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Introduction

Throughout the text, the British term ‘learning disability’ is used. It is identical in meaning to the terms ‘mental retardation’ and ‘intellectual disability’ used in other English-speaking countries.

It has been known for at least one hundred years that people with learning disabilities suffer from mental illness, but it is only since the 1980s that this has been reflected in a growing international recognition of the need to respond more adequately to the mental health problems of this population. The reason that this recognition took so long to establish was partly because the pressing priority for many years was the establishment of basic human rights for people with learning disabilities. Since the 1960s huge achievements have been made in people's life circumstances – such aspects as housing, education, work and leisure opportunities, social engagement, interaction with the community at large, and other social domains. With these major human rights battles being largely achieved, the mid 1970s saw a major shift to subjective quality of life – focusing on what the individuals themselves say they wished for and aspired to. It was in this latter context that mental health issues came to greater prominence.

Mental health problems in people with learning disabilities present particular challenges because of the complex ways these problems often manifest themselves. There are numerous risk factors for mental illness in people with learning disabilities, including biological, social and psychological factors. A specific instance of behaviour can have potential multiple causes which can be very difficult to disentangle. For instance, a challenging behaviour (e.g. aggression to others, or self-injury) may be driven by a whole variety of causes, including: a history of inappropriately learned behaviour, an environment which is over or under-stimulating, an underlying psychiatric disorder, neurological or endocrine abnormalities etc. Overall, a major part of the diagnostic task is to disentangle these various effects within an individual, so that we understand the significance of the various behaviours and can begin to formulate a working hypothesis from which to build a treatment plan. The development of this level of understanding can only occur if we observe the individual over a period of time, so we can begin to see which behaviours change, and what factors influence this change.

In order to facilitate a thorough diagnostic and treatment formulation, clinical mental health assessments of individuals with learning disabilities thus need to integrate information from a wide range of relevant sources: the individual themselves, their family, support workers and other professionals, as well as clinicians.
Much of this knowledge needs to come from people who probably do not have training in psychopathology. Informants such as family members, care staff, nurses and social workers often possess knowledge about the individual which could be crucial to making the correct diagnosis. Unfortunately, this information often gets missed because, for one reason or another, the information has not been properly accessed. People are often aware of behaviour changes in the person for whom they care, but may not understand the significance of that behaviour.

About the original PAS-ADD schedules

‘PAS-ADD’ stands for ‘Psychiatric Assessment Schedules for Adults with Developmental Disabilities’. The PAS-ADD schedules were designed to provide a structured framework within which informants and clinicians could collect standardised information about mental health problems. A series of three instruments was originally designed, each targeted at a different level of knowledge on the part of the user. Overall, the instruments were designed to provide a flow of information from carers, through support staff, to the psychiatrists and psychologists responsible for making diagnostic assessments. The three original instruments are listed below.

The PAS-ADD Checklist: a 27-item questionnaire, couched 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 should be referred for further assessment.

The Mini PAS-ADD Version 1: a more sophisticated assessment schedule which can be used by staff who do not have a professional background in psychopathology, but who should have received some training in its use. To improve reliability, this schedule uses a glossary of symptom definitions to guide the coding.

The PAS-ADD 10: a semi-structured clinical interview for use with respondents who have learning disabilities and for key informants. It uses a computer algorithm to produce diagnoses and other diagnostic information under ICD 10, and is guided by a clinical glossary. This interview was targeted primarily at clinicians with a background in psychopathology, and expertise in interviewing people with learning disabilities.

Further details of the studies which have been conducted on these instruments can be found in Appendix 1 of this handbook.
About the PAS-ADD schedules in this pack

This pack contains a revised version of the Checklist, and a much enhanced version of the mini PAS-ADD.

The PAS-ADD Checklist (Revised). Revisions to the Checklist include a change in the order of the items, modifications to the item wording, and changes to the column headings giving definitions of symptom severity. All these changes have been made in response to knowledge and experience which has been built up in the years since the original version was devised. A number of inconsistencies and sources of confusion have been eliminated.

The Mini PAS-ADD Interview. This instrument is a completely new addition to the PAS-ADD family. Unlike the original Mini PAS-ADD, this version can be used to collect symptom information directly from an informant via a semi-structured interview procedure. The interview has been based on the same principles as those of the PAS-ADD 10 interview. The item order has been completely changed to enable the interviewer to conduct a natural conversation with the informant, within which the necessary information to code the symptoms is derived. The Glossary has also undergone substantial revision, and now includes much more precise guidance on making the ratings of severity. The Glossary definitions appear adjacent to their relevant interview questions, making it easy for the interviewer to keep the guidelines in mind while conducting the conversation.

