate services. The focus of this document will be the process for conducting evaluations for diagnosing PDD.

There are several purposes for developing best practice guidelines for the diagnosis of PDD for VT. They include:

- Increasing the consistency of the diagnostic process to allow for equitable access to appropriate services;
- Increasing accuracy of diagnosis which will lead to referral to appropriate treatment and services, thus improving outcomes and maximizing the use of limited resources;
- Providing a foundation for training additional evaluators and for offering professional development for existing evaluators;
- Increasing the quality and consistency of evaluations to assist various state provider agencies and schools in determining eligibility and planning for services;
- Providing a basis for recommending changes in the regulations for determining eligibility for Developmental Disability Services in Vermont.

These guidelines recommend best practice in conducting evaluations to diagnose PDD. They, however, do not constitute a mandate, requirement or regulation for access to school or other services.

Process for developing the guidelines

The VT Department of Disabilities, Aging and Independent Living invited clinicians currently involved in making PDD diagnoses in VT to participate on a committee to develop these guidelines. The participants are listed in the front of this document. The

committee met three times to provide input. The committee reviewed the following documents and used them as a basis for formulating the guidelines.

- Screening, Assessment and Diagnosis of Autism Spectrum Disorders in Young Children, Canadian Best Practice Guidelines, 2008
- Identification and Evaluation of Children with Autism Spectrum Disorders, American Academy of Pediatrics, 2007
- Practice Parameter: Screening and Diagnosis of Autism, American Academy of Neurology and the Child Neurology Society, 2000
- Autism Spectrum Disorders Best Practice Guidelines for Screening, Diagnosis and Assessment, California Department of Developmental Services, 2002
- Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia, British Columbia Ministry of Health Planning, 2003 and British Columbia Autism Network- Adopted Policy Changes, November, 2006 revision (for ages 0-19)
- Recognition of Autism Before Age 2 years, Pediatrics in Review, 2008; 29; 86-96.

The guidelines are the result of a group consensus process informed by the research literature on this topic and the clinical expertise of the committee members. The committee members also had an opportunity to review and comment on a draft of the guidelines.

In addition, other clinicians in Vermont were provided an opportunity to review and provide feedback on a draft of the guidelines. The following clinicians offered their feedback: William McMains, MD, psychiatrist from the VT Department of Mental Health, Mark Anagnostopulos, Ph.D, psychologist from the Retreat Healthcare, Daniel Larrow, MD, Developmental-Behavioral Pediatrician from Vermont Behavioral Medicine and Anna Hutton, Ph.D, psychologist in private practice. The committee members then provided additional input for finalizing the document after receiving this feedback.

Various stakeholder groups were offered the opportunity to provide feedback including the Developmental Services State Standing Committee, Division of Disability and Aging Services Developmental Services Team, Autism Plan Advisory Committee, Developmental Services Directors and Department for Children and Family - Child Developmental Division - Children's Integrated Services Team members. Some limited feedback was provided by these groups.

A. Professional Qualifications for Diagnosing PDD

The diagnostic category of PDD includes considerable variability in the presence and intensity of symptoms across and within the five diagnoses. Many of the symptoms of PDD also overlap with other childhood diagnoses including learning, language, cognitive and psychiatric disorders. These issues are indicative of the importance of having skilled clinicians differentially diagnose PDD. Because of the complexity in differentially diagnosing PDD, it is essential that clinicians rendering these diagnoses have specific training and experience in child development, PDD and other developmental and

childhood psychiatric disorders. Research indicates that clinical judgment, informed by the use of standardized assessment tools, is the most important factor in accurate diagnosis of PDD (Lord, et al., 2006). Clinical judgment is something that develops over time with continued training and experience. As research in the field continues to advance the knowledge base in the identification and treatment of PDD, it is critical that clinicians continue their professional development in this field to stay current.

Ideally, a comprehensive diagnostic evaluation is conducted by an interdisciplinary team of professionals with specific experience and training in diagnosing PDD. At least one member of the interdisciplinary team must have the professional qualifications listed below. In the absence of an interdisciplinary team, a single clinician with the qualifications listed below may conduct a multidisciplinary assessment integrating information from other professionals.

