

High-functioning pervasive developmental disorders in adults

Sarah J Abrahamson, Peter G Enticott and Bruce J Tonge

Pervasive developmental disorders (PDDs) are comprised of the neuropsychiatric developmental disabilities, autistic disorder (autism), Asperger disorder and PDD — “not otherwise specified”.¹ These conditions are also commonly known as autism spectrum disorders.² The key features are severe developmental difficulties with social cognition and communication, and non-functional obsessive interests, routines or activities (Box 1).¹

PDDs are considered to have been under-diagnosed worldwide,³ and the variety of presentations and outcomes has only recently been recognised.

The public profile of PDDs has increased dramatically in recent years, coinciding with media depictions of individuals with these conditions. Increased public awareness is likely to be associated with greater demand for knowledge of PDDs in general clinicians and specialised services.

There is debate among researchers and clinicians about whether the two major categories of PDDs, autistic disorder and Asperger disorder, are distinct conditions, or whether they lie on a continuum.⁴ The two disorders are partly differentiated by whether or not the patient's language development is impaired: individuals with a history of language difficulties attract a diagnosis of autistic disorder rather than Asperger disorder.¹ A further differentiating feature is IQ: for a diagnosis of Asperger disorder, the *Diagnostic and statistical manual of mental disorders, 4th edition* (DSM-IV) specifies an IQ within the normal range,¹ whereas only 20% of people with autistic disorder have a normal IQ.⁵

Alternatively, IQ criteria can be used to divide PDDs into “high functioning” (IQ of 70 or greater), and “low functioning” (IQ of under 70). Lower functioning individuals usually come to the attention of health and education systems at a young age and stay in the care of intellectual disability services. In contrast, higher functioning individuals were not widely referred for assessment or treatment until the 1990s, coinciding with the addition of Asperger disorder to the DSM-IV in 1994. Here, we discuss the prevalence and features of high-functioning PDDs in adults, and the professions that may potentially contribute to their diagnosis and specialist multidisciplinary management.

Prevalence

A recent Australian review concluded that about one in 160 Australian children has a PDD, with the most prevalent diagnosis being autism.⁶ Sixty per cent of Australian children diagnosed with PDDs have an IQ of 70 or greater,⁷ so can be defined as high functioning. A similar or higher proportion of PDDs in children with normal IQ was reported in recent overseas literature.⁵ Epidemiological studies of PDDs are of their occurrence in children, not adults.³ However, there is no evidence that PDD prevalence has increased in recent years,³ so it can be assumed that the prevalence in adults is probably similar to that in children. High-functioning PDDs are more common in males, with a male to female ratio of around 5.5:1.³

ABSTRACT

- High-functioning pervasive developmental disorders (PDDs) have only recently been widely recognised; they are diagnosed mainly in children.
- Key features are impaired social cognition and communication; obsessive interests, routines or activities; and social or occupational dysfunction.
- There are scant data about the prevalence of high-functioning PDDs in adults, and it is possible that many Australian adults with these conditions are undiagnosed.
- A specialist multidisciplinary approach is used for both children with PDDs and adults with other neuropsychiatric disabilities, and has the potential to help adults with high-functioning PDDs.
- Increased awareness and diagnosis of these conditions should not limit career or personal goals of individuals with PDDs but should aid them in finding happy and productive careers and lives.

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Key features

Impaired social cognition and communication

People with PDDs have severe developmental impairments in social communication¹ (Box 2). These may include difficulties with expression and interpretation of the social implications of speech, eye contact, body language and prosody (use of volume, pitch, pitch variation and timing of the spoken word to express meaning).⁸ There are often particular difficulties expressing and perceiving emotions.⁹ These social impairments may manifest in a variety of ways by adulthood. Those with IQs in the low-normal range may remain severely socially impaired, and present as if they have intellectual disabilities. Those who have good insight into their difficulties and a higher IQ may learn coping strategies and ways to relate to people, and, consequently, high-functioning PDDs may be more difficult to detect.^{10,11}

Obsessive special interests, routines or activities

Unusual, non-functional obsessive interests or routines, or odd motor mannerisms are required for the diagnosis of PDDs.¹ Interests are diverse among people with high-functioning PDDs, and may include typical interests, such as music, sport or movies at a more intense level than is usual, or more unusual interests such as air conditioners.¹² There are no clear guidelines for defining unusual or obsessive interests; this is decided by individual clinicians. An obsessive routine might manifest in lifelong habits similar to those seen in obsessive-compulsive personality disorder. Individuals may also have abnormal motor mannerisms, such as hand flapping.