The Mini PAS-ADD Score Form. A further enhancement relates to the Mini PAS-ADD Score Form. This new version enables two different clinical episodes to be rated on the same form. This is important if the person has a cyclical disorder, or if it is otherwise suspected that the individual has changed significantly from one time period to another.

Key features of the PAS-ADD schedules

Points 1 to 4 below apply both to the original version of the PAS-ADD schedules, and to the revised versions in this pack.

The PAS-ADD schedules were designed to link with each other so that the flow of information from carers through support staff to clinicians is as unambiguous as possible. They are all based on the same underlying principles, listed below.

1 The focus is on commonly occurring Axis 1 psychiatric disorders. They do not include personality disorders (Axis 2), nor some of the rarer Axis 1 disorders. The aim was not to try and cover every possible mental health problem, but to develop a series of very usable instruments with maximum applicability. The PAS-ADD instruments should be seen as part of a range of techniques which are necessary to conduct comprehensive assessments.
Challenging behaviours are not covered by the PAS-ADD system. This was a deliberate choice based on the importance of distinguishing these behaviours from psychiatric symptoms. (See Appendix 2 for a discussion of these issues.)

The PAS-ADD schedules use diagnostic criteria as specified by the World Health Organisation's International Classification of Diseases, (ICD 10). Many people have argued that these criteria should be modified to include various challenging behaviours as 'equivalents' for symptoms which are more normally seen in the general population (e.g. aggressive behaviour rather than typical symptoms of depression such as guilt or hopelessness). Although the arguments are entirely reasonable, the problem is that the relationships between psychiatric disorders and challenging behaviours are both pervasive and complex. The evidence suggests a variety of potential linking mechanisms between challenging behaviours and psychiatric disorders. In a given individual, this means that the significance of a given piece of behaviour cannot be assumed to have a fixed relationship to a diagnostic category, and hence cannot be used as a reliable diagnostic indicator.

In line with ICD 10 and DSM IV, the algorithms used in the Mini PAS-ADD (and the PAS-ADD 10) Interview take a 'polydiagnostic' approach to diagnosis. This means that many different symptom patterns can lead to the same diagnosis. The algorithm is designed to relate closely to best practice clinical decision-making. In effect, the algorithms pose a series of questions: is the symptom present? If yes, is it sufficiently severe that it should contribute to the diagnosis, and how much weight should be given to the presence of this symptom?

When to use the PAS-ADD schedules

The PAS-ADD schedules are not designed to be locked away in a cupboard, only seeing the light of day at infrequent intervals. The potential of the PAS-ADD schedules is to provide a structured framework within which the mental health of all people with learning disabilities can be constantly monitored. It should never be forgotten that the first task facing any service wishing to improve the mental health of its learning disabled population is to ensure that those people who have potential psychiatric disorders are identified. However well trained the clinicians may be, they cannot help people who are not referred.

The following key tasks can be performed using the PAS-ADD schedules.

**PAS-ADD Checklist (Revised)**

- Regular population screening to identify at-risk individuals
- Monitoring of individuals thought to be at risk
Mini PAS-ADD Interview (Score Form and Glossary)

- Collection of detailed information on Axis 1 psychiatric symptoms either by
  - informant interview, or
  - self-completion by a professional staff member or team who already knows the client well
- Monitoring the impact of treatment

PAS-ADD 10 Psychiatric Interview
(Not included in this pack.)

- ‘Gold-standard’ clinical interviewing of people with learning disabilities and their carers

The Mini PAS-ADD Interview

The Mini PAS-ADD has been designed to provide a structured framework within which information on psychiatric symptoms in people with learning disabilities can be collected. The diagnostic decision rules of ICD 10 are built in to the scoring procedure, so it is not necessary for users of the instrument to know how these work. The instrument has been designed to produce a reliable and valid record of the person’s symptoms during the period (or periods) being rated, and can thus be used as a central part of a comprehensive multidisciplinary assessment.

The schedule produces scores relating to the psychiatric disorders listed below.

