The Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview

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ABSTRACT   The development of the Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI) is described. Preliminary data from a clinical study suggest that inter-rater reliability and test–retest stability may be excellent, with kappas exceeding 0.90 in both instances. The validity appears to be relatively good. No attempt was made in the present study to validate the instrument as regards the distinction between Asperger syndrome and high-functioning autism.

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Introduction

There is a strong need for clinically useful diagnostic tools in everyday clinical practice with patients suffering from disorders in the autism spectrum. Several good instruments exist for the diagnosis of low- and middle-functioning cases. While there are a few reasonably well validated screening tools (Berument et al., 1999; Ehlers and Gillberg, 1993; Ehlers et al., 1997; Siegel, 1996) that can be used with high-functioning individuals attending child and adolescent services, we are not aware of any diagnostic interviews *specifically* tailored for this group. This goes particularly for those with Asperger syndrome (American Psychiatric Association, 1994; Gillberg and Gillberg, 1989; Szatmari et al., 1989; Wing, 1981; World Health Organization, 1993). Such cases usually do not fit too well either with the

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Childhood Autism Rating Scale (CARS: Nordin et al., 1998; Schopler et al., 1988) or the Autism Diagnostic Interview–Revised (ADI–R: Cox et al., 1999; Lord et al., 1994). Screening instruments are important in locating possible cases, but they cannot replace diagnostic interviews which serve as adjuncts to the in-depth clinical evaluation. It is unclear at the present stage whether or not Asperger syndrome can be reliably separated from high-functioning or 'atypical' autism (Ehlers et al., 1997; Leekam et al., 2000; Manjiviona and Prior, 1999).

In this paper we describe the Asperger Syndrome (and high-functioning autism) Diagnostic Interview and its development. Preliminary clinical data for inter-rater reliability, test–retest stability and diagnostic validity are presented.

Methods

Development of the ASDI
The interview (see Appendix) was developed over several years on the basis of experience with several hundred patients with high-functioning autism spectrum disorders, including a large number with 'autistic psychopathy', 'schizoid personality disorder' and 'Asperger syndrome'. The first and second author compiled diagnostic criteria for Asperger syndrome for the First International Conference on Asperger Syndrome which was held in London in 1988. These criteria were published a year later (Gillberg and Gillberg, 1989) and were followed by more detailed operationalization and a diagnostic algorithm in 1991. The set of operationalized criteria was based on Asperger's first case histories (Asperger, 1944) and was gradually reworked so as to make them all fit the criteria (Gillberg, 1991). The six criteria comprise 20 different items (four 'social', three 'interests', two 'routines', five 'verbal and speech', five 'non-verbal communication' and one 'motor'; see Appendix).

The diagnostic interview was then developed and designed to cover the 20 items. It is a relatively highly structured interview intended for use with informants who know the individual very well – and who knew them well when they were children. The first version comprised three possible ratings for each item (1 = does not apply, 2 = applies sometimes or somewhat, 3 = definitely applies) and was used to select typical cases for research (into which would be recruited only those with ratings of 3 for diagnostic items). In a later version, mostly used in clinical practice, ratings 2 and 3 were collapsed, so that only two ratings per item were possible, 0 and 1 (see below). The whole interview is included in the Appendix.

The interview was not tailored for use in conjunction with making

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diagnoses of Asperger's disorder according to the DSM-IV or Asperger syndrome according to the ICD-10. These two manuals use virtually identical diagnostic criteria. However, it has been shown that Asperger's own cases did not meet criteria for Asperger's disorder according to the DSM-IV (Miller and Ozonoff, 1997). There is also (a) a strict exclusion criterion for cases with any kind of significant language, cognitive or social deviance in the first 3 years of life, and (b) a requirement for only three symptoms (two social and one behavioural) for a positive diagnosis to be made. Finally, almost every single individual fitting Asperger's description of 'his' disorder (not just his own cases) fails to meet ICD-10 criteria for Asperger syndrome (Leekam et al., 2000; Manjiviona and Prior, 1999). This seems to us to make the DSM-IV/ICD-10 criteria clinically (and theoretically) highly problematic. First, if Asperger's cases fail to meet criteria for 'his' disorder, there is obviously a problem. Second, if only cases developing normally in the first 3 years of life can be considered for diagnosis, there are major problems in that, clinically, such children are extremely rare – if they exist at all – and Asperger did not make such a requirement for diagnosis. Finally, if only three symptoms are required for diagnosis (and some of them are certainly not pathognomonic for autism spectrum disorders), this runs counter to the notion that Asperger syndrome is a severe disorder. For all these reasons, the ASDI was designed in order to tap cases with a clinically significant disorder that would be as closely similar to those described by Hans Asperger as possible.

