Diagnosis and Epidemiology of Autism Spectrum Disorders

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In this paper, we give an overview of the diagnostic categories of autism and other pervasive developmental disorders (PDDs) and discuss the changes in the DSM classification system over the past 20 years. We describe each subtype of PDD, along with comorbid psychiatric conditions, assessment guidelines, and tools for diagnosis. The epidemiology of autism has generated much discussion and research; we report the most recent data, as well as recent findings about controversial issues purporting to cause the increased prevalence rate observed in the past decade. Finally, we discuss the prognosis for individuals with autism, indicating the challenges faced by patients, families, and professionals aiming to optimize their outcome.

(Can J Psychiatry 2003;48:517–525)

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Clinical Implications

- In the past 20 years, the diagnosis of pervasive developmental disorder (PDD) has changed to include a broader range of social impairment, thereby increasing the numbers of children with this diagnosis.
- Autism has a high rate of comorbidity, which has implications for treatment.
- Prognosis is poor with respect to independent living and work ability, but it may improve with better early intervention.

Limitations

- The diagnosis of autism spectrum disorders needs further clarification, particularly with respect to PDDs not otherwise specified.
- More research is needed on the epidemiology of autism-related medical and psychiatric disorders and outcome.

Key Words: *autism, diagnosis, epidemiology, assessment, prognosis*

Autism is a neurodevelopmental disorder characterized by impairment in social interaction, in communication skills, and in behaviour, which is restricted and repetitive. In this article, we review the history of autism's classification and how this classification has affected its increased prevalence. We examine current diagnostic categories, methods of assessment, clinical correlates, and comorbid conditions. Finally, we discuss epidemiology and prognosis in autism spectrum disorders. Two companion papers discuss neuroimaging, genetic, and therapeutic aspects (1,2).

History

In 1943, Leo Kanner published his seminal paper on autism. He clearly described 11 children who were socially isolated, with "autistic disturbances of affective contact," impaired communication, and behavioural inflexibility (3). He coined the term "infantile autism" and discussed etiology in terms of biological processes when much attention was focused on analytic theories (4). His paper did not receive much attention, and children with these problems were diagnosed with childhood schizophrenia (5). The choice of the word "autism" may have created some confusion, because Bleuler first used the word to describe a mental state of fantastical, self-centred thought processes as symptomatic of schizophrenia. This implies a previously developed cognitive state and subsequent regression; it therefore belies the arrested social development, leading to isolation, described by Kanner (6).

The DSM Classification System

Autism did not become a diagnostic entity in its own right until the DSM-III was published, in 1980 (7). The DSM-III criteria used "objective, unambiguous, and precisely defined

Table 1 Comparison of ICD-10 and DSM-IV diagnoses

ICD-10	DSM-IV
Childhood autism	Autistic disorder
Rett's syndrome	Rett's disorder
Other childhood disintegrative disorder	Childhood disintegrative disorder
Asperger's syndrome	Asperger's disorder
Atypical autism Other pervasive developmental disorder Pervasive developmental disorder, unspecified	Pervasive developmental disorder not otherwise specified (including atypical autism)
Overactive disorder with mental retardation and stereotyped movements	No corresponding diagnosis

operational criteria" (8) and did not focus on causality. The term used to describe the disorder was "infantile autism"; criteria included onset before age 30 months, lack of responsiveness to other human beings, gross impairments in communication and language, and bizarre responses to the environment (7). The condition was one of a group of disorders brought together under a new term, "pervasive developmental disorders (PDD)," with "pervasive" indicating that the developmental disability affected or pervaded all spheres of the child's life. This term has been widely accepted and is currently used, although it is neither transparent to parents nor satisfactory to the clinical and research community (9). Other PDD subtypes were described but were discarded in subsequent DSM revisions.

The DSM-III-Revised changed "infantile autism" to "autistic disorder" and created 16 criteria in the areas of social development, communication, activities, and interests (10). Age criteria were qualified to before or after age 3 years, and "atypical" was changed to "not otherwise specified" (NOS) to avoid confusion with other concepts of atypical personality development put forth by Rank, in 1949 (see 11 for a discussion). A national field trial attempted to determine scoring rules for autistic disorder (12). With these changes in criteria, the DSM-III-R became overly inclusive, created false-positive diagnoses, and differed widely from the criteria set down in the ICD-10 (13).