1. Psychosis
2. Expansive mood (hypomania)
3. Autism
4. Depression
5. Unspecified disorder (including dementia)
6. Anxiety disorders
7. Obsessive Compulsive Disorder

Threshold scores are provided for each of these seven diagnostic areas. It is recommended that any person who reaches the threshold score on any scale receive a full mental health assessment, if they are not already doing so.

Is the Mini PAS-ADD valid for all levels of learning disability?

All the PAS-ADD instruments were field-tested on the full developmental spectrum found in British learning disability services (up to approximately IQ 65). However,
it is clearly more difficult to make diagnoses in people with severe and profound learning disabilities than in those individuals whose disability is milder. Not only are the communication barriers more difficult to overcome, but the presentation of symptoms is more likely to be overlaid by other behaviours which may be unrelated to mental illness.

The presence of these diagnostic obstacles makes it even more important to have the best possible record of the person's symptoms. Informants can often give crucial information about the people for whom they care, provided they are asked the questions in a careful, structured way. The Mini PAS-ADD is designed with this purpose in mind. It does, however, also require methodical completion by well trained assessors.

The greater the level of learning disability, the more likely it is that the individual will have multiple problems, of which the psychiatric dimension will be only a part. Other instruments and assessment techniques will also be needed to conduct a comprehensive assessment of mental health problems.

Knowledge and training requirements for using the Mini PAS-ADD schedules

There is no specific professional limitation placed on use of the Mini PAS-ADD. However, it is extremely advantageous to have a background or specific training in mental health and mental illness. Valid results depend upon accurate coding of symptoms. Accurate coding requires the user to have a good understanding of the psychiatric symptoms which are described in the Glossary. We have tried to make the definitions as self-explanatory as possible, but this does not replace the need for experience and training.

In order to produce valid results it is essential that users can a) reliably code symptoms in conjunction with the Glossary, and (b) have been trained to use the Mini PAS-ADD in real-life clinical situations. The Coding Exercises in this handbook provide six training vignettes which can be used for coding practice. **Note, however, that self-completion of these exercises does NOT constitute a full training.**

Unlike the first version of the Mini PAS-ADD, this pack includes a semi-structured clinical interview for completing the rating by interview with a key informant. Clinical interviewing, even of informants, is a skilled task. It is **highly recommended** that people wishing to use the interview format have received training in semi-structured interviewing. The SCAN system (Schedules for Clinical Assessment in Neuropsychiatry) offers training in many parts of the world. In the USA, the SCID is based on similar principles.

In the UK, the Estia Centre offers training in many aspects of mental health and learning disability, including use of the PAS-ADD tools.
How to Use the Mini PAS-ADD Interview

An overview

Take a look at one of the Interview Score Forms. The core of the Mini PAS-ADD is its tables of symptoms which make up the bulk of the form. Each of the symptoms has a corresponding glossary definition, which tells you what to look for when identifying the symptom, and also helps you decide the severity of the symptom.

The set of codes immediately to the right of each symptom in the Score Form shows the number to be entered in the rating box, depending on the severity of the symptom.

The knowledge about the client’s symptoms can come from one of two sources. It can be either a) self-completed by suitably trained staff who already have a good knowledge of the person, or b) completed by interview with someone who knows the individual well.

The symptoms are laid out in sections in the Score Form. Once the form has been completed, the scores in each section are added up. These sub-scores are then combined together in various ways to generate the seven scale scores.

The usual period for rating symptoms is the previous four weeks. However, it is sometimes important to rate another episode. This version of the Mini PAS-ADD enables this to be done.

The Glossary and Interview constitute the bulk of this handbook. Left-hand pages show the interview questions, while the corresponding Glossary definitions appear on the right-hand pages. The Glossary also gives information about interpretation of these final scores.

Completing a Mini PAS-ADD Score Form

The following table shows the steps to complete the Score Form, either by interview or through self-completion by yourself as a professional informant.
Conducting an interview

Selecting a suitable informant

Relatives, people with whom the individual lives, and care staff are all liable to have different information at their disposal. The person with learning disabilities may have been more likely to open up to his or her parent, and talk about things which it would be more difficult for a stranger to gain access to. On the other hand, a key worker may have access to information which parents do not see. Try and find out who is in the best position to report on the person's symptoms.

Semi-structured interviewing

The Mini PAS-ADD interview is a semi-structured interview. This means that it is not necessary to adhere rigidly to the question wording which is supplied, but it is important to have some knowledge of the symptom you are asking about. The Clinical Glossary provides this information.