Participants

Twenty individuals (15 male, 5 female), aged 6 through 55 years, comprised the target group for the inter-rater reliability study. Of these, 13 were patients with a neuropsychiatric disorder and the remaining 7 were 'normal comparison' cases (see below). All of these plus 4 further individuals (3 male, 1 female), aged 10 through 13 years, all of whom had neuropsychiatric disorders, were also included in the study of test–retest stability. Thus altogether 24 individuals (18 male, 6 female), 17 with a neuropsychiatric disorder and 7 comparison cases, were included in the study.

Diagnostic process

All diagnoses were made only after comprehensive neuropsychiatric workup. All those with a psychiatric diagnosis had been examined by at least two independent neuropsychiatrists or by a neuropsychiatrist and a neuropsychologist with special expertise in the field of autism spectrum disorders. Cases with Asperger syndrome were only accepted into the study if both experts had arrived at independent diagnoses of that disorder. The majority of individuals comprising the target group (15 out of 20: see below) had

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also received a neuropsychological test, usually one of the Wechsler scales. Diagnostic decisions were made using the DSM-IV in a systematic way. Individuals with Asperger syndrome, however, usually could not be convincingly shown to meet the criterion of early normal development. In addition to meeting the limited number of symptom criteria required for a DSM-IV diagnosis of Asperger syndrome, they also met full Gillberg and Gillberg (1989) and Szatmari (Szatmari et al., 1989) criteria for the disorder. The ASDI had not been used in the work-up of any of the target group cases.

Inter-rater reliability

Two experienced neuropsychiatrists used the ASDI when interviewing first-degree relatives of 20 individuals who either had a main diagnosis of Asperger syndrome (n = 8), atypical autism (n = 2), obsessive-compulsive disorder (n = 2), multiple personality disorders (n = 1), or had served as normal comparison cases in studies performed at the Department of Child Neuropsychiatry (n = 7). The relative – usually one of the parents – was interviewed, and the ASDI completed by one of the neuropsychiatrists with the other investigator participating as an observer. Independent, blind ASDI ratings were made by the observer. The neuropsychiatrists took turns interviewing and performed 10 interviews each. Both relative and interviewer were blind to diagnosis and whether or not the individual belonged in the normal comparison sample.

The ASDI version with only two scoring alternatives (1 = applies to some degree or very much, 0 = does not apply) for each of the 20 areas was used.

Intra-rater reliability

One of the neuropsychiatrists again completed the ASDI, 10–15 months after the first interview, for all 20 individuals contributing to the inter-rater reliability study (see above), plus four further cases with Asperger syndrome (n =2), atypical autism (n = 1) and ADHD (n = 1). The first-degree relatives interviewed were identical to those interviewed the year before. The neuropsychiatrist performing the follow-up interview was still blind to the individual's group status. However (usually for ethical reasons) this was not always true of the relative, who, in the three 'new' cases with autism spectrum problems, had some, often considerable, knowledge about the overall diagnostic considerations made at the time of the original assessment. However, this relative knew the 'exact' diagnosis in only one case (a boy aged 10 years who had been diagnosed as having Asperger syndrome), and was asked before the interview not to reveal any information about diagnostic considerations made by experts in the field.

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Results

Inter-rater reliability

Complete agreement across the two raters (20 paired ratings for 20 different items) was achieved in 383 out of 400 ratings (96 percent complete agreement). This corresponded to a kappa of 0.91.

For 10 of the 20 cases, there was complete agreement of ratings on all 20 items. For the remaining 10, there was complete agreement on 19 items in six cases, 18 items in two cases, and 17 items in two cases.

There was complete agreement for two of the four social items (1.1 and 2.5), one of the narrow interest items (2.7), and four of the five non-verbal communication items (5.16, 5.17, 5.18 and 5.19).

There was disagreement concerning 5.15 limited gestures (three cases); uninterested in peers, 2.5 narrow interest exclusive, and 4.10 delayed language (two cases each); and 1.4 socially inappropriate, 2.6 narrow interest repetitive, 3.8 routines self, 3.9 routines others, 4.11 over perfect language, 4.12 pedantic language, 4.13 odd prosody, and 4.14 comprehension (one case each).