At a minimum, an evaluation must be completed by a:

- Board certified or board eligible psychiatrist, or
- Licensed psychologist, or
- Board certified or board eligible neurologist or developmental-behavioral or neurodevelopmental disabilities pediatrician

With the following additional experience and training:

 Graduate or post-graduate training encompassing specific training in child development, PDD and other developmental and childhood psychiatric disorders, and a process for assessment and differential diagnosis of PDD,

OR

Supervised clinical experience in the assessment and differential diagnosis of PDD;

AND

2) Training and experience in the administration, scoring and interpretation of psychometric tests,

OR

Training in understanding and utilizing information from psychometric testing in the diagnosis of PDD;

AND

3) Experience in the evaluation of individuals for the age range of the person being evaluated (e.g. young children, adolescents, adults).

Clinicians must follow the ethical guidelines for their profession regarding practicing within their area of expertise and referring to other professionals when needed. When a single clinician is conducting the assessment, he/she should determine if other professionals need to evaluate the person to gain additional information before rendering a diagnosis. Additional evaluators may include psychologists, speech-language pathologists, medical sub-specialists, developmental-behavioral or neurodevelopmental disabilities pediatricians, occupational therapists, psychiatrists, neurologists, etc. For evaluations of children from birth to age six, the involvement of a developmental-behavioral or neurodevelopmental disabilities pediatrician or pediatric neurologist is

strongly recommended. In addition, clinicians should conduct evaluations and provide diagnostic information and supportive guidance in a culturally sensitive, person and/or family-centered manner.

B. Essential components of an assessment to diagnose PDD*

- 1. Review of history from multiple sources including:
 - a. Previous medical, educational, developmental, communication, cognitive, psychological, psychiatric, social history and other relevant evaluations;
 - b. Interviews with caregivers and other involved professionals regarding presenting concerns;
 - c. Developmental history, with particular attention to functioning from birth to age six, including;
 - i. pregnancy and perinatal history;
 - ii. communicative, motor and adaptive milestones;
 - iii. history of regression;
 - iv. developmental levels in social interaction, communication/play, restricted and unusual interests and behaviors and adaptive behavior;
 - d. Medical issues including:
 - i. hearing/vision impairments;
 - ii. neurological disorders;
 - iii. syndromes often associated with PDD or other genetic issues;
 - iv. General health issues such as sleep, nutrition, pica, elimination, allergies, medication history and sensory atypicalities
 - e. Psychiatric issues including:
 - i. mood and anxiety
 - ii. attention, restlessness, and impulsivity
 - iii. tics and obsessive-compulsive behaviors
 - iv. personality disorders
 - v. behavioral issues
 - vi. psychosocial stressors or trauma
 - vii. history of treatment
 - f. Family history of inheritable developmental, learning and psychiatric disorders.

^{*(}Section B has been adapted with permission from British Columbia Autism Network- Adopted Policy Changes, November, 2006 revision (for ages 0-19) of the Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorders in British Columbia, March, 2003, British Columbia Ministry of Health Planning)

