Autism Spectrum Disorders Special Interest Group

Best Practice Guidelines for the Assessment and Diagnosis of Autistic Spectrum Disorders for children and adolescents (birth to 18 years)

The Psychological Society of Ireland
Cumann Síceolaithe Éireann

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As Chair of the Autism Spectrum Disorders Special Interest Group (ASDSIG), I wish to express sincere appreciation to all of the members of the Group who have contributed their time and thoughts by attending many meetings and via email to the production of these guidelines.

As with any endeavour of this kind, it is right and appropriate that individuals should be singled out for special thanks. In particular, Ms. Aisling Whelan, Ms. Christine Chapple, Ms. Miriam O'Donohue, Dr. Rita Honan, Dr. Moira Kennedy, Dr. Mitchel Fleming, Mr. Damien Connolly, and Dr. John F. O'Mahony.

Given the changing nature of research and practice, the ASDSIG and the Society would always welcome any additional and ongoing input either from a clinical or research base from all wishing to contribute.

It has been a long journey from the first ideas to this guide. It is hoped, it will provide practical guidance to Psychologists in Ireland to enable them to provide best practice to meet the needs of children, and adolescents in relation to Assessment and Diagnosis of Autistic Spectrum Disorders.

Mark A Latimer

Chair Autism Spectrum Disorders Special Interest Group 2010

FORWARD

These Guidelines have been developed in response to the stated needs of members of the Psychological Society of Ireland and inquiries made by colleagues regarding best practice in the assessment of children and young people presenting with an autistic spectrum disorder. They are based on a review of the international literature in this area, changing practices over the past few years, and discussion at the Autism Spectrum Disorders Special Interest Group meetings.

Since the identification of Early Infantile Autism by Leo Kanner in 1943 and the initial publications of Hans Asperger in 1944, much has taken place in terms of increasing our understanding of autism and Asperger's syndrome. It is assumed that there is a biological base to these conditions, but currently the presence, absence, and configuration of particular behaviours are the best indicators we have. There is no definitively prescribed way of diagnosing an autistic spectrum disorder. Currently there are broadly agreed approaches to the process and professional and ethical documents to guide individuals engaged in this process. However, the Special Interest Group notes emergent research on the role of Magnetic Resonance Imaging (MRI scanning) to support diagnosis.

As psychologists, we have a responsibility to insure that we know the core behaviours and differentiating features of the various autistic spectrum disorders, including qualitative variations in: communication, social understanding, social skills, flexibility in thinking, unusual and/or rigid behaviours, and sensory nuances. There is also a responsibility for those engaged in the assessment process to be trained and experienced in the identification of the myriad of possible co-existing conditions, and those that may better explain the individual's presentation.

These Guidelines provide recommendations, guidance, and information about current international best practice. It is intended as a tool designed to help psychologists make informed decisions regarding their role in the process of identification, diagnosis, and assessment of autistic spectrum disorders.

Consensus was reached by members of the Special Interest Group to employ the term autistic spectrum disorder as the most familiar expression and the one most commonly used in the literature and by members of the group in practice. An autistic spectrum disorder refers to a pattern of behaviours involving three central features – impairments in socialisation, verbal and nonverbal communication, and restricted and stereotyped actions. These features can vary widely in terms of expression, degree of impairment, and developmental onset through the individual's lifespan.

The spectrum of conditions addressed in these Guidelines include: autistic disorder, pervasive developmental disorder – not otherwise specified (PDD-NOS), and Asperger's syndrome. Each disorder is defined in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revised (American Psychiatric Association, 2000), and the International Classification of Diseases, 10th Revision 2nd Edition (World Health Organisation, 2005). Clinical practice in Ireland has developed to include the use of Gillberg's (1992) criteria for Asperger's syndrome (see appendix). The Special Interest Group also draw your attention to a revision of diagnostic criteria being proposed in the forthcoming DSM V.

Recommendations in these Guidelines cover individuals from birth to 18 years. They were issued in 2010 and will be considered for periodic review.

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Introduction

As agreed among the group, and reflected within the literature, a multidisciplinary team approach is optimum to provide a comprehensive assessment and diagnosis of an autistic spectrum disorder. The gathering and integration of information from multiple sources strengthens the validity of a diagnosis, and increases the likelihood of a profile and intervention objectives of significance to the individual. The primary goal of the assessment process should be to characterise difficulties that can lead to the most appropriate intervention services for the child and family. Therefore, the outcome of the diagnostic assessment process is not solely a diagnostic label, rather a profile of strengths and needs leading to socially significant intervention planning and objectives.

The diagnosis of an autistic spectrum disorder for a child presents unique challenges to the psychologist and the multidisciplinary team. Addressing issues during the different stages of assessment, leading families towards an accurate description of the child's needs, and initiating services are complex issues.

Professionals who make a referral for diagnostic assessment should clearly transmit their concerns regarding the need for the assessment. The multidisciplinary team, who accept the referral, should have the capacity to consult with the referring professional regarding the child. The multidisciplinary team should be able to assist the referring professional in gathering background information and allow the professional to participate in developing the assessment plan.

The minimum age at which an autistic spectrum disorder can be reliably diagnosed is not clear (Scottish Intercollegiate Guidelines Network, 2007). However, the literature suggests that a diagnosis of autistic disorder is more reliable and stable than the diagnosis of other autistic spectrum disorders.

A diagnosis of an autistic spectrum disorder can be a lifelong label. It is therefore essential that those professionals involved diagnose, or discount it as a diagnosis accurately. It should be noted that the Ireland Code of Professional Ethics requires psychologists to work within their areas of competence only. Therefore, psychologists involved in the assessment process must ensure that they are informed and experienced in the full range of possible presentations within the autistic spectrum. In particular, as specified within the diagnostic criteria for pervasive developmental disorders, difficulties must be interpreted relative to a child's developmental level. Therefore, when skills and behaviours are consistent with a child's mental age, diagnoses other than an autistic spectrum disorder may well be more appropriate.

Accurate assessment of cognitive functioning is essential for prognosis and intervention planning (Vig & Jedrysek, 1999). Infants with a significant developmental delay have a high probability of having an intellectual disability during their school years. Early diagnosis of a significant intellectual disability is stable and persists over time. This statement is supported by a body of evidence which contends that performance of children with an autistic spectrum disorder on intelligence tests are just as stable and predictable for children without an autistic spectrum disorder from later preschool years to school age (Bernheimer & Keogh, 1998; Freeman, Ritvo, Needleman & Yokota, 1985; Lord & Schopler, 1989; Stevens, Fein, Dunn, Allen, Waterhouse, & Feinstein, 2000; Yang, Jong, Hsu & Chen, 2003).

Volkmar et al (2005) suggest that

> "As a substantial proportion of children with autism also present with mental retardation (Fombonne, 1999), it is important to cast both quantified and informal observations in terms of a developmental perspective. Hence the overall developmental or intellectual level establishes the frame within which we may interpret more meaningfully both the performance obtained and the behaviours observed during assessment." (p773).

Psychologists should be mindful of the following issues when engaging in cognitive assessment with young children:

- The evaluation of a child's level of cognitive functioning is central to determining the overall level of functioning and may highlight discrepancies between intellectual ability and social functioning. Such differences are frequently seen in children presenting with an autistic spectrum disorder and are noted in the literature.
- A best estimate of cognitive functioning is fundamental to the diagnostic assessment process and can be reasonably obtained by appropriate test selection, adaptation of procedures, use of visual schedules and supports, and preferred motivators. Those psychologists experienced in working with children in this area will be aware that young children with an autistic spectrum disorder are rarely motivated to perform for social praise. However, if external motivators or reinforcement are used it is crucial that they reinforce effort rather than correct responses.
- Assessment of children with an autistic spectrum disorder, who may be non-verbal and/or unmotivated, may present challenges to the psychologist. In selecting an instrument, the psychologist may employ a hierarchical approach to test selection, paying particular attention to the language loading of a test and the level of abstract versus concrete items.
- A differential diagnosis allows for the identification of clinical features consistent with an autistic spectrum disorder, as well as other disorders of childhood that have overlapping and coexisting symptoms. If the child's difficulties can be better accounted for by alternative explanations and/or coexisting diagnoses, it is crucial to delineate these challenges as far as they aid intervention planning and outcomes.

