Instrumental Assessment

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Contents

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Learning Objectives

The issues discussed in this chapter do no focus on a specific area of mental health, but they are pivotal to the whole field of mental health assessment, certainly in people with ID and LF-ASD, but probably also across the whole population. The basic questions we are asking is 'how should we be doing assessment, and who should be collecting the information?'. In many service contexts, it is assumed that psychiatrists and psychologists will work mainly on the basis of their clinical knowledge and expertise, while other staff are the ones likely to use structured instruments. For patients with ID and LF-ASD, the problems of language often lead to a great emphasis on the completion of structured assessments by informants. Very often, a patient will receive multiple assessments by a variety of health professionals, but then someone has the task of synthesizing this into a meaningful formulation. Many questions arise by this scenario. For example, should all the clinicians use structured methods? What type of assessments should be used? How should we bring all this information together? Should we actually be structuring the whole assessment process, including the final formulation? This chapter's main aim is to offer some practical and theoretical guidance on the incorporation of structured assessments into clinical services working with people who have ID and/or LF-ASD.

8.1 Introduction

The broad aims of this chapter are to offer some guidance on the use of structured assessment methods with people who have intellectual disability (ID) and/or low-functioning autism spectrum disorder (LF-ASD), and to give a review of the main tools available as well as some examples of their use.

In order to consider the potential contribution of using structured methods, it is necessary to look closely at the fundamental issues relating to the whole process of mental health assessment. There are many reasons why someone might wish to employ a structured method, and there are likely to be differing viewpoints of the potential users of such assessments. An informed decision about the use of, and choice of, structured assessment inevitably needs a close look at some difficult questions; the answers to which may not always be clear cut. If structured assessments are to be used in a clinical service, this may be to measure changes in response to treatment, or as part of the diagnostic process. In either case, it is desirable to examine the quality of information they generate, how this information will be used, whether it aids communication between different professionals and how much confidence clinicians have in the information. Potentially, the adoption of structured methods can significantly improve the overall quality of assessment and monitoring, but in order to do this there needs to be agreement among the clinical team about what methods are to be used and when to use them.

8.2 Why Use a Structured Assessment?

These are some of the numerous reasons why one may wish to use a structured assessment:

- To improve the quality of one's own clinical assessment
- To draw on the knowledge of other staff who may not have a formal training in psychiatry psychology, but who knows the patient better than yourself
- To free up expert clinical time by getting lesser-paid people to collect information
- To get the patient's own perspective by asking them to complete their own answers
- To enable a common assessment framework across professionals within the service
- To enable the use of a potentially 'free' resource, that is, the person themselves and their family

Many clinical services employ questionnaires and checklists to collect part of their information. However, the choice and selection of assessments are not always done with a coher-

ent assessment policy in mind. Broadly speaking, psychiatrists and psychologists are much less likely to use structured methods than other staff, as they rely too much and too often on clinical impression. Whether it is desirable for the senior clinicians also to include structure in their assessments is something we will also consider.

8.3 Structured Assessments and Developmental Level

The fact that many people with ID have very poor language, or no language at all, sometimes leads to the suggestion that structured assessments are more important with people who have ID than with the general population. Certainly, if the person has very poor language, we become highly reliant on third-party reports, and these reports are often aided by checklists and questionnaires. If the person is of a developmental level sufficient to have good language, and their disorder does not lead to a lack of insight, then assessment relies largely on what the patient says. This does, however, lead to a fundamental question: why do we often use structured methods to collect information from third parties, but rarely structure the clinical interview itself? Interviewing is a highly volatile process, open to influence by numerous factors that will be discussed shortly.

8.4 Fundamental Dimensions of Structured Assessments

There are a great many published assessments, making it sometimes difficult to decide which ones to employ. The following notes hopefully give some guidance on the main differences between them.

8.4.1 Different Models of Mental Disorder

This is probably the most fundamental dimension that determines how we assess, and what structured tools we might employ in the process. Within this dimension, one of the biggest problems that faces any designer of assessments is how to reconcile psychiatric and behavioural approaches.

8.4.1.1 The Psychiatric Approach

Over the hundred or so years that psychiatry has existed as a discipline, it has been observed that symptoms cluster together. For example, a person who is depressed is also highly likely to have lost interest in things, feel low in energy and perhaps feel hopeless about the future. Through these observations, the classic diagnostic constellations or syndromes have gradually been identified and clarified (see ► Chap. 5). One of the main focuses of psychiatric assessment is, thus, to collect the information necessary to decide on which of these clusters the person's symptoms belong.

8.4.1.2 The Behavioural Approach

A behavioural analysis does not seek to identify pathologies, but rather looks at the relationships between antecedent conditions and behavioural consequences. This is often done with the aim of changing antecedent conditions to reduce undesirable behaviours. Behavioural assessments may, therefore, simply collect information about various behaviours, and may additionally provide some form of scoring which is often based on factor analysis. Behavioural analysis and interventions are widely used when working with people who have ID.

8.4.1.3 Reconciling These Two Approaches

What is the difference between a 'symptom' and a 'behaviour'? In a sense, all symptoms manifest of course in observed behaviours. However, the behaviours identified in behavioural analysis are usually ones that are considered of major concern in their own right; for example, aggression or self-injury. In comparison, symptoms like depressed mood or anxiety are probably better described as *indicators* of a general condition that may be manifested in many other ways beyond the actual listed symptoms in ICD-10 or DSM-5.

A real problem of reconciling behavioural and psychiatric approaches arises with symptoms/behaviours that can be viewed in radically different ways, for example:

- Worry about being abandoned
- Chaotic relationships
- Impulsiveness
- Self-harm
- Splitting
- Anger

From a behavioural/ecological perspective, such symptoms may be regarded primarily as a response to long-term history, including early childhood development, bonding and attachment, and ecological factors. These are, however, also symptoms for *borderline personality disorder*. These two different views require two different assessment approaches. If one is seeking primarily to determine whether the person meets the criteria for this disorder, then the chosen assessment tool would need to focus closely on severity and duration of the symptoms. If one is wishing to conduct a behavioural analysis, then the relationship between the behaviours and the person's wider ecology would need to be assessed. Each of these approaches would require a different assessment tool.

For people with ID/LF-ASD, a particular issue arises in relation to *challenging behaviour*. Challenging behaviours are highly prevalent in people with ID (see ▶ Chaps. 5 and 7), and it is notable that the term 'challenging' has been introduced in preference to the term 'problem behaviours'. What is the difference between a 'challenging behaviour' and a 'problem behaviour'? Many people with ID, particularly those with most severe cognitive impairment, can exhibit aggressive or destructive behaviours, but probably do not fully understand their impact or social significance. The term 'challenging' implies that the person with ID is not really in control of these behaviours, and that we, as service providers, have a responsibility to help the person. Diagnoses such as conduct disorder and personality disorder, on the other hand, imply that the person *does* understand the consequences of his/her action but nevertheless does it (or even enjoys doing it in the knowledge that it will cause upset to others).