DSM and ICD

Because it was critical that future research should compare different populations, it was necessary to align the DSM and ICD classifications. To achieve this, a literature review, a reanalysis of existing data, and a large multicentre international field trial were undertaken. The ICD-10 included Rett's disorder and childhood disintegrative disorder (CDD) under the umbrella of PDDs. It also separated research and clinical criteria (Table 1). Studies using ICD-10 criteria showed that they correlated well with expert clinical diagnoses (14). The DSM-IV classification system kept the research and clinical criteria together but brought criteria into line with the ICD-10 and included the other PDDs (15). Hence, the 2 systems' descriptions of the different disorders are now close (Table 1).

DSM-IV PDDs

Autistic Disorder

Previously known as infantile autism or Kanner's syndrome, this condition is sometimes referred to as "classical autism." It is defined by impairment in social interaction; in communication; and in behaviour and play, which is repetitive, stereotyped, or restricted in range of interests and activities. A delay in social development, in language, or in symbolic play must be present before age 3 years. A typical example is a 3-year-old child who does not speak and does not respond when parents call his or her name. Such children seem to be in their own world when left alone; in day care, they tend to isolate themselves from the group. They do not play with toys but, instead, perhaps repetitively stack blocks or push a toy car back and forth while lying on the floor . They are sensitive to loud noises and cover their ears when trucks pass by. They flap their hands and turn their bodies in circles.

Rett's Disorder

This is a progressive developmental disorder with a prevalence rate of roughly 1/20 000, appearing primarily in girls. After a normal early infancy, the head circumference begins to decelerate between age 5 and 48 months (16). Previously acquired fine motor skills are lost, and a characteristic hand-wringing movement appears. The lower limbs and trunk are also involved; affected girls develop a wide-based gait and gradually lose gross motor function. Thus, the initial presentation may be for motor delays, rather than language delays as in

autism. There is concomitant loss of language skills, interest in the environment, and social interaction; affected girls appear autistic. However, in a later stage of the disorder's evolution—between age 2 and 10 years—social interaction improves and attempts to communicate emerge; there is more eye contact and social ability than is seen in a child with autism. Rett's disorder is associated with severe mental retardation. By adolescence, affected girls have muscle wasting, scoliosis, spasticity, and decreased mobility. Some may also have seizures. A sporadic gene mutation encoding X-linked methyl-CpG binding protein 2 (MeCP2) has been identified as the cause in at least some cases (17). This mutation has a recurrence rate of less than 1%. Variant forms of the disorder exist (for a review, see 18). This disorder is included in the DSM-IV and ICD-10 to allow clinicians to make a differential diagnosis in girls presenting with language and social delays.

Childhood Disintegrative Disorder (CDD)

Also known as Heller's syndrome, this extremely rare progressive disorder has a prevalence rate of 1.7/100 000 and affects male subjects more than female subjects (19). The DSM-IV defines this disorder as beginning after 2 years of normal development with acquisition of language, social ability, and age-appropriate play. To meet the criteria, the child must manifest deterioration in 2 of the following areas of development: language, social skills or adaptive behaviour, bowel or bladder control, play, or motor skills. This deterioration should occur before age 10 years. Once established, the course is in some ways prototypical of autism, with, if anything, a worse outcome (4). The disorder was difficult to diagnose prior to publication of the DSM-IV, since it was unclear whether a marked regression had really occurred or whether the regression was actually associated with a demonstrable neuropathological process. However, with the advent of videotape it is now possible to document what appears to be normal development prior to the regression. Extensive investigation fails to pinpoint any additional medical causes (4).

Asperger's Disorder (AD)

First described by Hans Asperger (20), this disorder is apparent at a later stage of development than is autistic disorder. It reveals itself in impaired social interaction and a restricted range of interests and activities. Early language skills are preserved, but motor delays are common, and interests are circumscribed. Thus, language development appears normal at age 3 years, although communication skills are impaired in many of these children. For example, conversational ability is hampered by intense interest in a topic (such as the solar system or information on video covers), about which affected children may speak incessantly. They may make socially inappropriate statements in public or, sounding like little professors, use unusual and sophisticated words. Their prosody is affected, and they may speak in a boring monotone. Affected children are usually detected when social difficulties are apparent. Although they may have normal cognitive ability, some have learning disabilities. These children can often complete high levels of education, but their functioning in adult life is severely compromised by their lack of social ability.