Intra-rater reliability

There was complete agreement on 465 of 480 ratings (97 percent). This corresponded to a kappa of 0.92. There was complete test–retest stability for all 20 items in 16 cases, for 19 items in five cases, for 18 items in two cases, and for 14 items in one case. There were disagreements on items 4.13, 5.17, 5.19 and 6.20 in two instances each. The other seven instances of disagreement concerned seven different items.

Validity

All the 13 individuals with a clinical diagnosis of Asperger syndrome or atypical autism met five or six of the six algorithm criteria for an Asperger syndrome diagnosis according to the ASDI on at least one rating, out of two (n = 4) or three (n = 20) possible ratings. Twelve of these 13 individuals met five or six criteria on all ratings.

Of the remaining 11 individuals only one met five criteria (and he did so on all three ratings). He had been given a clinical diagnosis of multiple personality disorder.

Both the boys with OCD (14 and 16 years of age) met the criterion level for routines and rituals (3.8 and 3.9). One of these in addition met the non-verbal communication and motor problem criteria (5.18 and 6.20).

One 10-year-old 'normal' girl met the criterion for routines and rituals (3.9), but showed no other symptoms of Asperger syndrome.

One young 'normal' man aged 20 years met the social criterion (1.3 and 1.4) and the non-verbal communication problem criterion (5.17) for a diagnosis of Asperger syndrome.

Discussion

This study reports preliminary reliability and validity data for a new structured interview (the ASDI) for establishing the diagnosis of Asperger syndrome. The study sample was small, and so all conclusions need to be tempered by this knowledge. There is clearly a need for more studies on considerably larger samples.

Based on these preliminary findings, the ASDI appears to have very good inter-rater and test–retest reliability.

Validity also seems to be acceptable, which is to be expected given that the ASDI covers all the diagnostic items for Asperger syndrome in the Gillberg criteria list, and clinically derived ('gold standard') diagnoses were based on those criteria (but not on information derived at interview with the ASDI). The only individual 'misclassified' as belonging in the Asperger syndrome or atypical autism group was a young man clinically diagnosed as having 'multiple personality disorder'. Some individuals with high-functioning autism spectrum disorders cope with their social impairments by copying other people's behaviour, or, even adopting their identity. It is possible that the case referred to in this paper actually had some marked underlying autistic features, and that he should perhaps not be regarded as a false-positive case.

The ASDI was completed by neuropsychiatrists blind to diagnostic information, which should vouch for results not being skewed by prior knowledge about the individuals in the study's target group. It needs to be pointed out that the interview separated Asperger syndrome quite well from other psychiatric/personality disorders and from normality, but that the issue of its ability to distinguish between Asperger syndrome and autism has not been addressed. It seems likely that some of the Asperger syndrome cases in the present study would also meet criteria for autistic disorder according to the DSM-IV (Leekam et al., 2000). Even though not formally included as a criterion for the Asperger syndrome diagnosis in the Gillberg list, it now seems that it would be reasonable to have an explicit exclusion criterion for autistic disorder. However, this need not necessarily go in the direction of excluding Asperger syndrome when criteria for autistic disorder are met, as is the case in the ICD-10 and DSM-IV. It is interesting to note that Hans Asperger's own cases do not meet DSM-IV criteria for Asperger syndrome (Miller and Ozonoff, 1997). However, they do meet criteria for DSM-IV autistic disorder. 'Asperger syndrome', judging from

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our long clinical experience in the field, is a term much preferred over 'autism' by parents of affected individuals, and was introduced largely as a response to parental reactions. It is often difficult for parents of high-functioning individuals in the autism spectrum to accept a primary diagnosis of autistic disorder. The term 'Asperger syndrome' appears to them much more 'neutral' (particularly in that it does not carry the many mythical connotations of the term 'autism') and therefore acceptable. Maybe 'Asperger syndrome' should be the preferred diagnostic label for all cases meeting only Asperger syndrome criteria and for cases meeting both Asperger syndrome and autistic disorder criteria, but who score above IQ 70 on an age-appropriate IQ test.

The informants were either parents or siblings. This means that the results obtained can only be taken to support the use of the ASDI in clinical practice using first-degree relatives as primary informants. It is possible that many of the items (except, probably, the item referring to language delay) can be reliably checked by other informants who have known the individual for a long time. However, separate studies have to be performed before the ASDI can be recommended for use with informants other than parents and siblings.