For school aged children, language and educational assessment play a substantial role in the diagnostic assessment process and intervention planning. Psychological assessment focused on cognitive, social, emotional, and behavioural functioning is considered essential. In addition to informing intervention, diagnosis and assessment should be directed towards establishing the needs of the child and toward efficient collaboration of service providers to meet the identified needs.

Initial queries regarding a referral for a diagnostic assessment may originate with parents/guardians, carers, or professionals. In relation to older school aged children it should be noted that the diagnostic assessment process may be somewhat different from that of younger children as it may constitute a reformulation of earlier diagnostic impressions. Concerns regarding socialisation and behavioural difficulties often accompany older children who are presenting for an initial diagnosis. This is particularly true for children whose behaviours may previously have been regarded as unusual or exceptionally bright. These children may be identified when social difficulties with peers and behavioural difficulties become incompatible with formal learning environments.

For the older child, there will most likely be more information available for review and from a wider variety of sources. A review of records will assist the psychologist in identifying developmental trends and highlight areas for investigation during the observations and interviews. Previous records can supplement and support parents' recollections. Sources of records include medical, school, psychological, and other evaluation or intervention reports (e.g. speech and language or behavioural).

Factors leading to referral for older children include the following issues:

The presentation of an autistic spectrum disorder in children is subject to change over time with developmental maturation, and interventions. It is possible for children with an early childhood diagnosis of autistic disorder or PDD-NOS to grow and respond to intervention. The evaluation of change therefore serves the purpose of conceptualising the child's current profile to guide intervention planning and to re-evaluate service delivery needs. Children who present for diagnosis at a later stage may have previously presented with behaviours which did not give cause for particular concern or they may have been diagnosed with other childhood difficulties outside of the autistic spectrum (e.g. speech and language disorders). Although parents may notice differences, these differences may not be so exaggerated as to cause concern. In such cases, difficulties may not become evident until the child enters school, when behaviours may be viewed as different from that of their peers.

As social demands and expectations increase with age, difficulties with social interactions, difficulties in making and retaining peer relationships, and an inability to cope with environmental adaptation may become apparent. This is particularly true for children over the age of six as their more typically developing peers become more attuned to social conventions and less tolerant of oppositional, hyperactive, or fearful behaviours that are different from social norms.

As children move through the education system, curricular demands and expectations increase. Particular difficulties may become evident as learning moves from concrete operational to more abstract levels of reasoning. Children experiencing such difficulties may engage in inappropriate behaviours or may become further distanced from their peers.

Familial, cultural, or other demographic factors may lead to delays in identification of difficulties. Families experiencing significant psychosocial distress may be less attuned to subtle differences or tolerant of different behaviours. Others may be aware of their child's differences but compensate through adaptation, rationalisation, or ensuring a protective environment. It may not be until the child enters a school system that teachers and others recognise different learning and behavioural needs from typically developing classmates.

Psychologists should be alert to the possibility of diagnosing one or more coexisting conditions, even when clinical features that are specific to criteria for an autistic spectrum disorder are present. Children may be referred based on behaviours associated with a coexisting condition (such as attention deficit/hyperactivity disorder, behaviour disorders, or general learning difficulties). In such instances, placement within a single diagnostic category should be approached as an incomplete diagnosis and the purpose of the assessment for an autistic spectrum disorder should be viewed as a search for diagnostic unity and clarification.

Differential diagnosis necessitates careful attention to clinical features consistent with an autistic spectrum disorder, as well as other disorders of childhood that have overlapping and coexisting symptoms. A more detailed discussion of differential diagnosis is given in Section 2.1.11

Prevalence studies indicate fewer females than males are diagnosed with an autistic spectrum disorder and even fewer with Asperger's syndrome. Current literature suggests that there may be an under-diagnosis of girls which may be viewed as a cultural acceptance of differences in male/female behaviour. Kopp and Gillberg (1992) comment that the description of behavioural difficulties used in diagnostic criteria may be based on the presentation in boys. Their hypothesis suggests that the diagnosis of higher functioning girls may be masked by gender differences in development, with girls tending to have more language and stronger social imitation skills. This, they concluded, would account for the fact that girls identified with an autistic spectrum disorder would tend to experience more extreme difficulties, such as the learning-disabled population cited by Wing (1981). This may place girls at a significant disadvantage and leave them vulnerable to mental ill health. Anxiety is often associated with excessive worry and fear, isolation, depression, substance abuse, and suicidal ideation (Tatum, 2000).

Components of the assessment and diagnostic process

2.1 Assessment and diagnosis

Psychologists engaged in assessment and diagnosis must have broad experience in the area of autism and developmental disabilities. The diagnosis of an autistic spectrum disorder is based on the most current criteria in the DSM or ICD. In relation to Asperger's syndrome, Gillberg's criteria (Gillberg, 1992) may be employed.

The specific components of the diagnostic assessment process must be child centred and dependent on age, history, and previous evaluations and assessments. The referral question should remain central to the process.

The following components are noted in the literature as representing international best practice in the assessment and diagnosis of individuals with a query of an autistic spectrum disorder (British Columbia Ministry of Health Planning, 2003; California Department of Developmental Services, 2002; Children's Mental Health Ontario, 2003; Department of Education and Science, 2001; National Autistic Society, 2003; SIGN Guidelines, 2007):

2.1.1 Review of records/history.

2.1.2 Medical evaluation.

2.1.3 Parent/guardian interview.

2.1.4 Direct child evaluation.

2.1.4.1 Interview.

2.1.4.2 Direct observation.

2.1.5 Psychological evaluation.

2.1.5.1 Cognitive assessment.

2.1.5.2 Adaptive functioning assessment.

2.1.5.3 Mental health assessment.

2.1.6 Communication assessment (speech and language).

2.1.6.1 Verbal children and adolescents.

2.1.6.2 Nonverbal/minimal language children and adolescents.

2.1.6.3 Nonverbal communication assessment.

2.1.7 Evaluation of social competence and functioning.

2.1.8 Evaluation of restrictive behaviours, interests, and activities.

2.1.9 Assessment of family functioning.

2.1.10 Assessment of secondary components.

2.1.11 Differential diagnosis.

2.1.12 Feedback to parents/guardians

Integration of information from the various components is essential and must be incorporated in the diagnostic assessment process.

2.1.1 Review of records/history

A review of the records will assist the psychologist in identifying developmental trends and highlight areas for investigation during the observations and interviews.

In obtaining a history, the following areas must be considered:

- Presenting concerns.
- Development to date, including pregnancy and perinatal history.
- Neurological history (seizures, encephalopathic events).
- Motor and adaptive milestones.
- Development of social interaction, communication, and play.
- Restricted and unusual interests/behaviours and adaptive behaviour.
- Behavioural issues, such as aggression, self-injury, sleep disturbance, eating problems.
- Family history of developmental, neurological, or mental health disorders.
- Psychosocial stressors and coping skills.
- Intervention history.

2.1.2 Medical evaluation

The child should be referred for a medical evaluation, which is composed of four major components:

Comprehensive medical history

- To determine any clues to underlying aetiology of the difficulties.
- To assist in the differential diagnosis.
- To determine any co-morbid developmental disorders.
- To determine any other medical or health issues.

Family medical/mental health history

To assist with diagnosis and identification of any possible co-existing conditions in the nuclear and extended family, such as autism, intellectual disability, fragile X syndrome, schizophrenia, tuberous sclerosis and bipolar disorders.

