Diagnostic Interviews

Definition

The diagnostic interview (DI) is a central component of the process (diagnostic process) in which, for a variety of reasons ranging from research to the development of an intervention plan, a decision is made as to whether there is sufficient evidence in an individual's symptoms and signs for a diagnosis of one or more of the "disorder(s)" defined by the criteria of the internationally agreed diagnostic classification systems (ICD 10 Research Diagnostic Guidelines).

Historical Background

Following the initial descriptions of autism and Asperger syndrome in the 1940s, agreed criteria emerged slowly and a number of checklists were developed which matched a list of symptomatology against the criteria evolving at the time in ICD 9 (1975) and DSM-II (1980) (DSM-III) focusing on accounts of observable behavior, particularly in childhood, notably the E-2 (Rimland diagnostic form for behavior disturbed children (E-2)) and the Autism Behavior Checklist (ABC).

In the 1960s, in both America and the UK, the search for greater consistency and precision in psychiatric diagnosis led to the development of standardized diagnostic interviews; initially schedules of standard questions, these became elaborated into a more clinical interview that encouraged the interviewer to cross-examine the patient until the nature of the symptom was clear (Wing, Birley, Cooper, Graham, & Isaacs, 1967). A decade later, the same model led to the development of more systematic interviews in making the diagnosis of autism (as the prototypical disorder of the pervasive developmental disorders). Wing and Gould produced the Handicaps, Behavior, and Skills Schedule (HBSS) which they later refined into the DISCO (Diagnostic Interview for Social and Communication Disorder), Schopler and Reichler developed the Childhood Autism Rating Scale (CARS), and Le Couteur, Rutter, and Lord produced the Autism Diagnostic Interview (later revised to become the ADI-R) (Autism Diagnostic Interview-Revised). These standardized diagnostic instruments consist of a semi-structured interview (based on the agreed symptom criteria) with an adult informant and became recognized as the "gold standard" in terms of their comprehensiveness and reliability in obtaining a clinical history.

The identification of a broader spectrum of autism disorders (ASD), going beyond the original narrow definition for autism, led to an extension of the content and form of diagnostic instruments (diagnostic instruments in autistic spectrum disorders). Examples of these are the Asperger Syndrome Diagnostic Interview (ASDI) and the Autism Questionnaire (AQ) (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001) for Asperger syndrome, the Pervasive Developmental Disorder in Mental Retardation Scale (PDD-MRS) for people with intellectual disability (Kraijer & de Bildt, 2005), and the Diagnostic Interview Guide for use in general adult psychiatry (Royal College of Psychiatrists, 2011). The recognition of autistic traits (broader autism phenotype - broader spectrum prevalence) in the relatives of people with ASD has led to the development of a variety of interviews to identify these behavioral and personality characteristics. In many of these, the emphasis was on obtaining material from informants (usually parents) about behavior. At the end of the 1990s, the Autism Diagnostic Observation Schedule (ADOS) was developed as play and activities based assessment with the individual; this assessment is described as a series of tightly defined, detailed observations which systematically elicits autistic symptomatology.

In the last decade, the number of instruments, their use varying from screening to diagnosis, has reflected the mounting interest in ASD while increased public awareness and the Internet have fostered the growth of self-rating scales and the demand for confirmatory diagnostic interviews.

Current Knowledge

The Content of the Interview

There are a variety of models for conducting a diagnostic interview. The structure or framework for the DI is important, but there is no compelling evidence to recommend any particular interview format for any specific situation. For all DIs (irrespective of the interview format), the underlying context is the social engagement and interaction between the interviewer and the interviewee. The interviewing skills and attitudes of the interviewer (clinician or researcher) affect the
quality of the interaction which in turn influences the success of the information-gathering process. The responses of the interviewee (also affected by many factors including whether they already know the interviewer; the interviewee is in fact the subject of the interview; his or her intellectual and communicative ability, motivation, emotional state, and so on) and the setting can also influence the outcome and "success" of the diagnostic interview (DI).

For an ASD DI to be successful, it should include:

1. An account of the individual's current concerns - the symptoms that have brought to interview at this particular time, and their development.
2. A systematic survey of the symptomatology associated with ASD, especially that which is directly related to the diagnostic criteria. This review should also include consideration of other behavioral features known to be commonly associated with ASD such as motor coordination, sensory and perceptual symptoms, and feeding and bowel problems. It should include any other behavioral problems recognizing that these can occur in response to a variety of potentially modifiable influences from toothache to a change in school timetable or work colleagues.
3. The wider setting - the individual's everyday life and activities, relationships, and accomplishments.
4. The structure of their family and any history of developmental or psychiatric disorder.
5. An account of the individual's development and their acquisition of skills, not just in infancy and early childhood but subsequently, through school and after, to give a detailed "developmental history."
6. An account of any other anomaly, past or present, including developmental, psychiatric, or medical disorder as well as of any other adversity including deprivation or substance abuse.