The more severe the level of ID, the more difficult it becomes to judge whether the person understands the consequences of the action. While these judgements are very difficult, structured approaches to assessment can be helpful if they present the assessor with a formal framework that includes points to consider and appropriate choices to make. For instance, the Child and Adolescent Psychiatric Assessment Schedule (ChA-PAS) [1] section on Conduct Disorder offers the following four rating categories: *Staying out against parental/carer wishes*

1. Not present/not rated
2. [P] Has frequently stayed out at night against parental/carer wishes, but at least one of the following applies:
   (i) Does not fully understand the effect it has on others
   (ii) Behaviour appears to be driven by frustration, or an emotional reaction to life circumstances
   (iii) Gets genuinely upset by the resulting distress to carers
3. [P] Has frequently stayed out, and is more or less indifferent to the distress it causes to carers, despite being aware of the effect it is having
4. [P] Stays out repeatedly against carers' wishes, fully understands the effect it has, but responds in at least one of the following ways:
   (i) Takes pleasure in the upset it causes
   (ii) Makes up glib excuses that are clearly lies
   (iii) Expresses glib feelings of guilt and remorse that are clearly not genuine

Only levels 2 and 3 contribute to a diagnosis of conduct disorder. Level 1 scores as zero because of the extenuating circumstances that indicate it is not a symptom of this disorder.

8.4.1.4 The Statistical Approach

Some assessments do not start with the ICD-10 [2] or DSM-5 [3] rules, but instead take a purely statistical approach to the identification

problems. For instance, the Developmental Behaviour Checklist [4] was developed by starting with a very large number of behaviours, which were then subsequently rendered down into a number of factors using factor analysis. The advantage of such an approach is that it achieves a very wide coverage of all the behaviours of concern. The shortcoming is that the resulting factors may not be easy to interpret in terms of clinical practice or interventions.

8.5 The Coverage of the Assessment

This to some extent relates to the discussion of models of mental illness in the section above. However, it is important to distinguish broad-spectrum assessments from those that are for a specific area, such as autism, depression, and ADHD. When choosing a specific area assessment, it is important to consider whether the use of this tool might bias the final outcome in favour of the area covered. For instance, consider a clinic that specializes in ADHD, and routinely uses an ADHD-specific tool to collect the data. Unless adequate safeguards are in place, there is a risk that other potential explanations for person's problems, for example, bipolar disorder, will receive less consideration than they merit.

> Potentially, the adoption of structured assessment methods can significantly improve the overall quality of clinical assessment and monitoring, especially with reference to patients with lower levels of communication or cognitive ability. The selection of structured assessments, both informant based and self-rated, needs careful matching to the characteristics of the patient. If the assessment has a specific focus, for example, ADHD, it is important to consider whether that choice might bias the outcome in favour of the area covered.

8.5.1 The Level of Structure, Detail, Precision, Guidance and Analysis

The relationships between these five characteristics mentioned in the title are probably the most central aspects that distinguish between the various assessments that are available. To think about the interaction between these aspects, it is important to start with the desired outcome of using structured tools. There are actually many ways in which their use can be of benefit [5], but here we will consider four of the main reasons:

1. To screen for potential cases who will subsequently receive an in-depth assessment
2. To predict what an expert clinician would probably conclude if a full assessment was undertaken
3. To collect information that will form part of a subsequent diagnosis or formulation
4. To make actual diagnoses or formulations

Reasons 1 and 2 above have in common that no expert clinician is involved in the process: they both imply that the person competing it may not have a background in psychopathology. Screening tools are often highly structured, with little precision needed in categorizing the answers, and little guidance given beyond the wordings of the items themselves. Analysis takes the form of a built-in scoring system that renders an answer to the question, 'should this person receive a more in-depth assessment?'. Screening tools do, to some extent, predict what an expert would conclude, but research studies wishing to make more accurate predictions will often use a more complex assessment, probably requiring training. In either case, the psychometric properties of the assessment are very important. In the case of screening, the most important psychometric aspect is probably that no genuine cases are missed. To make more accurate predictions of expert opinion, the assessment must be reliable and valid. This is discussed in more detail shortly.

A very different form of structure is present in ICD-10 [2] and DSM-5 [3]. They are themselves structured assessments, in that they provide rules to determine what symptoms are associated with the various diagnoses, along with information relating to time course, etc. They have a high degree of general clinical guidance and distil the knowledge of a great many experts about, for example, the relationships between physical and mental disorders. They are, however, *low* in precision because they give relatively little guidance on how to identify different manifestations of the same symptom. This is particularly important in relation to people with ID because they very often show symptoms in a different way, particularly if their level of ID is severe. ICD-10 [2] and DSM-5 [3] also have low precision in terms of guidance on symptom severity. How severe should a symptom be before one includes it as present; how would a mild example of the symptom and a severe example differ?

The clinical interview is often one of the principal avenue by which these diagnostic decisions are made. Clinical interviewing is frequently conducted without a formal structure. In this next section, we will consider whether structuring such interviews could be beneficial.

Screening for cases to undergo in-depth assessment, predicting clinician conclusion, collecting information of clinical utility and making actual diagnoses or formulations represent the four main ways in which the use of assessment tools can be of benefit. It is important to know from the beginning the desired result of using structured instruments during the assessment, considering that the clinical interview is often the principal avenue by which the diagnostic decisions are made.

8.6 Clinical Interviewing

Interviewing patients and informants is one of the primary methods for collecting information on mental status. Generally speaking, nothing can replace the validity of the patient's own report; for which reason, clinical interviewing is often used to make pivotal decisions. Surprisingly, training in the process of interviewing is often neglected, and the use of structured formats is rarely employed. To illustrate the advantages of a structured approach, consider one of the core symptoms of depression, low mood itself. If a patient is showing evidence of this symptom, how should we decide if the symptom is strong enough to say it is present?

The Present State Examination, the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) [6] and the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) [7] assessments all take the view that it should be possible to rate a symptom as present, but that it is *below the threshold for clinical significance*. This is a very important point. Many of us experience symptoms of low mood or anxiety from time to time, but mostly these would not be considered pathological. The provision of a subclinical category also flags up the presence of a symptom that might subsequently become more significant in the future.

In order for the assessment of symptom severity to be workable and reliable, some rules need to be applied to each symptom. The Present State Examination relied mainly on use of the terms: *not present, mild, moderate* and *severe* as the rating categories. The limitation of this is that the terms mean different things to different people. The PAS-ADD [7] system has developed and evolved over about 25 years at the time this was written. Much of that evolution was in terms of the refinement of severity definitions. The current definitions for low mood (in the Mini PAS-ADD [8] Version 3) are as follows:

Item 7: Depressed mood

1. Not present or not rated.
2. Episodes of depressed mood occur most days, but [P] is sometimes more cheerful or can very often be cheered up by the intervention of others.
3. Depressed mood is a significant problem on most days, but attempts to cheer [P] will sometimes be successful.
4. The depressed mood is persistent and unresponsive to attempts to cheer [P] up.

When scoring, rating level 1 actually produces a score of 0. In other words, depressed mood is there, but it is considered to be sub-clinical.

The other dimension of structured interviewing is the wording of questions. It has been observed by one of us (SM) that it is easy to get involved in a lengthy discussion of a symptom with the patient or informant, yet still not have the information to tie down the symptom severity. The evolution of the PAS-ADD system has also resulted in question forms that are designed to determine symptom presence and severity as efficiently as possible. The question for low mood in the Mini PAS-ADD Version 3 (interview for informants) is as follows:

- **Item 7**
  - How is [P]'s mood?
  - Is [P] happy?
  - Does [P] feel depressed/low?
  - How does s/he show it? What does s/he do?
- **If Evidence of Depression:**
  - Is there anything you can do to cheer him/ her up when s/he is like this?
  - During {rating period}, has [P] been depressed all the time?
- **If not all the time:**
  - Are there some days when s/he is happier? Or just periods during the day?