Physical and developmental neurological evaluation:

- To rule out medical conditions.
- To investigate gait, tone, reflexes etc.

Medical evaluation

- The need for further or repeat medical evaluation may emerge in the course of the interviews or history. If tests were undertaken a considerable time ago, consideration should be given to the possibility of newer or more sensitive tests being available.

2.1.3 Parent/guardian/carer interview

A comprehensive developmental history in the form of a parental/guardian/carer interview is one of the cornerstones of the diagnostic assessment process as the diagnostic criteria include the onset of difficulties before the age of three years. Traditionally the interview provides a source of historical information and includes a review of medical and family history.

There is no one specific test or instrument that confirms or excludes autistic spectrum disorder as a diagnosis. The instruments designed to ascertain the likelihood of autistic spectrum disorder are not sufficient in themselves to gather information for a differential diagnosis or provide enough information regarding the presentation of other disorders. The following instruments are noted in the literature as reliable and standardised measures to obtain an early developmental history of autistic behaviours:

- The Autism Diagnostic Interview, Revised (ADI – R).
- Diagnostic Interview for Social and Communication Disorders: Algorithms for ICD 10 Childhood Autism (DISCO).

The developmental information collected for younger children is also appropriate for older children; however, this can be supplemented with information from school and home as well as any other activities and interests.

2.1.4 Direct child evaluation

2.1.4.1 Interview

With children and adolescents who are verbally fluent, information should be gathered from a direct child interview. This process may be formal or informal. The interview provides an opportunity to explore pragmatic difficulties. The factors for evaluation include:

- The ability to manage conversational reciprocity, initiation, shifting, maintenance, and extension.
- The ability to recognise and respond to clarification or requests.
- The ability to interpret non-literal language i.e. humour, sarcasm and irony.
- The ability to recognise indirect and polite forms.
- The awareness of a need to shift in register.
- The capacity to modulate tone, volume, and prosodic features.
- The flexibility in dealing with a range of situations and ability to modulate response.
- Non-verbal communication, such as gaze, body positioning, mirroring.

Instruments such as the Autism Diagnostic Observation Schedule (ADOS – G) have been designed specifically to elicit language and behaviours indicative of an autistic spectrum disorder.

2.1.4.2 Direct observation

Many aspects of behaviour may be elicited through unstructured and structured observation. Such qualitative data should be gathered during all aspects of the diagnostic assessment process. The findings from all the observations should be incorporated into an assessment across all domains e.g. communication, behaviour and social interactions. Objectives of the observational analysis include:

- Identifying behaviours relating to DSM/ICD criteria
- Corroborating information from other sources
- Identifying behaviours for discussion with parents to ascertain how representative or typical a particular behaviour might be.

2.1.5 Psychological evaluation

It is considered best practice that every child with a query of an autistic spectrum disorder receives a comprehensive psychological assessment. A number of developmental disabilities have associated 'autistic features'. Children with general learning difficulties, language, and emotional difficulties may also present with autism-like features at some stage in their development. The psychological assessment assists in making or confirming a diagnosis; as well as measuring cognitive skills, adaptive functioning and behaviour.

2.1.5.1 Cognitive assessment

While a cognitive profile alone cannot confirm or exclude a diagnosis of an autistic spectrum disorder, it forms an essential part of the differential diagnosis. It helps to distinguish which aspects of behaviour are characteristic of an autistic spectrum disorder and which may be due to the level of intellectual ability/ developmental level. It is noted in the international literature that a diagnosis of an autistic spectrum disorder is warranted in cases when the social and communication skills are impaired relative to the individuals overall intellectual ability/developmental level (California Department of Developmental Services, 2002).

The following points should be borne in mind:

- The psychologist should use up to date standardised, norm-referenced instruments. Normative data used in the computation of standard scores should be as appropriate to the Irish population as is available. Examiners should be aware of the limitations of normative data derived from non-Irish populations.
- The psychologist must try to obtain an accurate measure of the child's cognitive ability, which is then used to identify a child's strengths and weaknesses for planning and intervention.
- Selection of a specific instrument is a complex decision and should be individualised for each person. The individual's developmental level, language skills, ability to relate, and length of attention span should be considered when selecting an appropriate test.

Psychological Society of Ireland/International Test Commission (2007) state that tests considered should:

i. Be appropriate to chronological and/or mental age.
ii. Provide an appropriate range of standard scores based on current norms.
iii. Provide independent measures of verbal and nonverbal abilities.
iv. Consider the child's ability to remember, solve problems, and develop concepts.
v. Measure motor and visual motor skills.
vi. Give a measure of social understanding.

The following scales/tests are among the most commonly used for the assessment of general cognitive ability/developmental level:

i. Wechsler Adult Intelligence Scale, 3rd Edition (WAIS-III)

ii. Wechsler Intelligence Scale for Children, 4th Edition (WISC-IV) 6 – 16 years

iii. Wechsler Pre-School and Primary Scale of Intelligence, 3rd Edition (WIPPSI-III) 2 -6 years

iv. Stanford Binet Intelligence Scale, 5th Edition (SB5) 2 – 89 years

v. Griffiths Mental Development Scales (Extended Revised GMDS – ER) Scale 0 – 8 years 11 months

vi. British Ability Scales, 2nd Edition (BAS-II) 2 – 17 years

vii. Bayley Scales of Infant & Toddler Development, 3rd Edition (Bayley-III) 1 – 42 months

viii. Kaufman-ABC, 30 months – 12.5 years

ix. Woodcock-Johnson, 3rd Edition NU Tests of Cognitive Abilities (WJ-III) 2 – 90 years

Non-verbal measures

x. Leiter International Performance Scale, Revised, (Leiter-R) 2 – 20 years 11 months

xi. Test of Nonverbal Intelligence, 3rd Edition, (Toni-III) 6 – 89 years

xii. Ravens Progressive Matrices 5 years – Adult

The following factors should be noted in analysis of cognitive profiles:

- Children with an autistic spectrum disorder may vary widely in terms of cognitive functioning.
- Issues of diagnosis are more complex at the extremes of the cognitive range.
- Psychologists should be aware that children and individuals in the higher functioning ranges might test in the normal ranges of verbal ability through skills in recalling rote material, but demonstrate significant impairment in generating relevant social information.
- Psychologists should pay attention to floor effects of standardised tests for children and adolescents who are functioning at lower developmental levels. In the selection of tests, appropriate consideration should be given to the goals of the assessment and the strengths and weaknesses of the child. For older children, this may involve the use of instruments that are appropriate for younger children or nonverbal instruments.
- Individuals who are more able may continue to need assessment with instruments that minimise verbal requirements.

Psychologists should refer to the Psychological Society of Ireland/International Test Commission Guidelines on the use of psychometric tests (2007).

2.1.5.2 Adaptive functioning

This is an essential component of the assessment process because it provides information regarding the child's typical functioning at home or school and may contrast markedly with information obtained from the cognitive assessment. For instance, many children with an autistic spectrum disorder, while scoring in the typical range of cognitive ability are unable to generalise or demonstrate their abilities in daily situations.

Every child with an autistic spectrum disorder should have an assessment of adaptive functioning using a standardised norm-referenced instrument. Adaptive skills give a measure of the individual's typical patterns of functioning in familiar and representative environments and give an indication of the extent to which the individual is able to use his or her potential in the process of adaptation to environmental demands (Klin, Sparrow, Marans, Cater & Volkmar, 2000).

On tests of adaptive ability, children with an autistic spectrum disorder may present with social and communication domain. This may be marked in children of higher ability and may give immediate targets for intervention. Continuing difficulties in adaptive skills are considered to have a major impact on the child's adjustment and on family stress. Risk of adjustment problems increases as the child grows older and environments become increasingly more complex.