- 2. Systematic PDD diagnostic interview with primary caregivers (strongly recommend use of a standardized tool such as the Autism Diagnostic Interview-Revised (ADI-R). See page 14 for discussion of limitations of this tool for very young children). When a single clinician is making the diagnosis, he/she must be involved in the interview. When an interdisciplinary team is used, the person conducting the diagnostic interview should have the same level of additional experience and training as noted above in A.1-3.
- 3. A systematic observation of social and communicative behavior and play (strongly recommended use of standardized tools such as Autism Diagnostic Observation Scale (ADOS)). When a single clinician is making the diagnosis, he/she must be involved in the observation. When an interdisciplinary team is used, the person conducting the systematic observation should have the same level of additional experience and training as noted above in A.1-3.
- 4. An assessment of peer interaction, either through direct observation, video tape, narrative description and/or standardized tools (e.g. the Social Responsiveness Scale, the Social Skill Rating System, etc.).
- 5. For older children and adults who can report symptoms, a clinical interview.
- 6. Referral for relevant multidisciplinary assessment. The evaluator should determine what evaluations from other professionals are needed to complete the differential diagnosis and either secure existing evaluations, if recent and still relevant, or refer for additional evaluations. These might include:
 - Psychological assessment of cognitive level and adaptive functioning using standardized norm-referenced instruments, realizing limitations of psychological testing in very young children;
 - Comprehensive speech-language-communication evaluation using standardized, norm-referenced instruments, including measures of pragmatic language abilities;
 - Comprehensive medical evaluation including physical exam, appropriate laboratory investigations and/or hearing assessment;
 - Psychiatric assessment, when there are questions about co-morbid psychiatric conditions or overlapping psychiatric symptoms present;
 - Occupational therapy, neurology, nutrition, genetics, endocrinology assessments, when indicated.
- 7. Comprehensive Clinical Diagnostic Formulation. The diagnosis of PDD is clinical, based on the criteria in the current version of the Diagnostic and Statistical Manual for Mental Disorders (Currently DSM-IV-TR). The clinician must weigh all the above evidence, integrate findings and provide a differential diagnosis. Support for the diagnostic conclusions should be cited and should correspond to the DSM criteria. The specific criteria met should be listed with specific examples. Divergent data and the rationale for ruling out other diagnoses should be explained. Unresolved clinical issues that require further assessment must be clearly identified, along with a realistic plan for further evaluation and follow-up (including referrals if appropriate).

- 8. The report should summarize and reference the following:
 - a. History of presenting family and community concerns
 - b. List of records reviewed
 - c. Summary of past reports/assessments, including information pertinent to the referral question
 - d. Developmental history
 - e. Mental health functioning
 - f. Health and medical concerns
 - g. Relevant family history
 - h. Summary of critical information from the systematic PDD diagnostic interview and observation, assessment of peer interaction and clinical interview, including scores and interpretation of any standardized assessments completed
 - i. Summary of results from multidisciplinary evaluations
 - j. Summary and Comprehensive Clinical Diagnostic Formulation including components noted in #7 above
 - k. General guidance regarding resources for support and intervention

DIFFERENTIAL DIAGNOSIS:

General issues:

There are a number of issues that contribute to the difficulty of differential diagnosis of PDD. The heterogeneity of presentation within the autism spectrum, as well as the considerable symptom overlap with other learning, medical, cognitive or psychiatric diagnoses, can make the differential diagnosis of PDD particularly challenging. There is no test that confirms or rules out PDD; rather, the diagnosis is based upon clinical judgment regarding whether a person's functioning is consistent with the criteria described in the DSM. The DSM's use of qualitative descriptions such as "marked impairment", "encompassing pre-occupations", "delay in", "apparently inflexible" which do not quantify levels of deviance or delay makes accurate and consistent diagnosis difficult (Prelock, 2006, p.7). The criteria for diagnosing PDD-NOS are particularly lacking and vague. Even diagnostic tools such as the ADOS and ADI-R, which attempt to quantify the DSM criteria, lack boundaries or cut-off scores among various ASDs. There is also controversy in the field regarding the definition of Asperger's Disorder and whether it can be distinguished from Autistic Disorder for those described as "high functioning". Also, there are challenges with diagnosing very young children, as some of the symptoms of ASD do not manifest until age 4-5 or the child is too young to be expected to display a given skill (e.g., peer relationships) (Johnson, 2008).

Given these challenges, as noted previously, differential diagnosis necessitates having well trained and experienced clinicians involved. Clinicians must be familiar not only with the diagnostic criteria for PDD but also related disorders that may share overlapping symptoms of ASD. They "must understand the nature, age of onset and course of a particular disorder, as well as it's defining and associated features to make an accurate differential diagnosis" (Prelock, 2006, p. 38). Clinicians have the challenge of

determining whether symptoms are a component of a PDD, represent a co-morbid disorder or are a different disorder without a PDD. Below are descriptions of disorders that either commonly co-occur with PDD or need to be distinguished from PDD.

Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence

Autistic Disorder, Asperger's Disorder & Pervasive Developmental Disorder NOS

Autistic Disorder and Asperger's Disorder share the same DSM criteria for impairment in social interaction and restrictive, repetitive and stereotyped patterns of behavior. Those with Asperger's do not have significant language or cognitive delays. The challenge in differentiating these diagnoses generally occurs when a person is being diagnosed in late childhood or adulthood, when early developmental history may no longer be available. Those with autism without cognitive delays can appear very similar to those with an Asperger's diagnosis later in life. People with autism may have overcome some of their earlier difficulties with language and other symptoms. Clinically, differentiating those with autism without cognitive delays from those with Asperger's may not be of consequence.

Diagnosing Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) can be difficult given the lack of details in the DSM description. Although written in shorthand, the description of PDD-NOS in the DSM is referencing the diagnostic criteria in the other PDDs, with all the possible symptoms encompassed in Autistic Disorder. To receive a diagnosis of PDD-NOS, a person would need to display at least one of the symptoms described under impairment of social interaction along with either an impairment in communication or the presence of restrictive and stereotyped patterns of behavior as described under Autistic Disorder. It also must be differentiated from other mental health diagnoses such as Schizotypal Personality Disorder and Avoidant Personality Disorder (American Psychiatric Association, 2000, p. 84). The diagnosis of sub-threshold conditions such as PDD-NOS and Asperger's Disorder should only be entertained after a thorough, comprehensive evaluation which analyzes the presence and absence of the diagnostic criteria for Autistic Disorder, rules out of other possible diagnoses, and indicates that the symptoms result in significant impairment of functioning.

Intellectual Disabilities

Intellectual Disability (ID) (identified in the current DSM as Mental Retardation - MR) can co-occur with all the Pervasive Developmental Disorders except Asperger's Disorder. Determining when an additional PDD diagnosis beyond ID/MR is warranted can sometimes be challenging. Language delays, deficits in social skills and stereotyped behaviors are common in persons with ID/MR. With ID/MR, there is generally a global delay in most areas of functioning. To identify the diagnosis of a PDD, the person would need to display social skills that are not only delayed but significantly atypical and qualitatively different (as well as qualitatively impaired communication skills and/or the presence of restrictive repetitive or stereotyped behavior, interests or activities, depending

on the diagnosis) relative to his/her mental age. However, the DSM does not specify the level of discrepancy needed to warrant the additional diagnosis of a PDD (Volkmar, et al., 2005, p. 172). Differential diagnosis of individuals with very low cognitive functioning can be difficult as they may also exhibit self-stimulatory behavior; however, they can often be differentiated by the degree of social responsiveness observed (Volkmar, et al., 2005, p. 587).

Attention-Deficit/Hyperactivity Disorder

Although individuals with autism and Attention-Deficit/Hyperactivity Disorder (ADHD) both have challenges in attention, they differ in onset, course, associated features, familial patterns and prognosis. In autism, the person may be inattentive to some details and hyper-focused on other areas (Prelock, 2006, p.31). The challenge for people with autism might be best described as an inability to focus on the most meaningful social information in the environment. Also, particularly in young children, there is often a lack of joint attention. Some of these deficits could be mistaken for ADHD (Prelock, 2006, p. 31). Some children with ADHD, like children with PDD, experience social challenges related to the impact of their behavior, such as "impulsivity, reduced empathy, excessive verbalization and disregard for personal space", on others (California Department of Developmental Services, 2002, p. 120). However, ADHD and autism can be distinguished by the quality and degree of social reciprocity, and the presence of deficits in communication and repetitive, restrictive, stereotyped pattern of behaviors.

Differentiating ADHD from those with milder symptoms of PDD can be more challenging because of more overlapping symptoms. However, they can generally be distinguished by the quality and degree of social challenges. Children with PDD-NOS "appear to have significantly more difficulties in social understanding and in emotional and behavioral problems related to excessive affective reactions" (Jensen, et al., 1997 in Volkmar, et al., 2005, p. 177). Also, individuals with Asperger's show focused interests and fixations.

"Distinguishing between PDDs and ADHD can be difficult in individuals who have moderate to severe MR, developmental language disorder or severe hyperactivity." (Volkmar, et al., 2005, p. 177) A thorough developmental history can help make a differential diagnosis. In the DSM-IV- TR, PDD and ADHD cannot be diagnosed at the same time, as the inattention in people with PDD is considered part of the larger syndrome (American Psychiatric Association, 2000).