Note how the wordings enable each of the severity categories to be evaluated.

8.7 Interviewing People with ID

A sizeable proportion of people with ID *can* respond meaningfully to a clinical interview, but the questions need to be carefully formulated and sensitively asked. Using the PAS-ADD 10, Patel, Goldberg and Moss [9] showed the following ratings of interview adequacy by the interviewer (who was an experienced psychiatrist).

Rating of subject's account of symptoms	Adequacy (%)
Subject responds adequately	36
Account somewhat inadequate but interview can proceed	13
Account seriously inadequate but interview proceeds in an attempt to rate some subjective responses	12
Impossible to continue with interview	38

Thus, nearly half the adults who were interviewed were able to give a useful contribution to a clinical interview. Given the unique validity of the patient's own report, it is highly desirable that any way of improving the quality of patient interviewing in people with ID is worth the effort. Good structured assessments, designed specifically for people with ID, can help in this respect, partly because they can provide ways of asking questions that have been tried and tested over a period of time. Also, the structure provides a way of helping the interviewer probe other possible problem areas that may not be clearly visible at the beginning, and hence, may have been omitted.

Training in the process of interviewing is often inappropriately neglected, and the use of structured formats is rarely employed.

Specifically designed, structured assessment can improve the quality of patient interviewing in people with ID/LF-ASD for many reasons, including the provision of questions that have been tried and tested over time and the possibility to probe problem areas that could be omitted.

8.8 Psychometric Properties

It is not proposed to have a lengthy discussion of psychometric issues here; they are well described elsewhere [10]. However, it might be helpful to offer some thoughts regarding the interpretation of psychometric data.

8.8.1 Reliability

First of all, nobody doubts the desirability of making assessments reliably. Any assessment, structured or otherwise, that produces different results from the same case presentation is of questionable value. The problem is that reliability in structured assessments is a result of various factors:

- The number of items
- The number of rating categories
- The tightness with which the ratings are defined
- The amount of training the users receive
- Whether the user retain their training or drift away from it

In choosing a structured assessment on grounds of reliability, an appropriate balance must, therefore, be struck. Does it cover the information you need, at the level of detail you require? If training is required, are you able to ensure the users get adequately trained? Using an assessment designed for trained raters which is being used by *non-trained* raters runs the risk of producing results that look highly informative but may simply be wrong.

8.8.2 Validity

The issue of validity is far more complex than that of reliability, and there is one main reason why this is the case. Consider the process of diagnosis in physical medicine. Over hundreds of years, the relationships between symptoms and their causes have become more and more precisely clarified. The validity of a physical diagnosis can be measured by the extent to which it correctly identifies the pathology. Nowadays, thousands of different procedures are used to identify pathologies, and the diagnosis is made in the light of that evidence. In comparison, we are making diagnoses of mental health problems, usually *in the absence* of clear evidence of physical causes. This lack of relationship between cause and effect makes the process of diagnosis fundamentally different. Diagnoses of mental health are, generally speaking, clinical judgements. This does not mean they have no utility, but it is vital to recognize this fact when considering issues of validity.

How, then, do we estimate the validity of a mental health assessment? Bearing in mind that ICD-10 and DSM-5 are themselves structured assessments, how could we estimate their validity? One answer would be that they are of course valid because they represent the distilled knowledge of clinical experts, collected over a very long period of time. As such, they can be considered a *gold standard*. However, the fact that they are not precise means that the validity of an assessment as measured by its conformity to ICD-10 or DSM-5 is not a very useful measure. A more common gold standard is that of clinical expertise. How far does the assessment predict what a clinical expert would say about the case? This approach has merit, but the limitation is that people completing the assessments are often in a very different situation from the clinical experts whose opinion is sought. The clinical expert may indeed have greater expertise to sift and judge clinical material, but may not be in such a good position to actually know the client.

Linking the knowledge and expertise of the various stakeholders in the case, from families through to all the health and social service professionals who may be involved, is something that structured assessments can potentially enhance.

8.8.3 Factor Structure

From a psychometric perspective, structured assessments are often considered to be better if their underlying factor structure shows a meaningful relationship to the concepts being

measured. For instance, items purporting to assess obsessive compulsive disorder should be closely correlated together, and less correlated with items in another section, such as depression. To some extent this is undoubtedly true. The person who is low in mood is often someone who has lost energy, feels hopeless for the future, etc. However, there is another consideration to be borne in mind. Both DSM-5 and ICD-10 take a *polydiagnostic* approach to diagnosis, that is, two different people can have widely differing symptoms yet still receive the same diagnosis. Also, it is well recognized that some symptoms overlap different diagnostic constellations, for instance, there are clear overlaps between ADHD and bipolar disorder, and between obsessive compulsive disorder and autism.

These considerations mean that an assessment that conforms very closely to the rules of ICD-10 and DSM-5, and is, hence, clinically very useful, may actually perform more poorly in terms of factor structure than an assessment that was designed primarily using a statistical approach.

> In choosing a structured assessment, an appropriate balance must be struck between psychometric properties (reliability, validity and factor structure) and contextual clinical utility. When necessary, users have to be adequately trained.

8.9 Some Examples of Structured Assessments

This chapter does not attempt a comprehensive review of structured assessments. Rather, we offer a sample of these, showing how they differ in terms of the various fundamental dimensions:

- Area covered
- Sophistication of rating and questioning
- The method of collecting information
- The primary aim of the assessment
- Who are the likely users

8.9.1 Fully Diagnostic Interview

8.9.1.1 The PAS-ADD Clinical Interview

The PAS-ADD Clinical Interview [7] is the most complex of the PAS-ADD assessments. It generates ICD-10 and DSM-5 diagnoses on a criterion-by-criterion basis, allowing the user to see clearly the extent to which individual criteria have been fulfilled. It covers all the principal axis I psychiatric disorders in detail, and additionally has an informant interview for ADHD and a screen for autism. There is a strong emphasis on final interpretation and diagnosis by the users themselves. There are no restrictions placed on who may use the interview, although it is clear that a background in psychiatry psychology is highly desirable in terms of interpreting results.

The PAS-ADD Clinical Interview was derived originally from the Present State Examination [11]. The original version, the PAS-ADD 10, was subsequently revised more than 20 years later in the light of information derived from training users over that period. During that time, many changes in question wording and definitions of rating severity were made.

The PAS-ADD clinical interview can be used with anyone who has sufficient language and cognitive development to be able to participate in a clinical interview. This includes children as well as adults, both with and without intellectual disability. The interview can also be used with an informant only.

Information is gathered through patient and/or informant interviewing, for whom there are separate sets of questions. Symptoms are rated on a 4-point scale of severity, the use of which enables a lot of precision to be built into the fulfilment of the diagnostic criteria. As with all the PAS-ADD assessments, the PAS-ADD clinical interview is equally valid for the general population, in which case questioning of the patient can use the informant questions. The PAS-ADD assessments are now also available in digital versions,

available via a website which can also be used off-line for conducting interviews where no Internet is available.