A neuropsychological diagnosis of nonverbal learning disabilities (NLD) has many symptoms in common with a diagnosis of AD but is not well recognized in psychiatric literature. Differences in right and left hemispheric functioning differentiate NLD from high-functioning autism, and neuropsychologic testing may help to distinguish these entities (21).

PDD Not Otherwise Specified (NOS)

This diagnosis is used when the criteria for the other categories are not met. Therefore, children who do not fit the diagnosis because of onset age or who do not have key symptoms described in the criteria for other PDD diagnoses, or who have a less severe clinical presentation would fit this diagnosis. The DSM-IV does not lay out clear criteria, leaving this category open to interpretation by clinicians. However, it is a frequently used diagnostic category despite its ambiguities. It is usually taken to mean a child who has acquired language skills and who may be able to participate in regular classroom teaching, that is, a child with a milder form of autism. Children with this diagnosis overlap with children suffering from autistic disorder who later develop language or who have normal cognition and are considered to have high-functioning autism (11). However, the diagnosis of PDD NOS could also encompass children with global developmental delay who have some symptoms of autism but not enough to qualify for a diagnosis of autistic disorder. PDD NOS has become a diagnosis with enormous clinical variation, creating much dissatisfaction among parents and professionals.

Critique of the DSM-IV

Problems still exist with the DSM-IV system. The criteria are less stringent than the ICD-10 research criteria and are therefore more inclusive. Among the disorders, autistic disorder is the most clearly defined, while AD and PDD NOS are less so. Diagnosing AD is extremely difficult if the DSM criteria are strictly followed, because many affected children also meet the criteria for autism (22,23). The criteria for PDD NOS are even less well delineated. Parents and clinicians tend to drop the NOS and refer to children in this group as suffering from PDD. This diagnosis is not specific and creates many false positives, with ramifications not only for research but also for service providers and schools. However, there is a high degree of international consensus regarding concepts about autism, compared with other psychiatric conditions.

Assessing Autism Spectrum Disorders

Autism Diagnostic Assessment

The assessment of the child, adolescent, or adult with suspected autism should begin with a clinical assessment by a multidisciplinary team of specialists (24). It should include a pregnancy, birth, and developmental history, together with the age at which parents first became concerned and observation of the presence or absence of developmental regression. Questions about general health, including sleep and eating habits (particularly in regard to food sensitivities) are important information. A family history is necessary to identify clusters of neurodevelopmental disorders. Questions about the child's functioning should include current and past behaviours; some children will improve with neuromaturation, obscuring the fact that some typical autistic symptoms were present at a younger age.

The clinical evaluation should also include a physical exam with growth measurements (especially head circumference), a neurological examination, and an examination of the skin using a Wood's lamp to look for depigmented markings, such as those seen in tuberous sclerosis. For children with abnormal findings on a neurological examination, an EEG and magnetic resonance imaging (MRI) are necessary. Children with definite loss of language skills need a sleep-deprived EEG to evaluate the possibility of Landau–Kleffner syndrome. Finally, an audiogram is needed to rule out any hearing loss that may account for the language delay.

Laboratory investigations may include testing for fragile X syndrome and chromosome analysis, although a positive yield is low and may not warrant routine testing. More recently, molecular genetics testing using fluorescence in situ hybridization (FISH) techniques has demonstrated abnormalities on chromosomes 7 and 15 (25). Other laboratory investigations for immune deficiency or metabolic problems have very low yield (less than 5%) and are not warranted unless clinical symptoms or signs are present (26). The same is true of tests for antigliadin antibodies that look for gluten enteropathy. Unless the child has a history of diarrhea, anorexia, or failure to thrive, the test yield will be extremely low.

Diagnostic Assessment Tools

Until recently, diagnostic assessment tools for autism lacked precision and reliability (27). One of the earliest autism-specific tools developed is the Childhood Autism Rating Scale (CARS) (28). The evaluator uses this 15-item observation instrument to rate various behaviours (such as response to name, use of objects, and verbal ability) according to a 4-point scale. The rating scale is imprecise in its descriptive ability but has good reliability. It tends to capture a more global impression of the child. Because it lacks detail, newer tools have been devised.