Specific instruments for the assessment of adaptive skills include:

i. Vineland Adaptive Behaviour Scales 2nd Edition

ii. Adaptive Behaviour Assessment System 2nd Edition (ABAS-II)

iii. AAMD Adaptive Behaviour Scales

iv. Adaptive Behaviour Scale-School-Age: 2nd Edition (ABS-S:II)

v. Adaptive Behaviour Scale-Residential and Community: Second Edition (ABS-RC:II)

2.1.5.3 Mental health assessment

The relationship between mental health and autistic spectrum disorder is a complex one, and consequently assessment in this area is often overlooked in the diagnostic process. Research in this area generally points to a higher rate of mental health difficulties among individuals with an autistic spectrum disorder with some studies reporting coexisting mental health conditions among 65% to 80% of individuals (De Bruin, Meester, De Nijs, & Verheij, 2006; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1996; Lefyer, Bacalman, Davis, Dinh, & Morgan, 2006). The reasons for this interrelationship are not well understood. Studies have focussed on areas such as:

- Biological vulnerabilities (Lainhardt, 1999; Simonhoff et al., 2008)
- Developmental Influences (Ghaziuddin et al., 2002; Rutter, 1970; Brereton, Tonge & King, 2004)
- Nature and Severity of autistic spectrum disorder (Pearson et al., 2006; Ghaziuddin, 2002)
- Cognitive Skills (Sterling et al., 2008; Solomon et al., 2004)
- Environmental Factors (Gadow et al., 2008; Simonhoff et al., 2008; Shtayermman, 2007; Ghaziuddin et al., 2006; Gadow, de Vincent, & Scheider, 2008)

Issues in identification include diagnostic overshadowing, atypical presentations, communication difficulties, and cognitive difficulties. These factors can complicate a mental health assessment both in terms of differential diagnosis and in identifying co-existing conditions. This can lead either to an under diagnosis of an autistic spectrum disorder for individuals presenting at mental health services, or under diagnosis of mental health conditions for persons with a diagnosis of autistic spectrum disorder. Mental health difficulties, which may be associated with an autistic spectrum disorder include:

- Attention Deficit Hyperactivity Disorder
- Mood Disorders
- Sleep Disorders
- Anxiety Disorders
- Behavioural Disorders
- Catatonia
- Tic Disorders

While it is beyond the remit of this document to detail a comprehensive mental health assessment the following elements should be considered:

- Past history
- Current presentation
- Level of risk

This information may be obtained through interview, observation, and psychometric instruments. Parents can provide historical information regarding the child's early presentation, developmental and risk factors associated with mental health difficulties, in addition to current presentation. Children themselves may also provide a further perspective on their experiences to inform the process.

Diagnostic interviews designed to confirm or rule out other diagnoses in children and adolescents are useful, if careful consideration is given to differentiation of communication patterns typically found in autistic spectrum disorder. The use of such instruments may be supplemented with additional interviews and play/activity-based assessment as appropriate.

Self-report measures appropriate for use with children and adolescents may be helpful in the differential process. The majority of these instruments are appropriate for older children and adolescents with a query of an autistic spectrum disorder. The same precautionary measures apply as for the use of all self-report psychological tests with particular emphasis on cognitive ability, verbal comprehension, and literal interpretation. When interpreting these measures the individual's social deficits, level of concreteness and overall cognitive abilities must be taken into account.

The assessment requires clinical familiarity with mental health disorders. Psychologists may have prerequisite competencies, or may refer on to another professional.

2.1.6 Communication assessment

The assessment of communication should provide information on the communicative abilities of children who are both verbal and nonverbal. Particular attention should be paid to the semantic pragmatic, social communicative functions of language as well as to nonverbal skills used to communicate and regulate interaction.

2.1.6.1 Children and adolescents - verbal

For differential diagnosis, an assessment of language use is essential. Although standardised assessments may provide important information about specific parameters of speech and language functioning, such assessments may provide only limited information about social-pragmatic abilities. Such abilities are characteristically limited and difficult to detect in children with an autistic spectrum disorder, who are more verbally fluent.

A variety of strategies should be used, including: direct assessment, naturalistic observation, and interviewing significant others including parents and educators, who can be invaluable sources of information. It is recommended that observations include a child's interactions with a variety of persons, including family members and peers, as well as professionals, because variability in communicative functioning across persons and settings is to be expected (Wetherby, Schuler, & Prizant, 1997).

Developmental language disorders

Children with expressive language disorders invariably have difficulties with peers, although, there is typically compensation through nonverbal means of communication, appropriate imaginative play and social reciprocity. Children with receptive language disorders can be more difficult to differentiate. In this group, social skills and imaginative play are consistent with language level and are often delayed relative to same-age peers. Clinically, though, skill deficits begin to improve as language improves and are typically more in line with language level. While these skills also improve in children with an autistic spectrum disorder through development and intervention, imaginative and social capacities are often markedly behind language level.

Asperger's Syndrome

Children with Asperger's syndrome may demonstrate age-appropriate skills on traditional tests of language, including articulation, fluency, vocabulary, syntax and reading (Minshew, Goldstein & Siegel, 1995). In Asperger's syndrome, the lack of clear language delay usually leads to later recognition than with other autistic spectrum disorders (Volkmar & Cohen, 1991b). A review of the literature identifies the following characteristics commonly found among children with Asperger's syndrome (Klin, Sparrow, Marans, Carter, & Volkmar, 2000):

- Speech is often concrete and literal
- Speech marked by poor prosody.
- Rate of speech that is unusual or lacking fluency.
- Frequent failure to appreciate the nuances of social situations in modulating voice volume.
- Tangential and circumstantial speech.
- Marked verbosity.

Other disorders

Children with a cognitive impairment often demonstrate language skills commensurate with their overall mental age. Those with Attention Deficit Hyperactivity Disorder (ADHD) often blurt out responses impulsively and may have concomitant language disorders. Anxious children may be reluctant to speak, or do so in a whisper or low tone of voice. A similar situation may occur with an adolescent with a history of conduct problems who demonstrates a refusal to speak or answers in monosyllables. Finally, the language of children with an autistic spectrum disorder who are more able must be carefully disentangled from that of schizophrenia spectrum disorders when characterised by tangential or loose associations, but lack the other hallmarks of an autistic spectrum disorder.

2.1.6.2 Children and adolescents with minimal language or nonverbal

Children with limited or no functional language also require a detailed language/communication assessment. An accurate assessment of comprehension is especially important and as much information as possible should be gathered regarding the child's preferred mode of communication. The psychologist must examine the child's level of language skills relative to overall developmental level. Language tests may be used to gain an understanding of comprehension skills and should include a detailed examination of nonverbal communication, particularly deficits typically associated with an autistic spectrum disorder.

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

2.1.6.3 Nonverbal communication assessment

The assessment of nonverbal communicative behaviours consists of analysis of socio-communicative and socio-affective behaviours. These can include:

- Eye contact and the use of gaze to communicate intent and share attention.
- Gestures such as pointing and coordination of gesture and eye gaze.
- Body language – recognition of personal space.
- Turn-taking skills.
- Use of facial expression to communicate.

Observation of the non-language aspects of communication should ideally occur across settings and under differing degrees of structure and interactive partners. The goal is to generate maximum information regarding the child's capacity for social communication (with or without language) and the level of support and structure needed for optimal performance.

In relation to children who present as significantly delayed, the communication assessment should focus strongly on the nonverbal aspects of communication, communicative intent and symbolic skills within the context of overall development. Children with intellectual disability often show communicative behaviours commensurate with their mental age.

Measures that include nonverbal/preverbal communicative components include:

- Communication and Symbolic Behaviour Scales.
- Autism Diagnostic Observation Schedule (ADOS-G).

2.1.7 Evaluation of social competence and functioning

Children with an autistic spectrum disorder vary widely in their capacity for social comprehension and successful interaction. Difficulties with peer relationships are a common basis for referral. The assessment of social functioning requires data collection from multiple sources. These include:

- Observation during the evaluative assessment.
- Parent interview.
- Naturalistic setting.
- Teachers and other care providers.