The refinement of the scoring system is illustrated by its approach to psychosis. Psychotic symptoms are notoriously difficult to identify reliably. In the PAS-ADD clinical interview, scores can only get the top severity rating if they are based on the patient's own account of symptoms rather than on an informant report. As such, diagnoses based on informant interviewing alone usually result in 'query' diagnoses for psychosis. The relationship between mood and psychotic symptoms undergoes a complex analysis to determine the final diagnosis.

Field trials investigated the validity of PAS-ADD in relation to the clinical opinion of referring psychiatrists [12, 13]. Inter-rater reliability of the PAS-ADD 10 [2] gave a mean Kappa of 0.65 for individual item codes of, and Kappa 0.7 for agreement on index of definition (clinical significance of the symptoms) [14]. The relationships between respondent (patient) and informant reports of symptoms, and the implications of deriving diagnoses solely from informant interviews, are discussed in Moss and colleagues [15]. The issues of using care staff as informants are discussed in Moss and Patel [16].

8.9.2 Other Structured Interviews

There are various structured assessments using an interview format that produce what would be better referred to as diagnostic 'indications'. These are not screening tools because they potentially provide enough information to actually make a diagnosis. They do not, however, provide a detailed criterion-by-criterion analysis that directly maps onto ICD-10 or DSM-5 criteria.

8.9.2.1 The PIMRA

The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) [17–19] was designed for the use with adults who have mild-to-moderate levels of intellectual disability, and was originally derived from DSM III [20]. It is available in an informant interview version, and also for self-report (meaning self-completion by the informant). Questions have to be answered by yes or no. The PIMRA is designed to assess psychiatric disorder and psychopathology. It has eight sub-scales, scores from which measure seven diagnostic categories: schizophrenia, depression, psychosexual disorders, adaptation disorders, anxiety, somatoform disorders and personality disorders.

Many research studies have been conducted on the PIMRA, producing mixed conclusions about its psychometric properties. Thus, while the authors showed good internal consistency and acceptable test-retest reliability [18], others have shown lower reliability [21–25]. The construct validity was examined for the schizophrenia sub-scale first by Linaker and Helle [26] and then by Swiezy and collaborators [27], for the psychosexual sub-scales by Matson and Russell [28]. The construct validity of the remaining five sub-scales has not yet been rigorously evaluated. The factorial analysis of PIMRA was carried out first by Balboni and collaborators [29] and then by Sturmey and Ley [21]. The investigations did not produce clear and consistent results: only four main factors were identified and not all the eight sub-scales of the instrument were referred to independent constructs. The results of other researches indicate that the PIMRA is useful above all for research purposes, and therapeutic planning and outcome evaluation [27].

8.9.2.2 The DASH

The Diagnostic Assessment for the Severely Handicapped (DASH) [30, 31] assesses the presence of psychiatric disorders in people with severe and very severe ID. It consists of 84 items and organized in the following sub-scales based on the diagnostic criteria of DSM-III-R [32]: control of impulses, organic disorders, anxiety disorders, mood disorders, mania, pervasive developmental disorders, autism, schizophrenia, stereotyped behaviour, self-injurious behaviour, elimination disorders, nutrition disorders, sleep disorders and sexual disorders. The assessment is an informant interview, where each item is scored on a 3-point Likert scale for frequency, duration

and severity. The psychometric characteristics of the instrument have been well established, especially for the sub-scales of depression, mania and autism [33–37]. Overall, these confirm the reliability of the instrument, although further research is needed to prove the construct validity of many sub-scales.

The two-factor analysis conducted across time [31, 38] identified six and five factors, respectively, of which only the following three were in common: emotional lability, language disorders and sleep disorders.

DASH-II has been used in numerous clinical and epidemiological studies, including those referred to adolescence or early adulthood [39] and senescence [40].

8.9.2.3 Mini PAS-ADD and ChA-PAS

The Mini PAS-ADD [8] and the Child and Adolescent Psychiatric Assessment Schedule (ChA-PAS) are for completion by informant interview, and are widely used in Europe and Australia. They adopt the same four-point rating structure as in the PAS-ADD Clinical Interview, and similarly cover the principal axis I psychiatric disorders. Both include the autism screen, and the ChA-PAS [1] additionally covers ADHD and conduct disorder. In most cases, the scoring conforms exactly to the rating criteria laid down in ICD-10 [2] or DSM-5 [3]. However, there are some minor departures to enable a single score to be generated for each of the diagnostic constellations. For instance, the requirement for specific core symptoms of depression (low mood, loss of interest and loss of energy) is not specifically required.

The Mini PAS-ADD was conceived as an assessment that could provide an in-depth investigation of symptoms, but could be completed by people who did not necessarily have a background in psychology or psychiatry. The ChA-PAS follows this format, and was produced in response to requests for an assessment whose symptom definitions and questions were more appropriately directed towards younger people. These two assessments include a lot of guidance on how to recognize the various symptoms, and provide a semi-structured interview structure to help guide the way in which questions are formulated.

Psychometric properties of the Mini PAS-ADD can be found in Prosser et al. [41]. Results of a major study on the Dutch version of the Mini PAS-ADD have also been reported [42].

8.9.2.4 The CIS

The Clinical Interview Schedule (CIS) – mental handicap [43] – was created originally for the general population and adapted subsequently for the use of persons with ID. The version for the general population [44] was designed to be used by experienced psychiatrists, following a specific training, as a support in the formulation of ICD diagnosis. It is divided into four parts: one with the pathological anamnesis, both remote and near; one with a structured interview including ten groups of symptoms; one with additional information on the family and personal history and the last with a detail of anomalies communicated during the interview. This last part is the one that has undergone multiple changes in the adaptation to use with the ID, with seven additional items. It is also the one that, in the adapted version, presents the lowest inter-rater reliability. In general, the few data available on the psychometric characteristics of this scale are not encouraging and the terminology maintained in the various items seems to be less usable by most people with ID [45].

8.9.3 Full-Spectrum Questionnaires

These are wide-spectrum assessment, but are primarily checklists rather than interviews.

8.9.3.1 The P-AID

The Psychopathology Checklists for Adults with Intellectual Disability (P-AID) [46] is a battery of checklists to be used with informants, and is able to identify 10 different psychiatric disorders and 8 types of problem behaviours according to the Diagnostic Criteria for psychiatric disorders for use with adults with Learning Disabilities/mental retardation (DC-LD) [47]. It shows internal consistency, reliability and acceptable inter-rater, 8 units orthogonal to factor analysis,

while sensitivity and specificity are still to be explored [46].

8.9.3.2 The DBC

The Developmental Behaviour Checklist (DBC) [4] is an excellent example of an assessment whose development started from a primarily statistical standpoint. A large number of different kinds of behaviour in children were investigated in a large population of children with emotional or behavioural difficulties. From the scores, factor analysis derived a number of factors, and subsequently a smaller, refined set of items. The parent/carer version has 96 items in five different sub-scales. The items are scored on a 4-point Likert scale. The six factors identified by factor analysis are as follows: disruptive behaviour, self-absorbed behaviour, communication disturbance, anxiety, autistic-relating behaviour and antisocial behaviour.