The Autism Diagnostic Interview-Revised (ADI-R) (29) is a detailed parent interview divided into 4 main subject areas: communication, reciprocal social interaction, play, and developmental history. Items are scored on an algorithm to give cut points for autism. This instrument has shown good sensitivity and specificity, and it is now considered a necessary component of a diagnostic evaluation, particularly for research.

As a companion to the ADI-R, the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (30) was devised to provide evaluators with a standard direct-observation measure. The ADOS-G has 4 modules designed for children, adolescents, and adults with varying levels of language ability. The procedure takes about an hour and uses specific play interactions called "presses." Each of these presses is coded and scored on an algorithm. Scores in communication and reciprocal social interaction, as well as the total score, fall above or below a cut point for autism or the autism spectrum. The ADOS-G has good reliability for determining children in the autism spectrum.

Both of these tests require training and reliability checks, especially if they are to be used for research. However, teaching for the ADOS-G is available to clinicians who wish to become familiar with the test and its administration.

Developmental Testing

Psychological Assessment. Assessing levels of intelligence and adaptive behaviour in children and adolescents with autism is important to understand their ability and prognosis and to determine school placement. Verbal reasoning, abstract or conceptual thinking, problem solving, capacity to acquire knowledge, and linguistic and mathematical competence can be tested using the following measures: the Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R) (31), the Wechsler Intelligence Scale for Children (WISC-III) (32), the Stanford-Binet Intelligence Scale (SBIS) (33), and the Mullen Scales of Early Learning (34). For individuals with autism and low linguistic levels, the Leiter International Performance Scale (LIPS) (35) can be used.

The most frequently used scale for adaptive behaviour is the Vineland Adaptive Behavior Scale (VABS) (36). This scale assesses 4 areas of functioning—communication, daily living skills, socialization, and motor skills—and can be helpful in diagnosis.

Speech and Language Assessment. Assessing the child's communication skills is important, particularly in children with a diagnosis of either high-functioning autism or semantic- pragmatic language disorder. Listing the numerous available language tests is beyond the scope of this paper, but commonly used ones are the Peabody Picture Vocabulary Test-Revised (PPVT-R) (37) and the Reynell Developmental Language Scales (RDLS) (38).

Table 2 Prevalence rates of autism and autism spectrum disorders

Diagnosis	Rates/10 000
Epidemiological studies since 1987	
Autistic disorder	10.0
PDD NOS	15.0
Asperger's disorder	2.5
All disorders	27.5
Epidemiological studies since 2000	
Autism spectrum disorders	60.0

PDD NOS = Pervasive Developmental disorder not otherwise specified

Occupational Therapy Assessment. Although motor skills are often less affected in autism than are other developmental skills, many children have problems in fine or gross motor functioning and motor coordination. The Beery–Buktenica Developmental Test of Visual-Motor Integration (VMI) (39) scores graphic and motor skills, perceptual accuracy, and hand eye coordination. Other useful tests are the WeeFIM instrument (functional independence measure) (40), which can be used with young children, and the Peabody Developmental Motor Scales (PDMS) (41). Finally, it is important to evaluate sensory problems, such as acoustic or tactile problems, to understand how children with autism respond to environmental stimuli. The Sensory Integration and Praxis Test (SIPT) (42) is one tool to assess this; however, it may not be needed for every child.

Functional Evaluation

Behavioural Assessment. Difficult and disruptive behaviour is a common symptom in autistic individuals of any age. Evaluation of specific behaviours, taking into account setting and antecedent stimuli, will help the clinician determine an intervention approach. Questionnaires such as the Aberrant Behavior Checklist (43) or the Nisonger Child Behavior Rating Form (Nisonger CBRF) (44) can provide pre- and post-treatment ratings to guide the intervention.

Family Assessment. There is no doubt that a family caring for a child or adult with autism is under much stress, owing to the demands of an individual with special needs and the lack of support in the health and education system. To obtain knowledge about the autistic patient's environment, clinicians should evaluate the parents' awareness of their child's needs, their knowledge of autism, their ability to cope with the extra parenting demands, and the extent of family and community support. As in any family, parents with other stressors, such as financial difficulties or relationship problems, will have more difficulties meeting the needs of their child. A social worker can provide the family with support and community resources particular to their needs.

Epidemiology

The prevalence rate for autism and autism spectrum disorders has increased worldwide over the past decade (45). In epidemiologic studies done in the 1960s, autism rates tended to be determined based on severe impairment of language, social interaction, and behaviour. Such cases, known as "classical autism," had prevalence rates of 4/10 000. These rates have changed with changing diagnostic criteria as well as parents' and professionals' increased awareness of developmental problems.