Social deficits are also present in numerous childhood disorders and often affect children's ability to interact successfully with peers. A comprehensive description of the child across settings and interactions is essential to put behaviour in perspective for differential diagnostic purposes.

Measures include:

- Vineland Adaptive Behaviour Scales II.
- Adaptive Behaviour Assessment System 2nd Edition 2003.
- Child Behaviour Checklist.

2.1.8 Restrictive behaviours, interests and activities

The evaluation of repetitive behaviours, interests, and activities should be evaluated within a developmental and contextual framework. Stereotyped behaviours and preoccupations with parts of objects and sensory stimuli can be observed in children with an autistic spectrum disorder and in children with significant cognitive impairment. Motor excesses such as hand flapping, twirling, spinning, and rocking are typically observed in children who function at lower cognitive levels. The multidisciplinary team must distinguish between behaviours characteristic of an autistic spectrum disorder and those that are consistent with an overall global impairment. These must also be separated from the over-activity seen in younger children with attention deficits. Routines, rituals and restricted activities and interests can be observed across the autistic spectrum and may be features of other childhood disorders (social anxiety and phobia, obsessive-compulsive disorder, etc.).

The psychologist's task is to assess the functionality of routines, establish the developmental appropriateness of interests and activities, and note restricted interests in other conditions.

2.1.9 Family functioning

An assessment of family functioning is important for the diagnostic assessment process and intervention planning. The referral of a child or adolescent with a query of an autistic spectrum disorder is likely to be highly stressful for the family, regardless of the outcome of the assessment. Family functioning and ability to adapt to the child's needs is central for assessment and intervention.

The assessment of family functioning has two major components:

- Assessment of the family system in terms of strengths and needs in fostering development of the child within the context of the family and community. This would include family needs for support, respite, and management of child challenges within the home.
- For purposes of differential diagnoses, the assessment is important, given the strong association between environmental factors and biological vulnerability known to occur in other childhood disorders. For children whose diagnosis is unclear, assessment of the family system is important to identify environmental and biological factors that contribute to the child's presentation.

2.1.10 Secondary components

In the diagnostic assessment process, school readiness, academic and neurological testing may be useful for differentiation and overlap of an autistic spectrum disorder with nonverbal and other learning difficulties.

2.1.10.1 Academic assessment

Educational assessment in the school age child or adolescent plays an important role in the intervention planning process. In an older child or adolescent, the results of any tests or instruments may add significantly to the knowledge base about the individual. Gathering information directly from educators may add specific information useful in establishing a diagnosis. Identifying areas of strength and weakness through achievement testing has important implications in the decision-making processes pertaining to teaching methodology and curricular content.

Achievement testing may also identify specific learning difficulties, which may either provide a differential explanation for the child's difficulties or co-exist with an autistic spectrum disorder.

2.1.10.2 Neuropsychological assessment

Neuropsychological assessment may be used in the differential diagnostic assessment process when:

- Concerns exist about specific behavioural deficits such as attention and impulsivity
- Indications of neurological involvement are present
- To explore the nature of a learning disability

Although specific executive function deficits have been found in autism (Ozonoff, 1998), a full neuropsychological examination is rarely warranted to establish a diagnosis, although it may be required to arrive at an accurate description of the child's difficulties after an autistic spectrum disorder has been ruled out.

2.1.11 Differential diagnosis

In establishing an accurate and reliable diagnosis in children and adolescents, autistic spectrum disorders must be differentiated from each other and, more importantly, from other developmental disorders such as language and sensory impairments (American Academy of Child and Adolescent Psychiatry, 1999).

In order to examine possible factors that have prompted suspicions of an autistic spectrum disorder, the psychologist must have knowledge of the qualitative and quantitative indicators of autism, as well as the developmental expression of behaviours in both typical and atypical development in childhood and adolescence. Upon presentation, the diagnostic issues are complex and require careful examination and expertise. Behavioural issues can co-occur with an autistic spectrum disorder and mask underlying difficulties, or mimic features of an autistic spectrum disorder.

Differential diagnosis consists of discriminating an autistic spectrum disorder from other mental health and developmental conditions that lead to atypical language, play, and social development. Often it is helpful to begin chronologically and to consider if there has been a period of typical development. If such a period extended beyond two years, the possibility of selective mutism, disintegrative disorder, and schizophrenia in children must be considered (Rutter et al, 1994). Psychologists must be skilled in the way they question parents around infant and toddler development to insure both accurate descriptive data and appropriate interpretation of this information. Parents/guardians should be asked to provide specific examples of behaviours.

Common differential dilemmas

Asperger's Syndrome

There is a lack of agreement regarding the clinical picture of children and adolescents with Asperger's Syndrome. Ghazzudian, Tsai and Ghazzudian (1992) have pointed out that the diagnostic criteria used by authors such as Gillberg and Gillberg (1992) and Wing (1983) to diagnose Asperger's Syndrome are often quite variable which makes it difficult to draw comparisons. There is also debate as to the separation of Asperger's Syndrome from "high-functioning" autism.

However, it is important to recognise that there are individuals with severe social impairments and behaviours (much like those seen in other autistic spectrum disorders) who do not have an intellectual disability or even a language delay in a way that is easy to measure. They may be identified somewhat later, require fewer specialised educational services, and have somewhat better outcome than most children with classic autistic disorder (Szatmari, Tuff, Finlayson, & Bartolucci, 1990).

Intellectual disability

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

Children with intellectual disability, who do not have autism, may not show deficits in reciprocal social interaction, and their language development is typically consistent with their overall level of intellectual ability (Carr, 1999).

The specificity and degree of cognitive impairment for children with intellectual disability who present after age 5 years for initial contemplation of an autistic spectrum disorder are likely to have been inadequately described in the infant, toddler or preschool years. Children with a milder global impairment may have been initially classified as developmentally or language delayed; or were not identified at all. As these children enter preschool or primary school, their differences from peers become increasingly marked.

Some children with previous diagnoses of intellectual disability present for assessment in the hope that difficulties may be better accounted for by an autistic spectrum disorder and intervention planned accordingly. As toddlers or preschoolers, this group of children is often assessed as developmentally or globally delayed. At school age, differences in social skills, communication, and behaviour may become more apparent due to increased demands, necessitating a re-evaluation.

It is important both to discriminate intellectual disability (alone) from autistic spectrum disorder and to describe the cognitive abilities of children and adolescents who are found to have an autistic spectrum disorder. Teachers in classes for children with autistic spectrum disorder in Ireland identified the assessment of the level of intellectual functioning as highly significant to their teaching (Kinsella, 2000). Teachers found that knowing whether an autistic spectrum disorder or the existence of an additional cognitive disability is the primary barrier to learning, is highly relevant in configuring the class, the curriculum to be followed, and teaching procedures utilised. The Report of the Task Force on Autism (2001) also acknowledged the need to identify intellectual levels of functioning and primary barriers to learning.

Selective Mutism

Children who are selectively mute may, like children with a diagnosis of autism, be socially withdrawn and unresponsive, but they generally do not show the specific language difficulties associated with autism, except for delay and articulation problems (Kolvin & Fundudis, 1981). They have spontaneous, creative play, carry on conversations and have appropriate attachments and typical verbal social interactions with family members, and show reciprocity with some people (Rutter et al., 1994).