The version for adults (DBC-A) [48, 49] includes 107 items, which are completed by family members, paid carers or someone else who know the person with ID well, reporting problems over a 6-month period. Each descriptive item of behavioural and emotional disturbance is scored on a 3-point Likert scale, from 'not true' to 'very true'. The DBC-A can be scored at three levels: (1) the overall measure, total behaviour problem score or alternatively the mean item score (MIS), the proportion of items checked (PIC) and the intensity index (II); (2) sub-scale scores measure disturbance in six dimensions, which may also be scored as total scores or as MIS with PIC and II and (3) scores on individual items.

Because it was derived from a statistical viewpoint, its psychometric properties are very good [50–54]. As such, it is very useful for epidemiological studies, but the factor scores may relate less to routine psychiatric practice.

8.9.3.3 The BSI

The Brief Symptom Inventory (BSI) [55] is an instrument of self-evaluation of psychological distress, developed for the general adult population, which essentially represents the brief form of the Symptom Checklist-90-R (SCL-90-R) [56]. It evaluates a wide range of symptoms through 53 items organized in the following nine sub-scales: somatization, obsession compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. It also allows to obtain three global indices of psychopathology: general gravity, symptom distress and general symptomatological positivity. The BSI has been judged to be a valid tool for the self-assessment of psychological symptoms in people with mild ID or borderline intellectual functioning, although internal consistency and reliability were found to be rather low for all sub-scales [57–59]. The validity of the construct was verified by comparing sub-scales' average scores of three different groups of persons: persons living in the community attending a specialized clinical unit for assessment of ID severity (community group), persons under evaluation for co-occurrent psychiatric disorders (clinical group) and persons convicted of a crime (forensic group). The three groups presented significant differences in eight of the nine sub-scales and in two of the three global indices. The community group showed the lowest number of symptoms, followed by the forensic group and the clinician [58].

8.9.3.4 The PPS-LD

The Present Psychiatric State – Learning Disabilities (PPS-LD) [60] is an adaptation of the Present State Examination [61] and supports the psychiatric diagnosis according to the Diagnostic Criteria for Research-10 [62]. It contains 116 items and complements the information gathered by the evaluator and his closest assistants.

8.9.4 Screening Checklists

Screening assessments do not claim to provide comprehensive assessment on which a formulation or diagnosis can be made. Rather, they aim to make a statistical prediction of what an in-depth assessment would conclude, were to be undertaken, in the same way that a cancer screening gives an estimate of the probably presence of the disease. Very often, this simply takes the form of a yes/no conclusion, that is, 'yes', the person probably has a problem that

needs further assessment, or 'no', they probably do not have a mental health problem. Of course, the scores generated by screening assessments can also be valuable in their own right, giving an indication of the kinds of areas where problems might exist.

Two of the most important statistical characteristics of screening assessments are *sensitivity* and *specificity*. An assessment that is sensitive will be good at identifying all potential cases. An assessment that is specific will be good at distinguishing between non-cases and cases. Of course, one cannot get something for nothing. Checklists, when used by non-trained users, are very unreliable, and hence, not very specific. In order to increase sensitivity, it is inevitable that one has to lower the threshold score for identifying 'caseness', and this in turn increases the number of false-positive results (i.e. people who appear to have a problem when they actually do not).

In choosing a screening assessment, these points need to be considered carefully. If one wishes to definitely identify all possible cases, and then follow them up, a very sensitive assessment would be the choice. The disadvantage is that there will be many false positives, that is, people who triggered the screen but do not actually have a disorder. If resources for full assessment are limited, it may be appropriate to choose an assessment with higher specificity, on the assumption that all the severe cases would be identified. One would have to accept that some cases would be missed, but they would hopefully be the more mild ones.

8.9.4.1 The PAS-ADD Checklist

The PAS-ADD Checklist is a 25-item questionnaire, written in everyday language, designed for use primarily by care staff and families, the people who have the most immediate perception of changes in the behaviour of the people for whom they care. The Checklist aims to help staff and carers decide whether further assessment of an individual's mental health may be helpful. It can be used to screen whole groups of individuals, or as part of a regular monitoring of people who are considered to be at risk of mental illness. It is designed to record the presence of a range of problems, all of which may be part of a psychiatric condition. The scoring system includes threshold scores which, if exceeded, indicate the presence of a potential psychiatric problem, which may then be more fully assessed.

The PAS-ADD Checklist produces three scores, relating to:

1. Affective or neurotic disorder
2. Possible organic condition (including dementia)
3. Psychotic disorder

It also has a checklist for life events.

Factor analysis of the checklist completed on a community sample of 201 individuals yielded eight factors, of which seven were readily interpretable in diagnostic terms. Internal consistency of the scales was generally acceptable. Inter-rater reliability in terms of case identification, the main purpose of the checklist was quite good, 83% of the decisions being in agreement with expert clinical opinion. Validity in relation to clinical opinion was also satisfactory; case detection rising appropriately with the clinically judged severity of disorder [63]. Subsequent independent studies have further investigated the Checklist's psychometric properties [64], and established norms for an adult sample [65].

8.9.4.2 The ADD

The Assessment of Dual Diagnosis (ADD) [66] was developed to evaluate the full range of psychiatric disorders in adults with mild or moderate ID. To overcome any verbal capacity limits of the proband, the instrument can be administered to someone who knows the person to be evaluated well, such as a caregiver or family members. The scale consists of 79 items and 13 sub-scales organized according to the DSM-IV diagnoses: mania, depression, anxiety, post-traumatic stress disorder, substance abuse, somatoform disorders, dementia, conduct disorder, developmental pervasive disorder, schizophrenia, personality disorders, eating disorders and sexual disorders. Authors found good psychometric characteristics [66]. One study examined the correlations between the ADD sub-scales and a short version of the MMPI-168 (168-item Minnesota Multiphasic Personality

Inventory), adapted for use with people with ID [67]. The sub-scales of the two instruments, which measured similar psychological constructs, resulted not to correlate with each other, suggesting that ADD may have problems of construct and convergent validity.

8.9.4.3 The RSMB

The Reiss Screen for Maladaptive Behavior (RSMB) [68, 69] is one of the older and well-established scales evaluating psychopathology in individuals with ID through an interview to their caregiver or family member. It includes 38 items accompanied by a definition and some examples. The tool provides scores for the following eight dimensions: aggressive behaviour, autism, psychosis, paranoia, behavioural signs of depression, physical signs of depression, dependent personality disorder and avoidant disorder. The score assigned to each item is chosen on a 3-point scale based on symptom severity, that is, the impact of symptoms on the person's functioning during the last 2 months. A high score at one or more of the tools dimensions indicates a need for referral for more detailed evaluation.

The RSMB showed good psychometric properties across the range of ID, although some uncertainties on its factorial structure were pointed out as well as a higher sensitivity to depression than to other areas of psychopathology [68, 70–75].