Prevalence Rates for Autistic Disorder

Fombonne has reviewed the epidemiologic data published in 32 studies (46,47). Since 1987, 21 epidemiologic surveys have been done in 13 countries, with subjects ranging in age from birth to adult and a median age of 8 years. Methodological problems, such as differences in case finding, population sampling, and diagnostic procedures, create values that range widely, from 2.5/10 000 to 30.8/10 000 (Table 2). According to Fombonne, a best estimate for the prevalence rate of autistic disorder is 10/10 000 (46).

Prevalence Rates for Autism Spectrum Disorders

Of the 32 studies reviewed by Fombonne, 12 gave data on other PDDs (46,47). The prevalence rate for unspecified PDDs and PDD NOS is 15/10 000. Prevalence data for AD is less precise, it being one of the newest disorders in this diagnostic category, but the best estimate is around 2.5/10 000 (Table 2) (48).

From Fombonne's review, the most recent estimate for all autism spectrum disorders, taken together, is 27.5/10 000. Owing to the methodological vagaries, this estimate is thought to be conservative and somewhat imprecise. Fombonne notes improved case finding methods and diagnostic precision in the 3 most recent studies reviewed (done in 2000 and 2001): for all PDDs, including autistic disorder, these studies show prevalence rates between 57.9 and 67.5/10 000 and a convergence in the range of 60/10 000 (Table 2). However, these studies varied in the reported rates of autistic disorder, PDD NOS, and AD, despite the use of the ADI-R and the ADOS. Therefore, it is still difficult to get a sense of prevalence rates for PDD subtypes.

Whether there is an increased incidence of autism has yet to be determined. Surveys attempting to find incidence rates used referral statistics that were confounded by changes in referral patterns or did not account for the changes in diagnostic classification during the study period. Therefore, it is not possible at this time to say that the incidence of autism has increased. Further, because the condition is somewhat rare, future large-scale population studies will be needed to detect a small change in incidence rates (46,47).

Clinical Correlates of Autism

Sex Ratio

In Fombonne's review, the male-to-female ratio in children ranged from 1.33 to 16.0, with a mean of 4.3 (46). This is consistent with early descriptions of autism (49). For higher-functioning autism, the male-to-female ratio is higher (5.8). The male predominance is striking, yet researchers have given it relatively little attention.

Social Class

Kanner reported that a greater proportion of families having children with autism were from the upper classes, with high levels of education and occupations (3). This trend was reported in studies prior to 1980 but is not demonstrated in later studies, which may reflect the fact that, formerly, those in lower classes lacked access to services. It is now clear that this disorder cuts across all socioeconomic levels (45–47).

Cognitive Function

Cognitive deficits observed in the studies reviewed by Fombonne indicated that 30% of subjects had mild-to-moderate impairment, while 40% had severe levels of mental retardation, leaving 30% with normal IQ. Thus, most children with autism have mental retardation. However, the 3 surveys done in 2000 and 2001 reported lower rates of impairment, with 29% to 60% of subjects having normal IQ. This finding raises the possibility that early detection and intervention may make a difference in the overall rate of mental retardation, but it needs more research to be clearly ascertained.

Regression in Autism

It has been known for many years that autism can present as either a lack of language development or as a loss of previously acquired language, usually single words. This differs from the loss of language skills previously defined in CDD. The ADI defines early regression of language: it indicates that the child should have 5 meaningful words used over a period of 3 months, which he or she then ceases to use, causing the parents to become concerned about language development. This pattern occurred in 25% of children studied in a British sample of 473 children suffering from autism (50).

Vaccinations

The issue of regression in autism came to the forefront as part of the measles, mumps, rubella (MMR) vaccine controversy. A 1998 article appearing in Lancet described a small group of children with autism who had diarrhea (referred to as autistic enterocolitis) and who lost previously acquired developmental skills after receiving an MMR vaccine at age 15 months (51). However, another study found that 17% of the children had bowel symptoms and that this rate did not change over the 20-year period for which data were examined and which included the introduction of the MMR vaccine in 1988 (50). Additional epidemiologic studies examining this question have not confirmed a link between the onset of autism and the administration of the MMR vaccination (49,52–55). A recent population study undertaken in Denmark, where almost all children are accounted for through a government registry, found no difference in the relative risk of autism between the vaccinated (n = 440 655) and unvaccinated (n = 96 648) groups (56). To date, this is one of the best studies demonstrating the lack of association; however, there has been some criticism of the methodology, which the authors are in the process of correcting (57,58).