Reactive Attachment Disorder

Reactive Attachment Disorder (RAD) and PDD overlap in terms of onset in early childhood and impact on social relatedness. The DSM-IV-TR indicates that RAD is not diagnosed if the criteria are met for a PDD (American Psychiatric Association, 2000). RAD is diagnosed when there has been a verified history of "pathogenic care" in the early years of the child's life. This is characterized by persistent and gross disregard for

the child's emotional and physical well being or repeated changes in primary caregivers that prevent the formation of stable attachments. The abuse or neglect results in disturbance of social relatedness in most contexts. In many cases, the symptoms remit after the child has been placed in a nurturing environment and received treatment. In other cases, clinical signs persist despite a supportive environment and treatment. Information gained regarding the response to treatment can help tease out whether barriers to relating are psychological versus neurodevelopmental. In PDD, the social challenges typically occur in the presence of a reasonably stable, supportive environment. Children with PDD also display additional challenges with communication and/or restricted, repetitive behaviors. It can be difficult to do a differential diagnosis as some children with RAD also display repetitive behaviors such as rocking. The deprivation of children with RAD can also result in developmental delays, further complicating the presentation (American Psychiatric Association, 2000, p. 127-130).

Schizophrenia and other Psychotic Disorders

Schizophrenia

Historically, autism was not distinguished from childhood schizophrenia. Despite being described by Leo Kanner in 1943, prior to DSM-III, published in 1980, autism was classified under the category of childhood schizophrenia. They are now recognized as two distinct disorders.

There are some similarities between schizophrenia and PDD in presenting symptoms such as "poor social relatedness, lack of pleasure in activities, flat or constricted affect, restriction of facial expressions, poor use of gesture and eye contact, poor speech and presence of stereotypic behaviors and manners" (Ghaziuddin, 2005, p. 176-7). In addition, high functioning autism or Asperger's can be mistaken for schizophrenia because individuals may appear to have a thought disorder or because of their eccentricities and pre-occupation with topics or interests. In addition, several studies show that some children later diagnosed with schizophrenia exhibited symptoms similar to children with PDD, including language impairment, social challenges, withdrawal, and restricted interests (Watkins, Asarnow & Tanguay, 1988; Asarnow & Asarnow, 1996; Hollis, 1995 & 1996 in California Department of Developmental Services, 2002, p. 119). However, there are many differences between the two disorders that can help distinguish them. Most of the PDD have an onset in early childhood, while schizophrenia generally has an onset in late adolescence or early adulthood following a period of typical development. Onset of schizophrenia prior to age 7 is extremely rare (California Department of Developmental Services. 2002, p. 118). Hallucinations and delusions are common in schizophrenia but are rare in PDD. Mental retardation and seizure disorders are common in autism but not in schizophrenia. Family history plays a role in both PDD and schizophrenia, with both occurring more frequently in first-degree relatives with the respective disorders (Ghaziuddin, 2005, p. 175).

Schizophrenia and PDD can co-occur, but this is rare. Some children with autism suspected of having schizophrenia actually had co-occurring depression instead

(Ghaziuddin, 2005, p.177). The DSM-IV-TR indicates that for individuals with a previous PDD diagnosis, the diagnosis of schizophrenia is warranted only if prominent delusions or hallucinations are present for at least a month (American Psychiatric Association, 2000, p. 312).

Mood Disorders

Mood disorders can co-occur with PDD. Depression is one of the most common co-occurring disorders with PDD. Indications of depression in persons with PDD are a change from typical functioning including symptoms such as increased irritability, withdrawal or obsessive-compulsive behavior or regression in skills. Bipolar Disorder is rarer, both in the general population and in those with PDD. Those with Bipolar Disorder demonstrate periods of elation alternating with periods of depression. Those with a primary mood disorder generally experience a period of normal functioning prior to the onset of symptoms (Ghaziuddin, 2005, p. 130-133). Mood disorders are also more prevalent in those who have a family history of mood disorders. (American Psychiatric Association, 2000, p. 382) Differential diagnosis rests on a thorough developmental and family history and presenting symptomatology.