The diagnostic interview will usually be complimented by a direct examination of the individual together with the collation of background reports (including direct observation in other settings). All these sources of information will contribute to the accuracy and value of the final, "best estimate," diagnostic conclusions which, in turn, will inform the multiagency needs and skills-based management plan.

While the DI and examination are conceptually distinct, in practice, there is likely to be a substantial overlap. For example, when an individual is being interviewed and asked to provide their own account, the clinician will be considering the way the account is being given, the quality and content of the social interaction, and other individual characteristics (such as their appearance, behavior, and communication). These factors will inevitably affect the interaction between the clinician and the interviewee, thus shaping the course of the DI.

How the DI progresses is at least in part dependent on the skills of the interviewer, their training and expertise, as well as the setting of the interview and the expectations of the interviewees. All these different aspects can foster a "dialogue" between clinician and individual. Instruments may be combined for history-taking and observation although, in the end, the distinction between them is one of emphasis rather than clear-cut. For example, while the framework of observational ratings is central to the ADOS, it is also a semi-structured interview, fostering a "dialogue" between clinician/researcher and individual.

The Format of the Diagnostic Interview

The interview may take a range of formats depending on its purpose:

1. Unstructured. The structure is not immediately apparent, but the interviewer's clinical impression (or equivalent) determines the content, purpose, and conclusions of the interview. Its primary purpose may be a different one with diagnosis as a secondary consideration. Such an assessment depends greatly on the individual clinician's experience and for this reason it is likely to be difficult to understand or replicate.
2. Semi-structured/interviewer based. The interview, usually based on a predetermined diagnostic framework, has well-defined symptoms to be explored. Usually conducted in a conversational style, it takes the form of required questions supplemented by additional, optional, open-ended prompts as necessary until there is sufficient information for the trained interviewer to make the coding judgment for each item and section of the interview. The precision and clarity with which symptoms and their codings are defined contribute to the quality of the instrument.
3. Structured/respondent based. The trained interviewer closely follows a defined format without deviation; the interview may be restricted further by giving the interviewee a limited number of choices. The interviewer is not called upon to make any clinical judgment (and, indeed, may not know very much about ASD and other diagnoses to complete the interview).
The result is a relatively high inter-rater reliability and an interview that lends itself to being turned into a self-completion questionnaire. This can be administered as a preinterview contribution or completed in a computerized format (e.g., the E-2) or Autism Spectrum Quotient (AQ) questionnaires. Increasingly for some individuals, access to this type of questionnaire has been a staging post in their journey to diagnosis.

4. A composite. The interview incorporates the material from a preinterview questionnaire. Not only is this a more effective use of time, substantially shortening the DI, but many individuals are more comfortable (and therefore more open) with the impersonality of a self-completion questionnaire. Examples of DIs that use information-collected preinterview include the Developmental, Dimensional and Diagnostic Interview (3Di) (Skuse et al., 2004) and the Adult Asperger Assessment (AAA) (Baron-Cohen, Wheelwright, Robinson, & Woodbury-Smith, 2005).

It is difficult to define the point at which the self-completion or screening checklist becomes a more formal diagnostic instrument as this will depend on the skill, experience, and intent of those employing it.

The more standardized the format for gathering and organizing the information, the greater the consistency in the data collected and the diagnoses arrived at by clinicians and researchers of varied experience and views from different centers. However, validity is lost with increasing rigidity that limits the clinician's skills. Using agreed diagnostic systems permits prospective research as well as making clinical material available for retrospective review for service and academic analysis. The whole process is more transparent and can be taught to trainees.

The style of interview has to be appropriate to the task in hand: a structured interview, with its very narrow, specific remit, will be used for screening or surveys and as such can be administered by a technician. The semi-structured interview provides the framework for a more in-depth assessment when a definitive research or clinical diagnosis is required, and usually includes one or more summary algorithms to identify ASD using prespecified thresholds. However, the protean presentations of ASD and the demands of clinical work mean that, in the end, even the best of these instruments does not remove the need for knowledge and experience of ASD in coming to a clinical diagnosis which will inform the diagnostic formulation and intervention planning. There are cases, notably in adulthood, of individuals with less clear-cut presentations where it is difficult to discern the pattern of symptoms. It is here that the experience of working with a wide variety of people across the variations of age, ability, gender, ethnicity, and comorbidity makes it possible to appreciate the characteristic impairments of ASD. In addition, within the assessment team, there needs to be sufficient knowledge and experience to recognize the developmental and psychiatric disorders that are associated with ASD (notably attention deficit hyperactivity disorder (ADHD) (Attention Deficit/Hyperactivity Disorder) and developmental coordination disorder (Developmental Coordination Disorder)).