In summary, given the promising preliminary findings of good inter- and intra-rater reliability for the ASDI, it would seem reasonable to recommend the interview for preliminary diagnostic decisions in clinical settings whenever adolescents and young adults are suspected of suffering from a high-functioning autism spectrum disorder, including Asperger syndrome. It should not be used as the only and 'final' instrument, but rather as an aid in guiding the direction of further in-depth clinical examination.

Appendix

The Asperger Syndrome Diagnostic Interview (ASDI)

Name of individual rated:

Date of birth:

Age at examination:

Name of informant and relation to individual rated:

Rater:

Date of interview:

This interview is intended for clinicians well acquainted with Asperger syndrome and other disorders in the autism spectrum, even though there is no requirement for 'expertise'. The interview is investigator-based, i.e. the rater is expected to score each item only after determining that he/she has elicited sufficient information for a qualified rating to be made. This means that all the 20 areas listed need to be probed in some detail. Examples of behaviours should be provided by the informant before a

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rating is assigned. The questions should, if at all possible, be read to the informant as they are written, but may occasionally be slightly reworded in order to assure that the relevant area of functioning has been adequately covered.

Scores: 0 = does not apply, 1 = applies to some degree or very much

Area 1: severe impairments in reciprocal social interaction (extreme egocentricity)

1 Does he/she exhibit considerable difficulties interacting with peers?   0   1
   If so, in what way?
2 Does he/she exhibit a low degree of concern or a seeming lack of
   interest in making friends or interacting with peers?   0   1
   If so, please specify:
3 Does he/she have problems appreciating social cues, i.e. does he/she
   fail tonote changes in the social conversation/interaction or to take
   account of such changes in his/her ongoing interaction with other
   people?   0   1
   If so, please describe:
4 Does he/she exhibit socially or emotionally inappropriate behaviours?   0   1
   If so, in what way(s)?

(Two or more scores of 1 = criterion met)

Area 2: all absorbing narrow interest pattern(s)

5 Is there a pattern of interest or a specific interest which takes up so
   much of his/her time that time for other activities is clearly restricted?   0   1
   If there is, please comment:
6 Is there a repetitive quality to his/her interest patterns or specific interest?   0   1
   If so, please specify:
7 Are his/her interest patterns based more on rote memory than on true
   meaning?   0   1

(One or more scores of 1 = criterion met)

Area 3: imposition of routines, rituals and interests

8 Does he/she try to introduce and impose routines, rituals or
   interests on himself/herself in such a way as to produce problems
   for himself?   0   1
   If so, in what way?
9 Does he/she try to introduce and impose routines, rituals or interests
   on himself/herself in such a way as to produce problems for others?   0   1
   If so, please describe:

(One or more scores of 1 = criterion met)

Area 4: speech and language peculiarities

10 Was his/her language development delayed?   0   1
   If so, please comment:
11 Is his/her language 'superficially perfect' regardless of whether or
   not there are comprehension problems or other speech and language
   problems?   0   1
   If so, please comment:

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12 Is his/her language formal, pedantic or 'overly adult'?   0   1
    If so, please describe:
13 Is there any characteristic about his/her voice (pitch, volume, quality,
    intonation, word stress, 'prosody' etc.) which you find peculiar or
    unusual?   0   1
    If so, in what way?
14 Are there any comprehension problems (including
    misinterpretations of literal/implied meanings)?   0   1
    If so, what kind of problems?
(*Three or more scores of 1 = criterion met*)

Area 5: non-verbal communication problems
15 Does he/she make limited use of gestures?   0   1
    If so, please comment:
16 Is his/her body language awkward, gauche, clumsy, strange or unusual? 0   1
    If so, please comment:
17 Are his/her facial expressions limited to a rather small repertoire?   0   1
    If so, please describe:
18 Is his/her general expression (including facial) sometimes inappropriate? 0 1
    If so, please describe:
19 Is his/her gaze stiff, strange, peculiar, abnormal or odd?   0   1
    If so, please characterize:
(*One or more scores of 1 = criterion met*)

Area 6: motor clumsiness
20 Has he/she been noted to perform poorly on neurodevelopmental
    examinations either in the past or in connection with the present
    interview?   0   1
    If so, please comment:
(*Score of 1 = criterion met*)

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