There has also been recent controversy about the relation between high mercury levels in children with autism and the use of thimerosal in vaccines. The hypothesis is that vulnerable children will develop neurodevelopmental problems secondary to the neurotoxic effects of mercury. However, a recent review demonstrates that the clinical presentation and neuropathology of autism and mercury toxicity differ (59). In addition, there is no evidence that children exposed to mercury from any source have a higher rate of autism. Thimerosal has not been present in vaccines in Canada since 1992, except for one preparation of the Hepatitis B vaccine that children receive at birth, but this preparation contains mercury levels well below safety estimates (that is, 12.5 micrograms Hg) (60). Thimerosal was removed from vaccines in the US in 1999.

Related Disorders

Medical conditions were reported in 15 of the surveys reviewed by Fombonne (46). The rates of medical conditions associated with autism ranged from 0% to 16.7%, with a mean of 6%. This included disorders such as tuberous sclerosis, cerebral palsy, and Down syndrome. According to a study by Dykens and Volkmar, 4% of people with autism have fragile X syndrome (26).

Rates of epilepsy in autism range from 5% to 38.3%. The highest rates occur in adolescents and adults, where about one-third can have seizures (62,63). However, in one study, 39% of a sample of 41 children with autism and seizure disorder were under age 3 years (64).

Mental retardation is an important predictive factor for the development of seizures in children with autism. In one study (64), over 80% of the children with an IQ of less than 50 had seizures, which is consistent with other studies (65,66). In a study of children with autism and normal or mild cognitive deficits, the cumulative probability was 0.06, which is similar to that for children with language disorder (62). The risk of epilepsy is higher in Rett's disorder and CDD, being in the order of 75% to 90% (62).

Psychiatric Comorbidity

Individuals with autism of varying degrees of severity experience problems that may require intervention and could mask the diagnosis in higher-functioning patients. These problems include anxiety, depression, oppositional behaviour, hyperactivity, poor attention, tics, and compulsive behaviours (67). It is unclear whether these symptoms constitute a second diagnosis or whether they are associated problems, because the symptoms may be transient and not as severe as the full-blown disorder. The degree to which the problem interferes with the ability of the child to function will dictate whether treatment should be undertaken (68).

Of these disorders, depression is very common, although prevalence rates have not yet been determined. Depression as a condition comorbid with autism may reflect a population with a family history of depression or an increased frequency of negative life events, such as parental marital discord (69). Children with autism and epilepsy may also have higher rates of depression. Depression in the presence of autism may be expressed as increased behavioural disturbances, or exacerbated compulsive behaviours, or anxiety; symptoms may not be verbalized because of the communication impairment. Whether women are more affected than men, as in the general population, is not known.

Anxiety is manifested at an early age in autism spectrum disorders, but the prevalence is unknown. When symptoms are severe, appropriate behavioural or pharmacologic treatment will alleviate some of the difficulties for the patient and the family.

In children of all ages, attention and hyperactivity problems cooccur in autism spectrum disorders and sometimes confuse the diagnosis (67). When symptoms are present, an approach to treatment may be similar to that for attention-deficit hyperactivity disorder (ADHD).

Although the presence of tics with autism or AD has been reported clinically, the exact prevalence of this disorder is not known. A study by Baron-Cohen and others found a prevalence rate of 8.1% in a population of adolescent children with autism attending a specialized school (70). These authors note that tics are difficult to distinguish in this population but "are usually short-lived, contextually inappropriate, and interrupt the flow of behaviour or speech," in contrast to stereotypic behaviours (70).

There have been some reports of individuals suffering from autism having schizophrenia, but most studies looking at cooccurrence have shown that numbers are low. One review of 163 individuals with autism found a single individual with schizophrenia, resulting in a rate of 0.6%, which is comparable to the rate for the general population (71). The DSM-IV suggests that schizophrenia can be diagnosed in an individual with autism when hallucination or delusions have been present for at least 1 month. However, the 2 disorders may be difficult to differentiate when a patient has odd obsessions. These can look like delusional thought disorder, except that, usually, ideas of reference or other distortions of thinking are absent.