8.9.4.4 The ABCL

The Adult Behavior Checklist (ABCL) [76] was not specifically designed for ID or LF-ASD. In fact it is an adaptation of the Young Adult Behavior checklist (YABCL) [77], created to support the clinician in the assessment of psychopathological symptoms in young adults of the general population. The ABCL includes 118 items to be self-rated by a proxy of the person with ID through a 3-point Likert scale ('not true', 'a little bit true' or 'sometimes true' and 'quite true') and in reference to the last 3 months. When used with persons with ID, the ABCL confirmed the good psychometric characteristics showed with use with the general population, including high concordance with clinical diagnoses based on DSM-IV criteria [78, 79]. The factor analysis identified eight syndromic subgroups: anxiety/depression, social withdrawal, somatic complaints, altered thinking, problems of attention, aggressive behaviour, transgressive behaviour and intrusiveness. Furthermore, two broad groups were also identified and defined as 'internalizing' and 'externalizing' disorders. The former showed the strongest correlations with the sub-scales of social withdrawal, somatic complaints and anxiety/depression, the latter with the sub-scales of transgressive and aggressive behaviour. In addition, the ABCL showed good predictive abilities of individual functioning, as measured by the Global Assessment of Functioning (GAF) [79], the Social Functioning Scale for the Mentally Retarded (SRZ-P) [80] and the Best Status Index (Best) [78, 81]. An equivalent of the ABCL for the developmental age, the Child Behavior Checklist (CBCL) [82], has also been repeatedly studied in children and adolescents with mild ID, with as many results of validity [83–85].

8.9.4.5 The SPAIDD-G

The Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities – General screening (SPAIDD-G) [86, 87] is part of a wide tools system to support professionals working with persons with ID and LF-ASD in the identification of psychopathological symptoms and syndromes. It includes 56 items, which represent descriptions of the most frequent observable and behavioural aspects of all the symptoms that appear in the various DSM-5 diagnostic categories. These items were developed to be rated by a mental health professional through the information gathered by interviewing a family member of the person with ID/LF-ASD or any other proxy who have a good perception of changes in the behaviour of the people for whom they care.

Raters do not have to attribute or rate the severity of any score, they only have to indicate the presence or absence of an item by ticking the appropriate box.

The SPAIDD-G evaluates the following syndromic groupings, consistent with those included in the DSM-5: nutrition/feeding disorders, psychotic disorders, mood disorder –

depression, mood disorder – mania, anxiety disorders, side effects of drugs, delirium, dementia, substance-related disorders, odd personality disorder, dramatic personality disorder, anxiety personality disorder, impulse control disorder, autism spectrum disorder, dissociative identity disorder, somatic symptom disorder, sexuality disorder and obsessive compulsive disorder.

The SPAIDD-G showed very good psychometric characteristics. To date it is available only in Italian, although validations of the English, German and French translations are already underway.

8.9.5 Assessments Focusing on a Specific Area

Most of the assessment tools for specific psychopathological areas are adaptations of tools originally created for the general population. Their validity for use with persons with ID/LF-ASD is uncertain, especially with reference to those with greater difficulties of communication and psychological insight.

The vast majority of tools for specific psychopathology concern mood and anxiety disorders. In recent years, there has been an increasing focus of research on both autism spectrum disorder (in persons with ID) and dementia. This interest is likely to result in the development of further assessments in the future.

8.9.5.1 Mood Disorders

In the area of mood disorders, the literature includes significant reports for all the following tools: Affective Rating Scale [88], Hamilton Depression Scale – Mental Handicap Version [89], Beck Depression Inventory (BDI) [90], Mental Retardation Depression Scale (MRDS) [91, 92], Self-Report Depression Questionnaire (SRDQ) [93], Zung Self-Rating Depression Inventory: Mental Handicap Version [94–96], Intellectual Disability Mood Scale [97], the Anxiety, Depression and Mood Scale (ADAMS) [98], Mood, Interest and Pleasure Questionnaire (MIPQ) [99], Glasgow Depression Scale for people with a Learning Disability (GDS-LD) [100], Mood and Anxiety Semi-Structured Interview (MASS) [101] and interRAI Intellectual Disability Assessment System (InterRAI ID) [102].

8.9.5.2 The SRDQ

The Self-Report Depression Questionnaire (SRDQ) [93] is not, as the name suggests, for completion by the patients themselves. Rather, it is a series of questions posed *to* the individual themselves. There is a pre-test to determine whether the person is able to respond meaningfully to the questions. The items are rated on a 3-point scale.

The SRDQ has good psychometric properties [103, 104] and is probably helpful in clinical work around depression in this population [105–107].

8.9.5.3 The IDMS

The Intellectual Disability Mood Scale (IDMS) also showed good psychometric characteristics [97]. However, it has been studied almost exclusively with persons with mild ID. It is articulated in six dimensions: anger, confusion, depression, fatigue, tension and vigour. Given the possible difficulties of employing self-report measures with people who have intellectual disabilities, numerous extra procedures were used, including pictures of buckets filled to various levels and marked to represent the five points of the response scales.

8.9.5.4 The ADAMS

The Anxiety, Depression and Mood Scale (ADAMS) [98] is an informant interview and can be used for all levels of ID severity. It is composed of 28 items organized into five sub-scales: manic/hyperactive behaviour, depressed mood, social avoidance, generalized anxiety and compulsive behaviour.

8.9.5.5 The MIPQ

The Mood, Interest and Pleasure Questionnaire (MIPQ) [99] includes 25 items grouped into two sub-scales (mood and interest/pleasure). It is an informant interview with Likert scale scores and for use with reference to every person with ID or LF-ASD, regardless of communication and insight impairments. It showed good psychometric properties, including high concurrent validity with the Aberrant Behavior Checklist (ABC) [108].

8.9.5.6 The GDS-LD

The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) [100] integrates the information collected by interviewing the person with ID (mild-to-moderate degree) with that provided by their usual carer. For this purpose the instrument is divided into two parts containing 20 and 16 items.

8.9.5.7 The MASS

The Mood and Anxiety Semi-Structured Interview (MASS) [101] is a standardized diagnostic interview specific for anxiety and mood disorders, as indicated by its name. It has been designed to be used with the usual caregivers of the person with ID and is composed of 35 items corresponding to as many symptoms of DSM, whose presence or absence has to be indicated by the rater with respect to the month before the compilation. MASS showed good sensitivity and specificity, with high concordance rates both with clinical diagnoses and with the scores of the Hamilton Depression Rating Scale (HDRS) [109]. As mentioned above (see ▶ Sect. 6.1), about 10 years ago a diagnostic interview was also published for mood and anxiety disorders, called Mood and Anxiety Semi-Structured Interview (MASS) [101].

8.9.5.8 The InterRAI ID

The interRAI Intellectual Disability Assessment System (InterRAI ID) is a comprehensive, standardized instrument for evaluating the needs, strengths and preferences of adults with intellectual or developmental disabilities. It includes two sub-scales to assess depression and aggression. The InterRAI ID is in turn part of a wide tool battery developed in 2007 to promote social and community engagement by identifying persons who may benefit from additional supports or services in specific areas [102].

The concurrent validity of the InterRAI ID sub-scales for depression and aggression was evaluated through comparison with the RSMB and showed statistical significance [102].

Anxiety Disorders

In the area of anxiety disorders and obsessive compulsive disorder, the following tools have all been valued in the scientific literature across time: Zung Anxiety Rating Scale: Adults Mental Handicap Version [110, 111], Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) [112], Fear Survey for Adults with Mental Retardation (FSAMR) [113] and Yale-Brown Obsessive Compulsive Scale (Y-BOCS) [114, 115].