The choice to use a particular diagnostic instrument will be informed by both the purpose of the interview and the features of the instrument. For example, the ADI-R (Autism Diagnostic Interview-Revised) provides a summary lifetime diagnosis, using information about early childhood and the current state for key aspects of behavior and development and a record of the particular unusual behaviors (such as restricted, repetitive mannerisms and stereotyped behaviors) relevant to the decision as to whether a pervasive developmental disorder is present or not. The frequency and intensity of each symptom is carefully graded to give a detailed quantified picture of key components. The DISCO (Diagnostic Interview for Social and Communication Disorders) takes a rather broader approach to arrive at a systematic description that allows the identification of other developmental disorders. The 3Di is a computer-based interview designed to focus on current functioning to assess autistic traits, social impairments, and comorbidities in children of normal ability. The content of the interview generates a structured report with summary algorithms of symptom profiles for autism and common non-autistic comorbidities. By contrast, the CARS (Childhood Autism Rating Scale) draws on observation as well as interview. The format is much less structured, guiding the interviewer through the relevant domains rather than individual symptoms, requiring the researcher/clinician to reach the coding decisions through the integration of information from subject and informants.

Most structured instruments (Diagnostic Instruments in Autistic Spectrum Disorders) have been designed for a specific group, often defined by age (e.g., childhood) or ability. This means that the phrasing or materials might not be suitable for a different "client" group when adaptation of materials and further reliability and validity studies would be required.

As adults come forward for diagnosis, including, for example, those with a severe intellectual disability, women of normal ability, and individuals with preexisting psychiatric and personality disorder diagnoses, the challenge will be how best to tailor the format and content of the DI appropriately. A particular issue is the necessity of a developmental history to confirm that the evidence of delayed or deviant development dates back to early childhood. This becomes particularly important in adulthood should there be a need to differentiate ASD from other disorders (such as schizophrenia (
Schizophrenia) or dissociative or obsessive-compulsive personality disorders (Obsessive-Compulsive Disorder (OCD))). However, it is this client group who may experience real difficulty finding an informant with accurate knowledge about their early development.

Whatever the format of the DI, training in its use is required. This applies especially to standardized instruments where the more structured the interview, the more straightforward the training. While it may be obtained by attending a specific training course, receiving in-house individual tuition or by using a self-taught program, it should include a check that the clinician/researcher has achieved an acceptable standard of accuracy and reliability. This should be followed by regular opportunities to maintain consistency and reliability over time. Undertaking the rating of standardized videos or attending joint sessions with colleagues can help to maintain best practice in administration of the procedure as well as reliability between colleagues and different centers. However, because this is time consuming and may be seen as additional pressure on scarce resources, it is all too easily overlooked.

Implementing the Interview

A DI may take place as a single event in one setting or be spread across several sessions and settings. The venue (clinic, specialist center, home, school, or other setting) will depend on the needs of individual, their family/carers, clinicians, and services. For example, a very anxious individual or a disabled relative may only be accessible in the home; a clinic may be the only place to get the opinion of a busy clinician or be the best place to provide the structured, calm setting needed to see someone at their best. It may be necessary to go to a school, nursery, or workplace to see the context and thereby understand what is happening there. Observation in different settings may allow some distinction to be made between what behavior is pervasive and what is situational and in response to a particular environment or set of circumstances.

The DI must provide sufficient information for the interviewer to decide whether the symptoms and signs are:

1. Sufficiently pronounced in their intensity or frequency to cross the threshold that separates so-called normal variation for developmental progress and personal characteristics from disorder: threshold that may well vary according to the problems experienced by the individual, the context and situation, and the "demands" and expectations placed upon them. For example, a young child who has managed well in their home with a supportive family may find it much more difficult to settle into an educational setting such as preschool if they do not have sufficiently flexible communication, social, and play skills to join in with other young children or cope with new and unexpected changes in routine in an otherwise familiar environment. Similarly, an adult who may have learnt to manage effectively in a particular workplace may still find that he/she is less able to succeed in social and more personal relationships. For the diagnostic interview to be successful, the interviewer needs to understand the importance of gathering information about the development of the individual's behavior in different settings and contexts over time. This may well require (especially for children and young people but often also for adults) information from other informants who know the subject well in different settings.

2. Sufficiently close to the currently agreed criteria (ICD 10 Research Diagnostic Guidelines) for a diagnosis of ASD or might be explained better by some other disorder. ASD is a neurodevelopmental disorder defined by its onset in early childhood, something that may be difficult to confirm in later adulthood.

The interview therefore has to enable the clinician to distinguish the signals of ASD against the background noise of other complicating disorders, particularly other developmental and psychiatric disorders such as intellectual disability, specific speech and language disorders, attention deficit hyperactivity disorder (ADHD), epilepsy, and/or mental health problems such as anxiety or obsessive-compulsive disorder.