Prognosis

Outcome research in autism has been marred by methodological difficulties, making statements about prognosis tentative. Just as epidemiologic research has been hampered by the lack of precise diagnostic tools, so has outcome research. This type of research is further challenged by the variation in autism disorders, particularly with respect to language and cognitive abilities. Tsatsanis recently reviewed this topic and concludes that there are few prospective, longitudinal, population-based studies (72). However, from the available data reviewed, it is becoming clear that the diagnosis of autism is stable, but the outcome in school, work, or social functioning is varied. Of individuals suffering from autism, 75% have a poor outcome, and 25% have a better prognosis. Acquisition of language before age 6 years, IQ levels above 50 (9), and having a special skill, such as expertise in computers, predict good outcome. Howlin found that, with respect to independent living and employment, there was not much difference between high- functioning individuals with autism and those with AD (73). For people with severe autism, independent living and social functioning are unlikely; for those with higher-functioning autism, the jobs acquired are often below their education level and are found with the help of families or friends. A few adults with autism marry or have close relationships, but most have few friends.

In a comparison of outcome studies before and after 1980, Howlin found that individuals in the later studies tended to have better overall competence and higher language levels (73). In addition, more had jobs (20% vs 5%) and lived independently (12% vs 0%). Although these outcomes are still a cause for concern, it appears that earlier diagnosis and intervention has improved the outcome for individuals suffering from autism. Of critical importance is the need for services for autism sufferers of all ages. With greater numbers of diagnosed individuals, health, education, and community resources are in great demand and currently overburdened. As adults in the near future, these large numbers of individuals will need support, including help with living arrangements and job opportunities.

Appendix 1 Other reference sources

Web sites

1. Geneva Centre for Autism: www.autism.net. (This centre is located in Toronto and has a reference library for professionals and parents,as well as information on upcoming workshops and conferences.)
2. Autism Society Canada (ASC): www.autismsocietycanada.ca
3. Autism treatment services of Canada: www.autism.ca/atsclink.htm
4. Canadian Autism Intervention Research Network (CAIRN): www.cairn-site.com
5. The Institute of Medicine Immunization Safety Review Committee: www.iom.edu/ImSafety
6. National Alliance for Autism Research (NAAR): www.naar.org
7. National Institute of Mental Health (NIMH): www.nimh.nih.gov/publicat/autism.cfm
8. National Institute of Neurological Disorders And Stroke, Autism Research Institute: www.autismresearchinstitute.com
9. www.autism.com gives many other websites on a variety of topics on autism
10. On-line autism book resources: www.autism-resources.com. (This site gives a list of 700 books on autism for professionals and parents.)
11. On-line autism bookseller: www.exceptionalresources.com

Books

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(Note: Either Lorna Wing's or Bryna Siegel's book would be a perfect place for parents who have just heard their child's diagnosis to start. Both are current and cover the whole spectrum. Wing's book tends to cover educational resources in the UK rather than the US, while Siegel's is the reverse.)

Journals

1. Journal of Autism and Developmental Disorders. Plenum Publishing Corporation.
2. Journal of Child Psychology and Psychiatry. Blackwell Publishing.
3. Autism. Sage Publications.

Conferences

1. International Meeting For Autism Research (IMFAR). Held annually: next conferences in 2004, Sacramento (CA), and in 2005, Toronto (ON).
2. Geneva Centre International Autism conference. Held biannually in October, in Toronto (ON) (next conference, October 2004).

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Manuscript received and accepted June 2003.

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Résumé : Diagnostic et épidémiologie des troubles du spectre de l'autisme

Dans cet article, nous donnons un aperçu des catégories diagnostiques de l'autisme et d'autres troubles envahissants du développement (TED), et nous discutons des changements du système de classification du *DSM* des 20 dernières années. Nous décrivons chaque sous-type de TED, de même que les affections psychiatriques comorbides, les lignes directrices de l'évaluation et les outils diagnostiques. L'épidémiologie de l'autisme a provoqué maintes discussions et études; nous rendons compte des données les plus récentes, et des conclusions récentes sur les sujets controversés qui soi-disant causent le taux de prévalence accru observé dans les dix dernières années. Enfin, nous discutons du pronostic des personnes souffrant d'autisme, et indiquons les défis que doivent relever les patients, les familles et les professionnels visant à optimiser leurs résultats.