Rett's Syndrome

Rett's syndrome is a behaviourally defined syndrome that is quite different from autistic spectrum disorders in course and is found almost exclusively in girls. Although some toddlers and preschool children with Rett's syndrome may show some autistic features, there are many behavioural differences between autistic spectrum disorder and Rett's syndrome. Development appears typical in the first year, but then head growth begins to decelerate, and over the next two years there is a loss of intentional hand skills, and verbal communication (if it was already established). The child with Rett's syndrome presents with social impairment, stereotypical hand-wringing or hand-clapping, and midline movements (often these movements are accompanied by wetting of the hands with saliva). Hyperventilation is also quite common. Gait and truncal ataxia usually appears between 1 and 4 years. As the child with Rett's Syndrome grows older, motor and intellectual difficulties increase. In contrast to this, they may become more socially aware and social interests may increase within the limits of a profound intellectual disability. The differential diagnosis is not usually difficult after the age of 4 or 5 years (Olsson & Rett, 1987, 1990).

Schizophrenia

The research literature in recent years has expanded greatly with respect to the onset of schizophrenia in young children. Unlike an autistic spectrum disorder, the onset of schizophrenia before the age of seven is extremely rare. As the child approaches adolescence, frequency increases so that a differential diagnosis is much more plausible (Burd & Kerbeshian, 1987).

Guidelines for differential diagnosis of schizophrenia

- A high familial loading of mental illness indicates a strong possibility of a schizophrenic rather than an autistic spectrum disorder process.
- Children and adolescents with schizophrenia typically function within the borderline to low average ranges of cognitive functioning on standard intelligence tests with nonverbal strengths.
- Children with childhood schizophrenia tend to have a history of relatively typical development prior to the onset of the condition.
- Children with schizophrenia are able to understand nonverbal social cues and the pragmatics of communication with careful, sensitive interview techniques.

Depression

Depression is one of the most common co-existing conditions observed in children and adolescents with an autistic spectrum disorder. This is particularly true for children who are higher functioning and have an awareness of their difficulties. The psychologist's task necessitates a careful history of development and detailed descriptions of current presentation. Children with mood disorders are not typically characterised by a history of developmental delays; they often enjoy a period of relatively typical functioning preceding the onset of symptoms. Examination of family history generally reveals a greater preponderance of mood disorders that is not typically present in families of children with an autistic spectrum disorder.

Anxiety disorders

Anxiety

Children and adolescents with anxiety disorders can display extreme social withdrawal, sleep problems, agitation, and worry that interfere with social and academic functioning. The primary distinction for the psychologist is between the extreme shyness and social avoidance displayed by children with anxiety disorders and the primary impairments in social functioning observed in children with an autistic spectrum disorder. Differences must be highlighted between impaired capacity for interaction and avoidance, or lack of skills. In addition, children with primary anxiety disorders rarely display the developmental delays or ritualistic behaviours characteristic of an autistic spectrum disorder.

Obsessive-Compulsive Disorder

The differentiation of an autistic spectrum disorder from obsessive-compulsive disorder seems to vary in complexity with developmental level. Several features of obsessive-compulsive disorder have considerable overlap with behaviours seen in autistic spectrum disorder. A fine line often separates obsessions and compulsions from stereotypic movements and restricted/repetitive interests and activities. Other characteristics of an autistic spectrum disorder are not present.

Behavioural disorders

Attention Deficit Hyperactivity Disorder

It is often suggested that children with an autistic spectrum disorder presenting in the school years have been misdiagnosed with Attention Deficit Hyperactivity Disorder. Children with an autistic spectrum disorder, particularly those with more ability, often display reduced attention and focus, which may be due to lack of motivation or comprehension. Differentiation can be particularly challenging in those children with a moderate to severe intellectual disability who may display excessive motor activity. A careful developmental and school history is important for distinguishing between these disorders, as intervention can be misguided. Particular attention should be paid to the quality of attention in novel and familiar situations and descriptions of typical social breakdowns with peers.

Guidelines for differential diagnosis of Attention Deficit Hyperactivity Disorder

- Children with a diagnosis of Attention Deficit Hyperactivity Disorder often have the capacity for social relationships but may isolate peers due to their behaviours.
- Children with a diagnosis of Attention Deficit Hyperactivity Disorder are able to display typical social and communicative behaviours in structured and, often times, novel settings.
- Children with an autistic spectrum disorder often appear inattentive and unfocused in situations where the demands of a task are not clear or are beyond their capabilities.
- Many children with an autistic spectrum disorder display excessive motor activity, which may take the form of jumping, spinning, or flapping. This is more likely to occur when their time is not structured and when they are not actively engaged.
- Both groups of children typically demonstrate sensory difficulties, but those with an autistic spectrum disorder typically have one or more highly unusual behaviours in this area.

Oppositional Defiant Disorder/Conduct Disorder

It is not uncommon for school age children, especially adolescents, to present for an initial evaluation of an autistic spectrum disorder with a history of aggressive behaviour and social defiance. This group of children may have received several diagnostic labels in the past as their behaviours and responses to intervention have been puzzling to schools and clinicians and stressful for parents. A diagnosis of Asperger's syndrome or PDD-NOS offers a way to characterise such behaviour as poor understanding of social rules and restricted interests. However, careful evaluation and review may indicate the existence of substantial differences for these children.

Guidelines for differential diagnosis of Oppositional Defiant and Conduct Disorders:

- Individuals with an autistic spectrum disorder can display verbal and/or physically aggressive behaviour when they perceive intrusion into their personal space and activities or in response to something in the environment that they experience as aversive (e.g. noise). Aggressive behaviour may also be a product of difficulties with communication and frustration with situational demands. However, children with an autistic spectrum disorder rarely exhibit malicious intent, or aggressive behaviour to another person with explicit intent to cause harm.
- A lack of understanding of social rules and conventions by children and adolescents with an autistic spectrum disorder may also lead to inappropriate social encounters with strangers in the form of inappropriate verbalisations.
- When children and adolescents with an autistic spectrum disorder become aggressive or engage in antisocial behaviours, they make little attempt to hide or disguise their actions. Behaviours must be contrasted with behaviours wherein the adolescent or child has taken steps to conceal or lie or otherwise indicates knowledge that the behaviour is socially unacceptable.

Tourette's Disorder

Although Tourette's disorder can co-occur with an autistic spectrum disorder, the data regarding higher occurrences are inconclusive. The description of vocal and motor tics in children with an autistic spectrum disorder may be qualitatively distinct from those found in Tourette's, i.e. the form of vocalisations will differ between these groups, with those with Tourette's being out of context (e.g. impulsive cursing, guttural noises). Expertise is required to differentiate vocal and motor tics from the stereotyped, repetitive, and/or self-stimulatory behaviours and language anomalies found in an autistic spectrum disorder.

Schizoid Personality Disorder

Wolff and Barlow (1980) described a group of children that bore some resemblance to Asperger's syndrome and used the clinical term schizoid personality disorder. Through follow-up studies, Wolff (2000) identified marked differences between clinical presentation and outcome of schizoid personality disorder in children and Asperger's syndrome as defined by current diagnostic criteria. Children with a schizoid personality disorder were identified by Wolff (2000) as presenting with the following characteristics:

- Less socially impaired than children now defined as having Asperger's Syndrome.
- Lack of empathy with emotional detachment.
- Increased sensitivity with paranoid ideas.
- Unusual fantasy life.
- High rate of conduct disorders.
- Better outcome in adulthood.
- Higher rates of schizotypal personality and schizophrenia development in adulthood.
- Higher familial loading of schizophrenia spectrum disorders.

Disorders outside the DSM-IV/ICD-10 nomenclature

Some clinical presentations of impaired reciprocal social interaction may seem "autistic-like" but do not meet criteria for ASD (Scheeringa, 2001). Children with these characteristics are often referred because of disruptive behaviours and social interaction deficits, but they are inadequately described by current diagnostic categories. These categories can be problematic for children, families, and clinicians in that they describe features that are invariably subsumed in other diagnostic categories (i.e. semantic-pragmatic disorder) and rarely present in isolation, or they describe a broad range of possible symptom configurations (i.e. multi-system developmental disorder). Whether they serve a clinically useful purpose for determining appropriate services and intervention strategies has yet to be established. Perhaps those terms should be used only for descriptive clarification purposes for those children with atypical or unusual presentations, which do not meet DSM-IV/ICD-10 criteria. Other such terms include Nonverbal Learning Disability and Multiple Complex Developmental Disorder.