Anxiety Disorders

Many people with PDD experience anxiety. Symptoms of anxiety in people with PDD are often seen in extreme reactions to minor changes in their environment, schedule, staff, etc. These symptoms are generally thought of as part their PDD. However, at times, an additional diagnosis of an anxiety disorder is warranted, with "Obsessive-Compulsive Disorder (OCD), Post-Traumatic Stress Disorder (PTSD), complex developmental trauma, school refusal, selective mutism and social anxiety disorder being the most common in this population" (Ghaziuddin, 2005, p. 149-50). In other cases, there is a need to distinguish between these disorders. Like individuals with PDD, those with anxiety disorders may display social avoidance, sleep disturbance, agitation and excessive worry that impact daily functioning. However, individuals with anxiety disorders are capable of typical social interactions and relationships with familiar people and difficulties become evident with less familiar people or in the specific situations that provoke their anxiety. For people with PDD, the social deficits are more pervasive (California Department of Developmental Services, 2002, p. 120).

Obsessive-Compulsive Disorder

The restricted, repetitive, and stereotyped behaviors, interests and activities of individuals with PDD can resemble the obsessions and compulsions seen in Obsessive-Compulsive Disorder (OCD). Individuals with OCD generally do not display deficits in the social and communication domains. Adults, but not all children, with OCD also tend to experience anxiety and resistance to engaging in their obsessions/compulsions, whereas those with PDD do not and in fact appear to derive pleasure or comfort from their activities (American Psychiatric Association, 2000, p. 83). The ritualized behavior of those with OCD are often more complex, organized and elaborate than those of

individuals with PDD. OCD and PDD can co-occur. The additional diagnosis of OCD is warranted when there is an intensification of obsessive or compulsive behavior, accompanied by complaints of anxiety and distress related to these behaviors (Ghaziuddin, 2005, p. 156).

Personality Disorders

There is considerable symptom overlap between some personality disorders and the milder forms of autism and Asperger's. For example, all of the symptoms in the diagnostic criteria for Schizoid Personality Disorder (SPD) are seen in individuals with ASD, but not all individuals with ASD display the symptoms of Schizoid Personality Disorder. For example, those with SPD show a significant disinterest in social relationships, while many individuals with PDD indicate an interest in relationships but lack the skills to successfully develop them. Schizoid Personality Disorder should not be diagnosed if the person meets the criteria for a PDD (American Psychiatric Association, 2000, p. 695-7). PDD share symptoms with other personality disorders such as Schizotypal and Avoidant Personality Disorders. Personality disorders and PDD can generally be distinguished by age of onset and severity of symptoms. Those with autism and Asperger's generally display more severely impaired social interaction and stereotyped behavior. Also, onset of PDD is in early childhood, while Personality Disorders are generally identified as beginning in adolescence or early adulthood.

Other disorders not classified in DSM

There are some disorders, with symptoms that overlap with PDD, that have been identified in the literature, but have not been classified as disorders in the DSM. These include Nonverbal Learning Disorder, Semantic-Pragmatic Disorder and Specific Language Impairment. Until there is more formal acceptance and definition of these disorders, a discussion of the distinctions between these disorders and PDD seems premature. Clinicians should be aware of these labels.

In addition, overlap in presentation may be seen with medical disorders such as hearing or visual impairment, speech and language delay, and issues regarding English as a second language which may impact a person's ability to socialize with peers, develop relationships, and communicate effectively with others.

Boundaries with normality

The boundaries between typical and disordered functioning are not distinct. The descriptions of disorders in the DSM use terms like "significant" or "marked" impairment that require mostly qualitative clinical assessments, rather than quantitative measurements with clear demarcations of typical and disordered functioning. However, the DSM does define mental disorders as those that cause significant distress or disability in important areas of life functioning (American Psychiatric Association, 2000). While individuals may have certain traits or characteristics in common with those diagnosed with PDD, these disorders are only diagnosed when there is significant impairment in a

person's ability to function. Those who may share some common characteristics but do not have a disorder include people who are shy, gifted and talented, and people who are somewhat odd or eccentric. Social or cultural factors, such as deprivation or poverty may also impact social functioning but not necessarily result in diagnosable disorders.