The interview must also be appropriate to its immediate purpose: for example, the requirements for inclusion in a research study might be more stringent than those needed as the basis for clinical or administrative planning. A diagnosis may be sought for many reasons, ranging from inclusion in a research study, accessing specific treatments and interventions, eligibility for particular education provision, achieving financial benefits, and gaining family understanding, through to assisting a court to understand the needs of the individual. Most importantly, it can give the individual a more complete understanding of their profile of strengths and impairments. The diagnostic interview also provides a benchmark against which subsequent progress can be measured. It has to be tuned accordingly to meet these specific requirements.

The results of the interview should be valid (i.e., that others would agree with the diagnostic conclusions) and reliable (they would be the same if repeated, whether by the same clinician or others). The process needs to be acceptable to all,
sufficiently transparent to be understood, and sufficiently valued for the results to be useful. Most instruments require the interviewer to make judgments and ascribe a numerical score to each item in the assessment. These scores may be collated to symptom and/or domain scores which can be summarized within one or more instrument-specific diagnostic algorithms. For a number of instruments, usually those that have been developed for research, the reliability and validity of the algorithm scores and instrument-specific diagnostic thresholds have been tested and refined in different populations. However, it is important to recognize that a diagnostic algorithm score derived from a particular instrument may contribute to, but is not equivalent to, a clinical diagnosis. This is something broader, using an internationally agreed diagnostic classification system, based on information gathered from several sources, and often involving professionals working in different agencies to provide a multidisciplinary assessment. This information, in turn, will contribute to, but is not sufficient for, the development of a (needs and skills based) management plan. The DI, which may include the use of a structured instrument, is an opportunity for the development of a dialogue between the interviewer, the individual, and the family/carer and, as such, can also provide the context for sharing the outcome of the multiagency assessment.

One of the great values of using an agreed diagnostic classification system is that it facilitates the possibility of successful research collaborations between clinical academic centers as well as making clinical material available for service review and analysis. With greater transparency between services and centers, there is an increase in research capacity, the ability to share new knowledge and significant developments, and opportunities for trainees to learn from the experiences of their colleagues.

Future Directions

A number of standardized instruments are now in routine use for the DI providing both a valuable framework for the history as well as being the basis for the start of a therapeutic relationship with individuals and families. Many are time consuming and resource intense, and this has to be balanced against the benefits of the therapeutic alliance and detailed descriptions of behavior. While the use of a detailed DI may well be appropriate for a behavioral syndrome that has such a variety of presentations and underlying disorders, there is great pressure to develop briefer processes and ever greater consistency while maintaining validity.

The value of increasingly sophisticated online questionnaires as an adjunct to the DI needs to be investigated. New measures will also be required as further understanding of the complexity of the autism spectrum across the lifespan become available. However, the development of new instruments is a complex and expensive task. An equally important challenge is to investigate the best ways of getting reliable information from different sources to complement the DI and enable the clinician/researcher, referred individual, and family achieve a valid diagnostic formulation that in turn leads to an accurate needs- and skills-based management plan.

The recognition of autistic traits in the families of people with autism has led to the development of instruments to identify these which, once sufficiently validated and standardized, will be published.

In spite of many claims and much research, there is still no reliable laboratory test for ASD. However, even if such a test were ever developed, its results would complement the diagnostic interview rather than replace it, a model seen in other medical conditions as, for example, the use of genetic testing in the clinical diagnosis of Down or Rett syndrome.

With increasing awareness and understanding of ASD, there is likely to be greater emphasis on the identification of the strengths, skills, needs, and impairments of the individual and their family, as well as on diagnosis, to inform a dimensional diagnosis and profile across different domains of functioning. Although separate assessments may be needed to measure different aspects of an individual's functioning (e.g., social responsiveness, language and flexibility, anomalies in sensory sensitivity and motor coordination), this information will always need to collated alongside the findings of a DI to achieve a diagnostic formulation. At least for the foreseeable future, classification systems used in clinical and research practice, together with other social and resource pressures, will continue to require a categorical diagnosis of ASD.

See Also

Anecdotal Observation
Asperger Syndrome Diagnostic Interview
Autism Behavior Checklist
Autism Diagnostic Interview-Revised
Autism Diagnostic Observation Schedule
Broader Autism Phenotype
Childhood Autism Rating Scale
Developmental Coordination Disorder
Diagnostic Interview for Social and Communication Disorders
Diagnostic Process
Dimensional Versus Categorical Classification
DISCO
DSM-III
Dyspraxia
Evaluation of Sensory Processing
ICD 10 Research Diagnostic Guidelines
Informal Assessment
Obsessive-Compulsive Disorder (OCD)
Psychotic Disorder
Schizophrenia
Sensory Impairment in Autism
Theory of Mind

References and Readings