The interview wordings have been largely drawn from the PAS-ADD interview, and have been designed for maximum clarity. Each item consists of a main question followed by a number of suggested probes. The basic concept is to ask the main question, and then use the probes to clarify the informant's answer, and to prompt them where necessary.

<table>
<thead>
<tr>
<th>Completion by interview</th>
<th>Self-completion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify a suitable informant</td>
<td>Write a short description of the person's symptoms in your own words</td>
</tr>
<tr>
<td>Conduct the introductory session</td>
<td></td>
</tr>
<tr>
<td>Record the symptoms described by the informant in the initial interview</td>
<td></td>
</tr>
<tr>
<td>Decide on the time period(s) to be rated</td>
<td>Decide on the time period(s) to be rated</td>
</tr>
<tr>
<td>Interview the informant to complete the symptom ratings for the first rating period</td>
<td>Complete the symptom ratings for the first rating period</td>
</tr>
<tr>
<td>(If required), interview the informant to complete the symptom ratings for the second rating period</td>
<td>(If required), complete the symptom ratings for the second rating period</td>
</tr>
<tr>
<td>Ask the informant to complete the Life Events Checklist</td>
<td>Complete the Life Events Checklist</td>
</tr>
<tr>
<td>Calculate the final scores</td>
<td>Calculate the final scores</td>
</tr>
</tbody>
</table>
Each item should be probed until you are satisfied you know the answers to the following questions:

- Was the symptom present during the rating period?
- If so, how severe was it, and how often did it occur?

The interviewer needs to be sensitive to the informant’s level of knowledge about the symptom. It may be counter-productive to continue probing if the informant has no further information to offer.

**Starting the interview**

The start of a clinical interview is very important because it sets the context for the discussion which follows.

The attitude of anyone being interviewed is likely to be determined by their expectations of the interaction. Explain what you intend to do with the information, and to emphasise rules of confidentiality. The interview itself provides a checklist of points to cover in the initial discussion.

The introductory discussion gives you an opportunity to hear about the person’s problems in the informant’s own words. You also have an opportunity to learn about the person and their interests. This helps in framing the questions which follow.

**Asking the questions**

The question order provides a context for holding a natural discussion with the informant, starting with concrete symptoms, and moving on to the more complex and subjective items in the latter part of the interview.

Sections in tinted panels are instructions to the interviewer.

[P] refers to the person with learning disabilities. Substitute the person’s actual name when using the interview.

**Bear in mind the following points when interviewing.**

- **At the commencement of the coded items, reiterate the time period you are rating.**
- **Have a set of simple definitions for each symptom.**
  Interviewers should have a set of definitions in everyday language prepared for each symptom. This should include a set of situations in which the symptom might typically occur, and with which the informant is likely to be familiar.

- **Use positive question forms.**
  Avoid negatives and double negatives, eg ‘Can [the person] sit still?’ rather than ‘Can’t [the person] sit still?’
• **Probe each symptom thoroughly.**
  It will be necessary to use more than one probe to establish whether a symptom is present or not. A simple response of ‘yes’ to a single probe is not sufficient to rate a symptom as present. For all items, attempt to obtain a description of the symptom in the informant’s own words.

  The probes in the PAS-ADD are not the only possible ones. There may be other probes not listed which could in certain circumstances be more appropriate. Similarly, it is not mandatory to use all the suggested probes. The aim is to elicit the symptomatology as clearly and validly as possible, by whatever form of words is found to be best understood.

  Symptoms that require frequency ratings are often difficult to establish confidently. One useful probe to these questions is ‘How often does this happen?’.

### Deciding on the rating period(s) to be assessed

In the majority of assessments using the Mini PAS-ADD, the first rating period to be assessed will be the current one. The present state, defined as the last four weeks, is normally the first period which should be rated.

There will, however, be circumstances in which it is also important to rate another period. Consider a person experiencing manic and depressive episodes, who is currently depressed. Clearly, a rating based solely on the present state does not give the full picture. On the other hand, extending the rating period to cover both mental states does not work either, because it would appear that the person suffered from more symptoms at any one time than they actually did.

One of the first decisions a rater must therefore make is to decide whether there is evidence of a fluctuating symptom pattern or mood state. If an interview is being conducted, there are specific probes to enquire about this. If you yourself are the informant, and you are not sure about this, try asking yourself the same questions. If in doubt, it is better to make an additional set of ratings than to miss the opportunity.