1 High-functioning pervasive developmental disorders in adults

Key features

- Impaired social and high-level communication skills, verbal and non-verbal (eg, eye contact)
- Impaired development of normal peer relationships
- A special interest that is abnormal in intensity or focus; and/or obsessive non-functional routines; and/or repetitive motor mannerisms
- Social or occupational dysfunction

Other common features

- Impaired perception of own and others' emotions
- Impaired expression of emotions
- Delayed language development
- Executive function deficits
- Academic skills disorders (eg, mathematics disorder)
- Motor clumsiness
- Poor handwriting
- Over- or under-sensitivity to sensory stimuli
- Impaired recognition of faces (prosopagnosia)
- Psychiatric comorbidities, particularly depression and anxiety ◆

Social or occupational dysfunction

Although criteria for autistic disorder in the DSM-IV-Text Revision require symptoms to be “marked” or “encompassing”,¹ only criteria for Asperger disorder in the older edition of the manual (DSM-IV) include an expectation that the person has social or occupational dysfunction. This feature may have been included by the manual's compilers to ensure that only people with a disorder are diagnosed, and that the term is not used to describe a personality variant. It has been suggested that there is an autism spectrum of personality characteristics that does not cause social or occupational dysfunction and is seen in some successful members of the community, such as science academics.¹³

Language and speech impairment

Substantial language impairments are a key sign of autistic disorder, and are usually the first signs detected in younger children.¹⁴ Although some communication impairment in the social use of language is necessary for the diagnosis of any PDD, these language signs may be subtle in some higher functioning individuals. Problems may include impairment in pragmatic aspects of language, with inappropriate comments and style of communication and impaired interpretation of others' communication; impairments in prosody; terseness; pedantry; and perseveration on the special interest.⁸

Associated features

A number of developmental and other features are commonly associated with PDDs, but are not required to make a diagnosis, even though they may cause considerable difficulties (Box 1).

Motor skills

Many people with PDDs have impaired motor skills, often affecting coordination or praxis, especially gait. Most people with autistic

disorder or Asperger disorder in an Australian study reported clinically significant problems in this area.¹⁵ People with PDDs are also often slow, untidy writers;¹⁶ typing may not be affected, in which case learning to type fluently helps greatly with written communication.

Sensation and perception

Many adults with high-functioning PDDs describe unusual sensory experiences. In particular, hypersensitivities in many sensory modalities have been described, but there is little empirical evidence that these symptoms are more prevalent in people with PDDs than in the general population. Individuals with PDDs have described difficulties tolerating bright lights or particular sounds, especially high-pitched sounds.¹⁰ Hypersensitivities to particular textures, including difficulty wearing some clothes, can also occur.¹⁷ Texture difficulties may affect the ability to tolerate some foods.¹⁸ Some tastes may be very difficult to tolerate¹⁹ and there may be sensitivities to certain odours,¹⁹ leading to restricted diets.

Hyposensitivities are less commonly described. Hyposensitivity to pain, where usually painful stimuli may not be noticed, has been described,²⁰ as has hyposensitivity to cold.²⁰ Some individuals describe fluctuations between hypo- and hypersensitivities.²¹ Finally, higher level perceptual problems, such as prosopagnosia (difficulty in recognising faces), may also be present.²²

Visualisation, visual and verbal learning

The processing and use of different types of sensory information may vary widely between people with high-functioning PDDs. Some adults with PDDs describe thinking in pictures and having a photographic memory, and may have difficulty taking in information presented verbally.¹⁷ However, others have difficulty visualising or processing visual information, and find information easier to take in verbally: these individuals may be diagnosed with a non-verbal learning disability.²³