The GAS-ID consists of 27 items referring to physical symptoms and single phobic aspects, while the FSAMR is much more complex, including 85 items. Both instruments are designed to be used with people with mild-to-moderate ID or borderline intellectual functioning, but the GAS-ID shows the advantage of requiring a lower attention span.

Autism Spectrum Disorders

Tools to screen for ASD in adults with ID have to be chosen on the basis of their suitability with different levels of conceptual and communication impairments. The 10-item Autism Spectrum Quotient (AQ-10) [116] is one of the most common for use with borderline intellectual functioning and mild ID, while the Diagnostic Behavioral Assessment for Autism Spectrum Disorder – Revised (DiBAS-R) [117] and the Pervasive Developmental Disorder in Mental Retardation Scale (PDD-MRS) [118] seem to be more appropriate for moderate ID. In most severe cases, the Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities – Autism Spectrum Disorder (SPAIDD-ASD) [119] or the Autism Spectrum Disorder – Diagnosis Scale for Intellectually Disabled Adults (ASD-DA) [120] should be preferred.

To support clinicians in the refinement of the diagnosis, the Autism Diagnostic Observation Schedule (ADOS; ADOS-II) [121, 122] and the Autism Diagnostic Interview – Revised (ADI-R) [123] are widely employed, although they have shown to present some problems of sensitivity and validity

when used with adults with ID, especially in highest degrees of severity and in the presence of other psychiatric disorders [124]. The Gilliam Autism Rating Scale – Second Edition (GARS-2) [125] seems to show greater discriminative capacity, even if research evidence is limited.

The Diagnostic Interview for Social and Communication Disorders (DISCO) [126] also offers a comprehensive evaluation of the ASD across the range of ID, allowing to subtype on the basis of overall functioning [127] and supporting the differential diagnosis between ASD, ID and schizophrenia spectrum disorders [128].

Recently, the Social Communication Questionnaire (SCQ) [129] has been adapted for use with adults with ID of various severity (SCQ-AID) [130] and can be used as a screening tool. However, it still has major specificity problems: the high scores often do not derive from the presence of many DSA nuclear symptoms but from that of CP, co-occurring psychiatric disorders or undesirable effects of psychoactive drugs.

More information on diagnostic instrumental assessment of ASD in persons with ID is provided in ► Chap. 16.

Dementia

In the area of dementia and other major neurocognitive disorders, three well-known and widely studied tools are the Dementia Scale for Down Syndrome (DSDS) [131], the Dementia Questionnaire for Mentally Retarded persons (DMR) [132] and the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) [133]. For persons with mild ID and good introspective and communicative skills, some adaptations of instruments widely used in the general population are also available, such as the Shultz Mini-Mental State Exam [134] and the Cambridge Examination for Mental Disorders of Older People with Down Syndrome and Others with Intellectual Disabilities (CAMDEX-DS) [135].

The DSDS includes 60 items organized into three categories, one for each of the stages in which the progression of the disorder is normally divided. The DMR instead has two categories, in which it orders 50 items and 8 sub-scales: the first category concerns cognitive functions, such as memory and orientation, while the second refers to social-emotional skills, such as mood, interests, speech, practical skills and problem behaviour. Although DMR has been designed to be used with persons with ID of any degree of severity, its sensitivity has been shown to decrease in those with highest cognitive impairment [132].

Another instrument of interest is the Multidimensional Observation Scale for Elderly Subjects (MOSES) [136], which is also centred on the detection of significant changes in behaviour through the reports of reliable informants. Its structure is based on three behavioural factors: adaptive, maladaptive externalizing and maladaptive internalizing [137].

The Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) [133] was designed with the aim of overcoming the main limits of previous instruments. It focuses only on recent behavioural changes and shows very good psychometric characteristics. For these reasons it was included, with some adaptations, in the evaluation package of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), called NTG-Early Detection Screen for Dementia (NTG-EDSD) [138], and recently translated and validated into various languages.

A comprehensive review of measures used in the screening, assessment and diagnosis of dementia in persons with ID has been recently published by McKenzie and collaborators [139].

Personality Disorders

In the area of personality disorders, two relevant tools are the Standardized Assessment of Personality (SAP) [140, 141] and the Minnesota Multiphasic Personality Inventory 168(L) [MMPI-168(L)] [142].

Although initial studies using the SAP were limited to people with mild and moderate ID [141, 143], subsequently it has been used across the whole range of severity, showing good psychometric properties [144–147]. The SAP is a semi-structured diagnostic

interview which relies on having an informant who knows the patient well from at least 5 years.

The MMPI-168(L) [142] represents a modified version of the MMPI-168 [148], which is in turn a reduced version of the well-known Minnesota Multiphasic Personality Inventory. The MMPI-168(L) [142] was produced for use with persons with mild ID and includes simplified questions that can be answered yes or no, rather than true or false. A group of L (Lie) items was also added to increase validity. It provides scores for three validity scales and ten personality scales. The MMPI-168(L) has been shown in empirical studies to possess good psychometric characteristics, particularly towards odd cluster personality disorders [67, 149–151].

8.9.6 Structuring the Whole Case Formulation

Little attention has been given to the idea of actually providing structure to the way the whole case is formulated, but such an approach deserves consideration. It is very clear that most people's mental health problems are a complex mixture of fundamental factors: biological, developmental, psychodynamic and ecological. As such, it is rare that a single person provides all the information necessary to understand fully why the person is experiencing the problems that they have. Multidisciplinary assessment is normally used, but with it comes the problem that different professionals have different ways of thinking, and are often in very differing relationships with the patient. Family members know the person best, but rarely have professional knowledge of psychopathology. Senior clinicians have the best ability to synthesize clinical information, but are often not in the position to collect it themselves. In a large organization, different professional groups sometimes work so independently that it is difficult to bring together all the relevant information pertaining to the specific case.

It is often true in case formulation that a given set of observations and symptoms can be accounted for by a number of different hypotheses. Given all the information, how do we decide which hypothesis is true?

8.9.6.1 The PAS-ADD Clinical Interview: Formulation Section

The score form for the PAS-ADD clinical interview provides an opportunity to bring together all these disparate pieces of information in one place; essentially, to make a dossier of the information necessary to make diagnostic decisions. The last part of the score form provides a way of identifying the key elements of the case in relation to various fundamental dimensions: psychiatric assessment, birth history and developmental factors, problem behaviours, physical health status, intellectual adaptive and language functioning, current ecology and 'contingencies'. This last item refers to the pivotal evidence that can arise when something suddenly changes in the person's behaviour that relates to something that has happened in their life. Such contingencies can often give unique insight into what is actually happening.

The key to completing this section of the score form is that the various items are rated according to their judged relevance to *understanding the case*, rather than to their severity. For instance, someone may have a severe self-injurious behaviour, but it always happens in the same way and at the same level. This, in itself, does not tell us much about what is going on. In comparison, someone's self-injurious behaviour that fluctuates markedly in response to what is happening around them, or started after a major life event, can tell us a lot more.

This part of the form has not been tested in any study; indeed, it would be very difficult to mount such a study. However, clinicians have reported that the completion of this section by a small group of professionals over a short period of time can often highlight hypotheses for why the person is suffering the problems, and can also identify further key pieces of information that would be desirable to collect. This is of course the same process that goes on in many case discussions. As with

other structured assessments, however, the provision of a structure can sometimes help the team consider all the pieces of evidence in a more impartial way.