If you are rating two different episodes, **always complete one episode before rating the next.** Even if you yourself are the informant, it is more reliable to focus on one time period. Shifting between one time period and another is liable to cloud the informant’s memory.

**Always rate the present state first.** This is more recent, and hence brought more readily to mind.
Coding the symptoms

The essence of valid and reliable coding is to work very closely with the Clinical Glossary definitions. Even if you are an experienced clinician, do not assume that you know the definition or the rating categories! The validity of the scoring algorithms depends on the use of these specific definitions.

The other main point about coding is to take each symptom as if it is being rated in isolation. Do not infer that, because the person has certain symptoms, they must have others. Only rate an item as present if the behaviour closely meets the Glossary definition.

Each item on the Score Form has a corresponding entry in the Glossary. This will tell you what to look for, and how to rate the severity of the symptom if it is present. Most of the items are rated on a four-point scale, (not present; mild; moderate; severe). However, some psychotic phenomena are difficult to rate by severity, so these have a two-point scale (present/absent). The ratings are colour-coded by severity, matching the coloured codes on the Score Form. This is to help you move more easily between the Score Form and the Glossary.

The following points are frequently asked about coding:

1 Why do the codes not progressively increase with the severity of the symptom?
   This is to do with the operation of the diagnostic algorithms. In many cases, the main clinical decision to be made about a symptom is whether it is present in sufficient severity to be considered diagnostically significant. Once a symptom reaches this level of severity, further severity does not increase its diagnostic significance. Hence, most of the items move from a zero rating to a positive number, usually between the mild and moderate levels. (Sometimes a symptom needs to be present only to a mild degree for it to be significant, in which case the change occurs between ‘not present’ and ‘mild’.)

   Different rating categories therefore often receive the same code. However, you should always code the symptoms as accurately as possible. If you do not, then valuable clinical information will be lost. For instance, a person may actually be improving due to treatment, with many symptoms reducing in severity from severe to moderate. Although they will still have a diagnosable condition, accurate coding enables the Mini PAS-ADD to be used as an accurate monitor of symptoms.

   You will also notice that the numbers in the columns vary from item to item. Some score a maximum of 1, while others are higher. This reflects the relative weighting to be given to the various symptoms. Some are very diagnostically important and specific, others are less significant and may be associated with a range of different disorders.
2 Why are some items not scored?
The section on situations where anxiety is manifested is not scored. This is because the actual place where it happens does not alter the clinical picture. However, it is an important part of the clinical record. Also, a person may still meet diagnostic criteria for an anxiety disorder, but may be showing improvements in anxiety because they are able to cope with situations which they previously could not.

3 What if I do not have enough information to confidently code an item?
The best response is to see if you can find the information from another source. If one informant does not know about social behaviour, for instance, then somebody else may. If, with all the information available, you remain doubtful, then the rule is to rate down (ie lower in severity), or to rate as not present. If you are unable confidently to rate an item, indicate this on the Score Form, but rate it as zero.

The Life Events Checklist

The Life Events Checklist is not a scored section. However, it is an important part of the clinical information because life events may be central to understanding why the person is behaving in the way they do. It is recommended that this section be completed at the end, because the thought or discussion which has occurred during completion of the other sections should have brought to mind all events which may have happened.

If the Mini PAS-ADD is being completed by interview, show the informant the Life Events Checklist and ask them to tell you the events and dates.

Calculating the final scores

Combine the sub-scores to produce the final scores as indicated on the Score Form. The end of the Glossary gives the threshold scores for each of the seven scales.

If the form has been correctly completed, anyone scoring at or over a threshold probably has an Axis 1 psychiatric disorder. If the person is not already being seen by a qualified mental health clinician, then such a score would indicate they should be referred for a comprehensive mental health assessment.
Before you start

The above completes the information for using the Mini PAS-ADD correctly. Remember it is vitally important that users of the Mini PAS-ADD receive supervised training in its use. Complete the Coding Exercises to improve your coding.

Finally, in order to reap maximum benefit from the PAS-ADD schedules, it is important for all staff members to co-operate closely. It is of limited use, for instance, if one group of professionals is trained to use the Mini PAS-ADD, but other clinical staff ignore the resulting information. Overall, it is essential to have a policy which ensures that all people concerned with the individual's mental state are involved in the assessment process.