Additional issues in diagnosis of PDD

There are a few other key issues that should be considered regarding the diagnosis of PDD. One issue is the age of the person being evaluated. Particular care should be taken when evaluating very young children under 2-3 years of age. Some of the criteria for the diagnosis of autism in the DSM-IV-TR address developmental skills that could not yet be expected in a very young child, such as "failure to form age appropriate peer relationships". Also, some of the stereotypies and repetitive behaviors often do not appear until after the third birthday (Johnson, 2008). The ADI-R, which is based upon the DSM criteria, is also less reliable in very young children. "For example, Lord (1995) found that the standard diagnostic criteria (in the ADI-R) tended to be overly inclusive at age 2 for children with severe cognitive disability and not inclusive enough for those without clear stereotypic/repetitive behavior or narrow interests" (California Department of Developmental Services, 2002). The ADI-R is recommended for use with children and adults with developmental ages of at least 18 months. Clinicians may wish to consider provisional diagnoses for very young children with the recommendation for reassessment when the child is over the age of 3.

Particular care should also be taken when evaluating adolescents and adults who have not been previously diagnosed with a PDD. PDD are developmental disabilities that are most often identified in early childhood. Therefore, the clinician should include as a part of the assessment consideration of why a PDD diagnosis has not previously been made. There are certainly situations in which the diagnosis was previously missed or the person was misdiagnosed; however, these situations are likely becoming less frequent as professional expertise in the field continues to grow. Ascertaining an accurate developmental history and information from early childhood can also be a challenge when records are lost, knowledgeable informants are unavailable or memories of details of early childhood have faded. Every effort should be made to get as complete a history as possible and to fully explain missed diagnoses or misdiagnoses.

"It is also important to note that individuals, families and providers may become frustrated when a person fails to meet the diagnostic criteria or fit a diagnosis of autism even though he/she exhibits obvious social challenges and requires services or additional supports. It is not appropriate to offer a diagnosis just so a person can receive services" (Prelock, 2006, p. 28) that the individual or team members feel are needed. The clinician can guide the individual or team to appropriate services or supports based upon the identified needs.

Another issue in the diagnostic process is to consider the impact of conducting an evaluation when the person is in the midst of a psychiatric crisis. There are a variety of challenges in making an initial PDD diagnosis when a person is experiencing a

psychiatric crisis, particularly if he/she is hospitalized or in a crisis placement outside his/her home. During a short stay, the evaluator may be unable to obtain a complete history, either through records or appropriate informants. Also, by virtue of the crisis, the person is not functioning as he/she typically does in his/her regular environment. The person may also act differently in a strange environment. Further, use of a standardized observation tool such as the ADOS may be less useful if the person is behaving in ways that are especially atypical from his/her usual behavior. This is not to say that a PDD diagnosis under these circumstances can never be made, and in fact, it may be helpful in identifying an undiagnosed PDD which precipitated the crisis. There are some children and adolescents who have been difficult to diagnose in the community. At times, these children and adolescents, who may not be in an extreme psychiatric crisis, are hospitalized to allow for a careful evaluation and clarification of diagnosis. For a hospitalized person, every effort should be made to get as complete a history as possible. When it is not possible to get sufficient information to make a conclusive diagnosis, the clinician should either defer diagnosis to a time when the person has returned to more typical functioning or provide a provisional diagnosis. This caution would also apply to community-based assessments when sufficient information is not available. An additional challenge for some inpatient settings is that they have rules that do not allow them to list other records reviewed or cite information from those sources that help support their diagnosis. The lack of supporting documentation would limit the utility of these assessments for community providers as basis for the diagnosis may be unclear.

Conclusion

These guidelines were developed based upon a review of information available and the clinical expertise of the committee members in 2009. As research and expertise in the field of autism spectrum disorders continues to grow, these guidelines should be updated periodically. A major revision will be needed when DSM-V is published, which is anticipated to be in May, 2012.

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