8.9.6.2 The SPAIDD: An Integrated System of Tools

As mentioned above, the Systematic Psychopathological Assessment for persons with Intellectual and Developmental Disabilities (SPAIDD) [87] is an example of a comprehensive set of tools for all the different practical needs related to psychopathological assessment and monitoring, to be used by mental health professional and the whole multidisciplinary team working with people with ID and LF-ASD. In fact, it includes tools for every phase of the clinical intervention, such as general psychopathological screening, diagnostic categorical specification, dimensional diagnosis and symptoms monitoring.

The items of the SPAIDD system have been kept unchanged across all the battery tools since they represent observable and behavioural aspects of cross-categorical symptoms.

In designing and implementing this system, authors tried to overcome also the other main limits of previous tools, such as the impossibility of being used for all the degrees of intellectual and communication impairment, the misalignment with the DSM or the ICD, the lack of some main symptoms or syndromes, the lack of chronological criteria, the long times of administration and the scarce interdisciplinary usability [152].

To date, the SPAIDD system includes tools for general screening, follow-up, autism spectrum disorder, mood disorders, anxiety disorders and psychotic disorders, which are available only in Italian, although validations of the English, German and French translations are underway.

8.9.7 Other Structured Assessments

The above sections covered only a small proportion of the numerous structured assessments that are available for use with people who have ID/LF-ASD. Hopefully, the ones we have highlighted give some insight into the dimensions that need to be considered when selecting appropriate ones. Useful sources of further information are represented by the reviews by Flynn and collaborators [153], Hermans [154] and Tyrer and collaborators [155].

Assessment tools can be distinguished on the basis of their fundamental dimensions, we can count: (a) fully diagnostic interviews such as PAS-ADD; (b) other structured diagnostic interviews like PIMRA, DASH, mini PAS-ADD, ChA-PAS and CIS; (c) checklists such as P-AID, DBC, BSI and PPS-LD; (d) screening checklists like PAS-ADD Checklist, ADD, RSMB, ABCL and SPAIDD-G; assessment focusing on a specific area, especially mood and anxiety disorder and dementia. New comprehensive sets of tools for all the different practical needs related to psychopathological assessment and monitoring are being developed for interdisciplinary use by mental health professional and the whole multidisciplinary team.

8.10 Choosing a Structured Assessment

The appropriate choice of assessment(s) for a research project may be very different from those needed for a clinical service. In either case, however, the choice should be guided by a consideration of the desired outcome of the assessment.

8.10.1 Measuring Change

One of the most straightforward uses of structured assessments is probably for the measurement of change, either in response to treatment or over a period of time. For this purpose, issues of validity become less significant. *Reliability* is the central requirement. One needs to have faith in the ability of the assessment to reproduce the same results in

the same set of circumstances. A change in these results, therefore, indicates a change in the person's mental status. Although most structured assessments give estimates of reliability, it is important to bear in mind that this often depends on the training of users. In a research study, it is relatively easy to obtain good reliability through rigorous training of the users. Some structured assessments suggest, or require, some form of training. If the particular assessment is to be used, therefore, it must be accepted that resources are allocated for that training. Even after training, however, it is possible that users will drift away from the correct procedure. Indeed, Havercamp and Reiss [24] indicated that problems of reproducibility of PIMRA results by different evaluators seemed to arise because professionals in different areas recorded differently, or had not received specific training in the use of the tool. In a real-life clinical setting, it would certainly be desirable to monitor and update the training of users from time to time.

8.10.2 Diagnosis and Formulation

Clinicians such as psychiatrists and psychologists often do not use structured methods. One possible reason is that they feel it would be more time consuming. Another is that they may feel their clinical training is sufficient that a structured approach is not necessary. The numerous studies of the reliability of clinical interviewing indicate that the latter reason is questionable. Diagnostic reliability tends to be low [156–158], but this is certainly not due to a lack of clinical skills. Rather, it is an indication of the multiple sources of information that tend to influence outcome, for example, reason for referral, or bias in the people who know the individual.

It would not be sensible to suggest that everybody always should use a formal structured assessment in every case. Rather, structured tools should be like any other tools, that is, to be used where appropriate. More broadly, it is very useful to learn how to use some of these methods so that even routine clinical interviewing can be conducted with a more rigorous structure in mind. This can help overcome sources of influence and bias and can also give the opportunity for other possible diagnoses and formulations to be given consideration.

Ultimately, the various assessments are probably best judged by their *usefulness*; do they help to achieve the desired outcome? In clinical work, structured assessments can contribute to the quality of the patient's clinical information, and any issues of reliability and validity can be handled at the level of case discussion. For instance, a structured interview may statistically be reliable and valid, but the clinical team knows that the informants are not giving a true picture, either because they have their own agenda or they are unable to be objective. In an extreme example, someone with psychopathy may *deliberately* mislead the assessors. Such things can only be judged in the context of the case, and lie outside the confines of the assessment's statistical properties.

8.11 Structured Assessments as Part of a Protocol

Finally, it is important to mention that the use of structured assessments in clinical work is much more beneficial if it is part of an overall policy or protocol on assessment in the service. Unfortunately, this often does not happen. It is sometimes perceived, for instance, that one professional group should receive training in a particular assessment, but the rest of the health professionals are unaware of this. As a result, the information from these assessments may be considered by other clinicians to be of questionable validity.

It is only by getting health professionals together to learn about and discuss the assessments that they can become part of the flow of information, leading hopefully to better case formulations in the future.

One of the most straightforward uses of structured assessment is probably the measurement of change, either in response to treatment or over a period of time. To this purpose, reliability is a central

requirement and consequently specific and updated training of users. More broadly, it is very useful to learn how to use some assessment tools so that even routine clinical interviewing can be conducted with a more rigorous structure in mind. This can help overcome sources of influence and bias and give the opportunity for other possible diagnoses and formulations to be given consideration.

Tip

The use of structured assessments in clinical work is much more beneficial if it is part of an overall policy or protocol on interdisciplinary assessment in the service.

The instrumental assessment of psychiatric disorders in persons with lower communication and cognitive skills needs substantial improvement and it is probable that this will be brought in the next years. Thus, constant update is suggested.

Key Points

- Interviewing is a highly volatile process, open to influence by numerous factors that can be very difficult for people with ID associated with a very poor language, or even no language at all. This sometimes leads to the suggestion that structured assessments can be more important with people who have ID than with the general population.
- When choosing to use a structured approach, however, it is important to distinguish broad-spectrum assessments from those involving a specific area with the aim of not influencing the final diagnostic outcome and determining the presence and severity of symptoms as efficiently as possible.
- An assessment tool should have good psychometric properties, in particular, reliability and validity associated with a factorial structure in significant relationship with the measured concepts. Reliability seems to be the central requirement so that a change in the results indicates a change in the person's mental state and is important to bear in mind that this often depends on the training of users.
- The ideal is a tool that allows both to synthesize all the information obtained from the patient himself, from third parties close to the patient or from other colleagues who have previously examined him or, at the same time, in the case of a multidisciplinary work group, and to evaluate the various symptoms significant for diagnosis. This is even more true in the case of mental health professionals who work with people with ID and LF-ASD.

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