Psychological deprivation

Children who have been exposed to severe neglect show delays in language development, may be withdrawn and unresponsive, and often have ritualistic or stereotyped behaviours. Studies of children who have experienced institutional neglect and/or deprivation suggest that many exhibited a number of clearly autistic features. However, children whose development has been affected by cruelty and neglect do not have marked difficulties of comprehension, nor do they exhibit the broader communication problems associated with an autistic spectrum disorder. This group of children tend to make appropriate use of what language they have to engage in reciprocal social interaction, and their behaviour and communication tend to normalise gradually when they are placed in a more typical social environment.

Diagnosing coexisting conditions

The complex, multifaceted nature of an autistic spectrum disorder and the fact that no two people with an autistic spectrum disorder are exactly alike in the type and severity of their presentation presents a challenge to psychologists in determining the most appropriate diagnosis. Some children and adolescents with an autistic spectrum disorder have cognitive and mental health challenges in addition to an autistic spectrum disorder. These coexisting challenges can be secondary to the experience of having an autistic spectrum disorder or conditions that coexist with an autistic spectrum disorder.

Other conditions that can complicate the diagnosis of an autistic spectrum disorder include seizure disorders and bipolar disorder.

Specific learning difficulties can be observed in children with an autistic spectrum disorder and may present additional challenges in the school environment. The following specific learning difficulties are noted as co-existing in the literature.

- Dysgraphia
- Dyscalculia
- Dyslexia
- Hyperlexia

Diagnostic formulation

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

The psychologist may face greater challenges when engaged in the evaluation process with school-aged children, than with younger children. The possibility of an alternative explanation for the child's presentation is greater for this older age group and should be considered. Therefore, broad clinical expertise in other disorders of childhood, in addition to specific expertise in autistic spectrum disorder, is necessary.

2.1.12 Feedback to parents

Psychologists should explore their own personal feelings, beliefs, attitudes, and expectations around the autistic conditions to ensure their own process does not impede their professional abilities and responsibilities when faced with delivering an autistic spectrum disorder diagnosis.

One of the most important aspects of the diagnostic assessment process is communicating findings to the family. The purpose of the feedback meeting is for parents and families to gain a comprehensive understanding of their child's diagnoses, developmental profile, and recommendations for future assessment and intervention. When parents are comfortable and confident in the assessment process they are more likely to assimilate the information presented. Emphasis should be placed upon giving parents and caregivers diagnostic information as soon as possible to avoid needless anxiety and stress.

The research literature reveals that when parents first seek answers for their child's differences, the primary feelings reported are confusion, worry, isolation, and fear. In a study of Irish parents, Coulthard (2001) found that at the time of diagnosis itself, parents retrospectively recalled the following reactions: shock, (74% of interviewees), sadness (33%), relief (25%), anger, acceptance (24%), confusion, depression, helpless (18%), and denial (17%). Teehee, Honan and Hevey (2008) found relatively low levels of perceived stress in the family, results that are inconsistent with previous literature. This may be culture bound, i.e. reflect the strong family structure in Irish society as findings further indicated that the quality of support from outside of the family and the amount of information accessed, a key stress reducer, pointed to insufficient levels in both areas, highlighting inadequacies in support systems and resources available generally in Ireland to date. Teehee, Honan, and Hevey (2008) identified the following sources of stress reported by Irish parents of children with an autistic spectrum disorder:

- Challenging behaviour
- Concern for the future
- Education
- Attaining support and services

In contrast, they ranked the following as sources of support

- Schools/School Services/School Staff
- Both informal (family and spouse) and formal supports (e.g. respite) were regarded as important.

The international literature suggests that when giving feedback to parents the following strategies should be considered:

- Listen and hear – What are the parents saying?
- Acknowledge their concerns.
- Query their perception – what are their thoughts, their feelings?
- Validate their feelings and thoughts.
- Empathise.

It is considered good practice for the psychologist to explain at the beginning of the meeting what will happen in the meeting, the sequence and who will be involved. The psychologist should name the assessment instruments that were utilised, as well as the diagnostic criteria used in making the diagnosis.

The following are recommended when giving feedback of an autistic spectrum disorder:

- Have both parents attend the feedback meeting.
- Have a maximum of two professionals in the room, one of whom should be a psychologist with competencies in the provision of childhood diagnoses and counselling or the provision of emotional support.
- Start at the scheduled time.
- Block out sufficient time for the session, including time for parents to ask questions.
- Have the child present in the room or building.
- Have appropriate toys for the child available.
- Have tissues in close reach (Understand and be prepared for a possible strong emotional response).
- Ask parents what they thought of the assessment process and to give you their impressions of what the findings will be.
- Use parents' language and incorporate their comments when delivering the diagnosis

During the feedback process, always use correct terminology. Non-diagnostic terms, e.g. 'high functioning', 'autistic features' should not be used. Clarity is very important so that parents have accurate information and are not placed in the position that they still are not certain. Research indicates that parents prefer clear labels of autism/autistic disorder or Asperger's syndrome, even though it is difficult for them to hear it at the time. Depending on the knowledge base of the parent/guardian, you may need to clearly and accurately explain the nature of the autistic spectrum disorder and if present, the accompanying intellectual disability. Although the focus may be on the diagnosis it is important to give feedback on all aspects of the assessment process including adaptive and academic skills. Set the stage for building a therapeutic relationship and alliance between the parents and professionals for the future.

When delivering the diagnosis, the psychologist should:

- Refer to the diagnostic criteria followed (i.e. DSM or ICD)
- Be honest, but also allow parents hope by presenting a balanced view.
- Be prepared for questions about the future as well as current concerns.
- Be wary of making any definitive long-term predictions and be honest but sensitive in this regard.
- Freely state if you do not know something.
- Provide information for parents to take home, e.g. an information leaflet, some references, both on the disorder and on interventions, but do not overload them at this stage. Providing sufficient specific information may improve their access to support services, facilitating their ability to cope.
- Advise them to write down any questions they think of over the next couple of weeks for later follow-up.
- Outline to the parents/guardians what happens next and when.
- Advise parents/guardians of sources of support, especially family-to-family/parent-to-parent supports.
- Do not expect parents/guardians to remember all that they have been told.
- Provide a follow-up appointment with the professional who gave the diagnosis
- Premature support can undermine the esteem of the parent, and if overdue, it may be inadequate to facilitate coping (Pierce, Sarason and Sarason, 1996), Lack of information may leave parents with a sense of hopelessness (Randall & Parker, 1999).
- Ensure self-care/support following the feedback meeting

Psychologists should be mindful that parents might be reluctant to use the word autism/Asperger's syndrome at the time of the diagnosis. However, as long as they are engaging in the assessment process and open to intervention recommendations, they are acknowledging the diagnosis.

Sometimes repeated delivery of the diagnosis over time and possibly from multiple professionals may be required before a parent/guardian can acknowledge the diagnosis of an autistic spectrum disorder. Their pace through this difficult process must be respected.

Be clear around the diagnosis. Randall and Parker (1999) reported that 70% of parents reported the "search" for a diagnosis of an ASD was difficult, including "much of what was said to them was platitudinous and sometimes demeaning". Howlin and Moore (1997) found that only 7.8% of parents received a diagnosis at first consult, 55% were referred on, 35% were told not to worry or no problem-come back if problem gets worse (50% in Randall and Parker's 1999 study), and 63% attended at least 3 different professionals before being given a diagnosis. These figures are striking when considering that 95% of Howlin and Moore's (1997) sample of parents who had very early concerns around their child's abnormal development, eventually did receive an autistic spectrum disorder diagnosis. Be aware that the length of time between parents' first expressed concern and the time of actual diagnosis results in increasing degrees.