Academic skills

Academic skills may be impaired in various ways in individuals with high-functioning PDDs. Around 20% of people with high-functioning PDDs have difficulty with reading and writing, particularly spelling, probably the outcome of earlier language delay and disorder.²⁴ In addition, although many people with PDDs are excellent at mathematics, almost 50% of children with Asperger disorder have difficulties in this area.²⁴

Executive function

Impaired executive functions are considered to be common features of high-functioning PDDs, although the exact type and extent of these varies substantially and no particular impaired executive function characterises all high-functioning PDDs. Impairments within a number of domains have been described, including working memory,²⁵ planning, inhibition, problem solving, judgement and idea generation.²⁶ Many people with PDDs have difficulty sustaining attention, and up to 38% of patients with PDDs fit the criteria for attention-deficit hyperactivity disorder.²⁷ Executive function difficulties, especially in attention-shifting, are thought to underlie the obsessive interests of many with PDDs.²⁸

Epilepsy

Up to 30% of individuals with PDDs have epilepsy,²⁹ although this may be more common in those with lower functioning PDDs.

Psychiatric comorbidities

Neuropsychiatric services have begun assessing adults with complex personality disorders for PDDs, and found substantial comorbidity between these two groups of disorders. Many adults with PDDs in a clinical sample were found to have personality disorders, with 4%–40% meeting criteria for individual personality disorders, the obsessive–compulsive type being the most common comorbidity, and all except the histrionic type represented.³⁰ This finding suggests substantial overlap between the symptoms of PDDs and personality disorders, particularly schizoid, schizotypal and obsessive–compulsive personality disorders. Although the DSM-IV criteria specify that some personality disorders and PDDs cannot be diagnosed together,³¹ their similarities suggest that they are closely related, and that these different categories may in many cases be alternative ways of describing the same conditions.

Twenty per cent of adolescents and young adults with Asperger disorder in a clinical sample were found to have major depressive disorder; 30% had generalised anxiety disorder; and 50% had clinically significant suicidal ideation.³² Twenty-three per cent of women with long-standing eating disorders were found to fit the criteria for Asperger disorder.³³ A small but significant proportion of adults with PDDs have bipolar disorder (7%) or a psychotic disorder (8%).²⁷

Diagnosis and management

Adults in Australia presenting with high-functioning PDDs are likely to fall into one of two categories. The first consists of those who were diagnosed as children and are facing a potential treatment gap as they leave the paediatric or child psychiatry systems. The second consists of adults who present to clinicians specialising in diagnosing adults with PDDs, usually after self-referral or referral by family members. Some of these adults may have become aware of PDD symptoms in themselves after their child was diagnosed with a PDD. The likelihood of adults with high-functioning PDDs being spontaneously diagnosed by general clinicians, whether in general practice, psychiatry or psychology, may be low in Australia. This suggestion is supported by Australians and New Zealanders with high-functioning PDDs who report long involvement with psychiatric health professionals without their PDD being diagnosed.^{11,34,35} Consequently, it is possible that many adults with high-functioning PDDs in Australia are managed under other diagnostic categories, or may even have no contact with mental health or disability services.

Clinicians use several tools in diagnosing PDDs, including the Autism Diagnostic Interview-Revised (ADI-R)³⁶ and the Autism Diagnostic Observation Scale (ADOS).³⁷ Several questionnaires have been designed specifically to aid screening and assessment of adults with high-functioning PDDs, including the widely known Autism Spectrum Quotient (AQ)³⁸ and a more recently developed tool with greater sensitivity and specificity than the AQ, the Ritvo Autism and Asperger's Diagnostic Scale (RAADS).³⁹

Multidisciplinary services for adults with high-functioning PDDs are rare in Australia, and there are no studies of the efficacy of such an approach in treating adults with these disorders.