Follow up on the initial feedback meeting

It is recommended that the psychologist make contact with the parents/guardians, either to follow up on information discussed during the feedback meeting, to offer support, or to check in to see how they are doing.

The purpose of the follow up appointment is to clarify their understanding and to discuss expectations and intervention planning. The long-term outcome for each individual with an autistic spectrum disorder will vary with a number of factors, including intelligence and social support (Siegel, 1996). The psychologist must be able to guide parents in realistic expectations for their child based upon the evaluation findings, empirical literature, and clinical experience. This may entail a pragmatic discussion of cognitive limitations as an indicator of outcome and functional achievement. After the age of five, cognitive findings are more stable and become increasingly so as children approach adolescence and adulthood (Sattler, 2001).

It is important that findings are translated into a cohesive view of the child with comprehensible, detailed, concrete and realistic recommendations provided (Kin et al., 2000). Realistic expectations for progress within a given amount of time should be provided for parents and families.

Parents and caregivers need concrete information regarding what can be done for their child. The team should be able to provide information regarding documented efficacy of different approaches as well as applicability to the particular child.

Appendix
Diagnostic criteria

DSM IV-TR Diagnostic criteria for the Pervasive Developmental Disorders

Diagnostic criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

1. qualitative impairment in social interaction, as manifested by at least two of the following:

a. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

b. failure to develop peer relationships appropriate to developmental level

c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

d. lack of social or emotional reciprocity

2. qualitative impairments in communication as manifested by at least one of the following:

a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

c. stereotyped and repetitive use of language or idiosyncratic language

d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3. restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

b. apparently inflexible adherence to specific, non-functional routines or rituals

c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)

d. persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairment in the use of multiple nonverbal behaviours such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction

2. failure to develop peer relationships appropriate to developmental level

3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)

4. lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus

2. apparently inflexible adherence to specific, non-functional routines or rituals

3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

4. persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

ICD 10 Diagnostic criteria for Pervasive Developmental Disorders

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" - presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or sub-threshold symptomantology, or all of these.

This group of disorders is characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations, although they may vary in degree. In most cases, development is abnormal from infancy and, with only a few exceptions, the conditions become manifest during the first 5 years of life. It is usual, but not invariable, for there to be some degree of general cognitive impairment but the disorders are defined in terms of behaviour that is deviant in relation to mental age (whether the individual is retarded or not). There is some disagreement on the subdivision of this overall group of pervasive developmental disorders.

In some cases the disorders are associated with, and presumably due to, some medical condition, of which infantile spasms, congenital rubella, tuberous sclerosis, cerebral lipidosis, and the fragile X chromosome anomaly are among the most common. However, the disorder should be diagnosed on the basis of the behavioural features, irrespective of the presence or absence of any associated medical conditions; any such associated condition must, nevertheless, be separately coded. If mental retardation is present, it is important that it too should be separately coded, under F70-F79, because it is not a universal feature of the pervasive developmental disorders.

F84.0 Childhood autism

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.

Diagnostic guidelines

Usually there is no prior period of unequivocally normal development but, if there is, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio-emotional cues, as shown by a lack of responses to other people's emotions and/or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity. Similarly, qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid

meaning in spoken communication.

The condition is also characterized by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood particularly, there may be specific attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines in rituals of a non-functional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypy's; a specific interest in non-functional elements of objects (such as their smell or feel) is common; and there may be a resistance to changes in routine or in details of the personal environment (such as the movement of ornaments or furniture in the family home).

In addition to these specific diagnostic features, it is frequent for children with autism to show a range of other non-specific problems such as fear/phobias, sleeping and eating disturbances, temper tantrums, and aggression. Self-injury (e.g. by wrist-biting) is fairly common, especially when there is associated severe mental retardation. Most individuals with autism lack spontaneity, initiative, and creativity in the organization of their leisure time and have difficulty applying conceptualizations in decision-making in work (even when the tasks themselves are well within their capacity). The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialization, communication, and interest patterns. Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made, but the syndrome can be diagnosed in all age groups.

All levels of IQ can occur in association with autism, but there is significant mental retardation in some three-quarters of cases.

Includes:

- autistic disorder
- infantile autism
- infantile psychosis
- Kanner's syndrome

Differential diagnosis. Apart from the other varieties of pervasive developmental disorder it is important to consider: specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F79) with some associated emotional/behavioural disorder; schizophrenia (F20.-) of unusually early onset; and Rett's syndrome (F84.2).

Excludes:

- autistic psychopathy (F84.5)

F84.1 Atypical autism

A pervasive developmental disorder that differs from autism in terms either of age of onset or of failure to fulfil all three sets of diagnostic criteria. Thus, abnormal and/or impaired development becomes manifest for the first time only after age 3 years; and/or there are insufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restrictive, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals whose very low level of functioning provides little scope for exhibition of the specific deviant behaviours required for the diagnosis of autism; it also occurs in individuals with a severe specific developmental disorder of receptive language. Atypical autism thus constitutes a meaningfully separate condition from autism.

Includes:

- atypical childhood psychosis
- mental retardation with autistic features

F84.5 Asperger's Syndrome

A disorder of uncertain nosological validity, characterized by the same kind of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. The disorder differs from autism primarily in that there is no general delay or retardation in language or in cognitive development. Most individuals are of normal general intelligence but it is common for them to be markedly clumsy; the condition occurs predominantly in boys (in a ratio of about eight boys to one girl). It seems highly likely that at least some cases represent mild varieties of autism, but it is uncertain whether or not that is so for all. There is a strong tendency for the abnormalities to persist into adolescence and adult life and it seems that they represent individual characteristics that are not greatly affected by environmental influences. Psychotic episodes occasionally occur in early adult life.

Diagnostic guidelines

Diagnosis is based on the combination of a lack of any clinically significant general delay in language or cognitive development plus, as with autism, the presence of qualitative deficiencies in reciprocal social interaction and restricted, repetitive, stereotyped patterns of behaviour, interests, and activities. There may or may not be problems in communication similar to those associated with autism, but significant language retardation would rule out the diagnosis.

Includes:

- autistic psychopathy
- schizoid disorder of childhood

Excludes:

- anankastic personality disorder (F60.5)
- attachment disorders of childhood (F94.1, F94.2)
- obsessive-compulsive disorder (F42.-)
- schizotypal disorder (F21)
- simple schizophrenia (F20.6)

F84.9 Pervasive developmental disorder, unspecified

This is a residual diagnostic category that should be used for disorders which fit the general description for pervasive developmental disorders but in which a lack of adequate information, or contradictory findings, means that the criteria for any of the other F84 codes cannot be met.

Diagnostic criteria for Asperger's Disorder Gilberg (1989)

A. Severe impairment in reciprocal social interaction as manifested by at least two of the following four:

(1). Inability to interact with peers.

(2). Lack of desire to interact with peers.

(3). Lack of appreciation of social cues.

(4). Socially and emotionally inappropriate behaviour.

B. All-absorbing narrow interest, as manifested by at least one of the following three:

(1). Exclusion of other activities.

(2). Repetitive adherence.

(3). More rote than meaning.

C Repetitive Routines

(1)

(2)

C. Speech and language problems, as manifested by at least three of the following five:

(1). Delayed development of language.

(2). Superficially perfect expressive language.

(3). Formal, pedantic language.

(4). Odd prosody, peculiar voice characteristics.

(5). Impairment of comprehension, including misinterpretations of literal/implied meanings.

D. Non-verbal communication problems, as manifested by at least one of the following five:

(1). Limited use of gestures.

(2). Clumsy/gauche body language.

(3). Limited facial expression.

(4). Inappropriate expression.

(5). Peculiar, stiff gaze.

E. Motor clumsiness, as documented by poor performance on neurodevelopmental examination.

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