2 Possible communication deficits in adults with high-functioning pervasive developmental disorders

- Impaired use and interpretation of appropriate eye contact
- Impaired use and interpretation of facial expressions
- Impaired use and interpretation of body language, including gestures, touching and respect of personal space
- Impaired use of prosody (volume, pitch, pitch variation and timing [eg, monotonous speech])
- Impaired interpretation of prosody in others
- Impaired expression and perception of emotions
- Severe emotional outbursts when distressed
- Impaired pragmatic aspects of language (ie, inappropriate use of words)
- Impaired interpretation and use of sarcasm and humour
- Pedantry
- Perseveration on the special interest
- Impaired interpretation of metaphors and proverbs
- Difficulty using and understanding colloquialisms
- Unconventional pronunciation of certain words (eg, pronouncing exactly as spelt)
- Idiosyncratic use of certain words and grammar (eg, referring to self in the third person)
- Socially inappropriate "thinking aloud" ◆

Nevertheless, we recommend a team approach, based on departments of health guidelines,^{40,41} and on widespread use and success of team approaches in treating childhood PDDs⁴² and adult-acquired neuropsychological disabilities.⁴³

One or more doctors, particularly psychiatrists, physicians or general practitioners, will usually be involved in assigning a diagnosis, coordinating care and diagnosing and treating comorbidities. No specific medications are used for PDDs, but all types of psychiatric medication may be used, based on the patient's symptoms.

Clinical psychologists or neuropsychologists with expertise in this area may diagnose PDDs independently, particularly in private practice, and in some cases coordinate patients' PDD care. They perform cognitive assessments, provide feedback to the person and family about cognitive strengths and weaknesses, and help guide future learning, career and lifestyle choices. Some individuals may benefit from further clinical psychology input such as cognitive behavioural therapy for anxiety or depression.⁴⁴ Clinical psychologists may also provide advice about PDDs and social skills training.

Speech therapists can help with the language, prosodic and social communication impairments seen in PDDs.

Occupational therapists can help those with substantial executive function difficulties, including those with difficulty organising and planning activities of daily living, such as grooming, dressing appropriately, running a household, managing finances and negotiating community activities. Occupational therapists can also help patients engage in vocational and avocational pursuits. Those with expertise in this area may give advice on dealing with specific sensory abnormalities.

Physiotherapists and exercise therapists can help those with coordination difficulties, correct postural or gait problems and find forms of acceptable exercise.

Dietitians can aid in designing appropriate diets. Many people with PDDs have odd eating habits, sometimes caused by specific

sensory difficulties. Others with PDDs have generally poor diets because they lack interest in food or find planning and preparing healthy meals difficult.

Social workers can help patients and their families access and liaise with community services, such as employment agencies and carer support services. Vocational service providers can help in finding appropriate training and employment.

Autism associations⁴⁵⁻⁴⁷ play an important role in advising about appropriate services, providing clinician services, educating the community about PDDs and also supporting people with PDDs and their relatives.

Outcome

Previously, the long-term view of the social and occupational outcome for adults with PDDs was pessimistic, with 4%–47% in employment of any type.⁴⁸ This view is slowly changing following the recent increase in diagnoses at the higher functioning end of the autism spectrum, and autobiographical reports of people with PDDs who have been successful in a variety of areas.^{10,17,18}

PDDs do not necessarily prevent individuals from living independently or having friendships, romantic relationships or families,¹⁰ but aspects of personal relationships are difficult for many adults with PDDs.⁹ Consequently, PDD diagnosis should not limit choice of career or personal goals, but should, by demystifying problems and opening doors to services, help individuals find careers and lives in which they are most happy and productive.

Conclusion

Australia needs to consider how to provide diagnosis and care for adults with high-functioning PDDs comparable with that available for people with paediatric neurodevelopmental disabilities and acquired adult neuropsychological disorders. The goal of treatment for a person with a PDD should be a fulfilled life as free from psychiatric comorbidities as possible. We hope research-based awareness and level of care available for people with these complex conditions will continue to increase, aided by public acceptance.

Competing interests

None identified.

Author details

Sarah J Abrahamson, MB ChB, FAFRM, GradDipClinEpi, PhD Candidate,¹ and Rehabilitation Physician²

Peter G Enticott, BAppSci(Hons), PhD, Research Fellow¹

Bruce J Tonge, MD, MRCPsyc, FRANZCP, Head¹

1 School of Psychology, Psychiatry and Psychological Medicine, Monash University, Melbourne, VIC.

2 Department of Rehabilitation, Royal Melbourne Hospital, Melbourne, VIC.

Correspondence: sarah.abrahamson@med.monash.edu.au

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