PSYCHOMETRIC PROPERTIES OF A NEW SCALE FOR MEASURING DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY: THE GLASGOW DEPRESSION SCALE FOR PEOPLE WITH A LEARNING DISABILITY (GDS-LD)

and Research Portfolio

PART ONE

(Part Two bound separately)

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Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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Chapter 1 - Small Scale Service Evaluation

EVALUATION OF A PATIENT INFORMATION LEAFLET DISTRIBUTED BY A PSYCHOLOGY DEPARTMENT IN CENTRAL SCOTLAND

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Abstract

Objectives

The aim of this study was to evaluate the effectiveness of an information leaflet regarding psychological therapy, which aims to increase patients' knowledge of what is expected of them and the therapist in treatment, and reduce anxiety and confusion. The leaflet is routinely sent to all new patients referred to the Psychology Department.

Design

A structured questionnaire was designed specifically for this survey and was distributed by post.

Setting

The study was undertaken in a Clinical Psychology Outpatient Department in Central Scotland.

Participants

210 patients who had no previous experience of psychological treatment took part in the study. They were referred to the Clinical Psychology Department over a four month period (April 1999 - July 1999).

Results

40% (n=84) of participants replied. Responses to the questionnaire indicated that the information leaflet had succeeded to an acceptable extent in achieving it's aims and that the majority of patients found it useful.

Conclusion

The information leaflet could be considered to be beneficial to patients waiting for psychological treatment. However, several areas of possible improvement were identified which may increase it's usefulness in the future.

Introduction

There is growing interest in the importance of providing service information to patients, and a vast quantity of leaflets and books now exist for that purpose. This is highlighted by The Government White Paper "Working for Patients" [1], which states that hospitals should provide "clear information about the facilities available and what patients need to know when they come to hospital".

The most common form of patient information is a leaflet or other form of written material. There is evidence that the provision of information leaflets can result in benefits to patients[2], however, this only occurs if the leaflets are read, and the contents are understood and remembered.

The majority of studies in this field have taken place in the USA, and focus on patients in a medical context. Patients provided information leaflets typically have quicker recovery times after surgery, through reduced anxiety and an increased sense of personal control[3].

The provision of written information can also lead to increased patient compliance[4]. For example, patients who received information on the side effects and benefits of anti-depressant drug treatment showed more compliance with future drug treatment when compared to those who had not received any information.

Treatment related anxiety can also be reduced by the provision of information leaflets. Baskerville, Heddle and Jarrett[5] demonstrated that 98% of surgical patients receiving pre-operative information reported a reduction in anxiety.

It is apparent from the above studies, although carried out in medical and surgical settings, that the provision of patient information leads to physical *and* psychological benefits. This may also be the case for patients undergoing psychological treatment. Providing patients with information can increase patient satisfaction, reduce anxiety, and lead to improved co-operation in treatment, including lower rates of missed appointments[6, 4, 7]. It has been shown that information leaflets also increase patient knowledge about why they have been referred and what their treatment will involve[7] . This leads to increased satisfaction with treatment, as patients have realistic expectations about what will happen.

A greater emphasis is now being placed on evaluating the effectiveness of written information, due to the financial implications involved in producing and sending the information to new patients. It has also been suggested that certain people find preparatory information daunting and unhelpful[8], thus increasing the need for thorough evaluation of this practice. Many information leaflets are also incomprehensible to the patients who receive them[9], indicating that ease of reading is a vital aspect when preparing patient information. Major issues, however, are still relatively unclear due to the lack of well designed and comprehensive research in the above areas[2].

A Clinical Psychology Service in Central Scotland routinely sends service information leaflets to all patients at the time of referral, along with an indication of expected waiting time. This system, although in operation for almost three years, has yet to be formally evaluated.

The information leaflet referred to above has several aims. In general, it aims to increase patients' knowledge of what is expected of them in treatment, and also what to expect of the therapist. It also includes reassuring messages with the aim of reducing any pre-appointment anxiety. A third aim of the leaflet is to reduce any uncertainty and confusion.

The questions asked in this study were;

- Does the leaflet achieve it's aims?
- Do the patients find the leaflet useful?
- Could the leaflet be changed to make it more helpful?

If information such as this is known, it may be used in future to address and alleviate patient concerns, and therefore increase the attendance rates and satisfaction of new patients.

Methodology

Participants

Participants were all new referrals to the Clinical Psychology Department over a period of four months (1st April 1999 - 31st July 1999). This was a total of 210 patients.

Measures

A structured questionnaire (Appendix 1.2), was used to elicit patients' perceptions of the usefulness and readability of the leaflet. This was designed by the author specifically for this survey, as no existing measures could be identified. The questionnaire was developed by approaching the member of staff responsible for writing the leaflet (Appendix 1.3). They were asked to define the aims and objectives of the leaflet, and the main messages they had attempted to impart to the reader. The questionnaire aims to discover whether these objectives were met.

The questionnaire generally required the participant to circle their chosen answer, although several open ended questions were also included to give respondents more freedom in specific answers. The Flesch Readability Yardstick[10] was calculated from the leaflet. This provided another measure on which to evaluate the leaflet, independent of answers to the questionnaire.

Procedure

Patients are routinely sent an information leaflet when their referral letter is received by the department, along with an indication of expected waiting time. Questionnaires were enclosed with the above information and posted to all new patients.

As postal surveys have notoriously poor response rates[11] several strategies were employed in order to maximise this :- Firstly, the questionnaire would have reached the prospective patient within one week of their referral to the department, therefore, their visit to the referring agent would have been fresh in their minds and motivation to seek treatment would have been high. This may have made them more likely to return the questionnaire than if it had been sent to them after many weeks on a waiting list. Secondly, the responses were all completely anonymous, which may have encouraged responding, especially of a negative nature. The enclosure of a pre-paid envelope also reduced the time and expense involved in replying and was intended to lead to an increase in response rates. A covering letter (Appendix 1.4) was sent with all questionnaires, explaining the importance of responding and the reasons for carrying out the survey. It also stressed that the quality and availability of future treatment would in no way be affected by participation or non-participation. Finally, reminder postcards were sent to all participants three weeks after receipt of the questionnaire, prompting them to reply and thanking them for their assistance had they already done so.

Results

Analysis of the responses was carried out using the Statistical Procedures for Social Scientists (SPSS) computer package (Version 10).

Response Rate

84 patients returned a questionnaire, resulting in a response rate of 40%. Moser and Kalton[12] found that response rates for postal surveys normally lie in the region of 30-40%, therefore, although 40% may be a low response rate, it is normal to find this for postal research.

Criteria for judging the success of the leaflet in meeting it's aims were set by the author of the leaflet before questionnaires were distributed. This was done by identifying relevant questions and applying numerical criteria to them, so that actual responses could be compared with the pre-set criteria. The questions included in this procedure were identified by whether it was possible to give them numerical values, and whether the responses to them would indicate a positive or negative attitude to the leaflet.

If the criteria were achieved, this would mean that the department perceived the leaflet as meeting it's aims. All criteria *were* achieved, indicating that this was the case. This is illustrated in Table 1.1.

Insert Table 1.1 here

Readability

The mean Flesch readability score, computed according to the procedure set out by Flesch[10] was 52.75, which indicates a fairly difficult style of writing, comparative to that of a quality magazine. However, 83.3% of respondents stated that they found the leaflet easy to read, while none reported that it was difficult for them. This point will be considered in the discussion section. The majority of individuals (95.2%) also found the length of the leaflet to be "about right".

Usefulness

3.6% found the leaflet was not useful. Most individuals found it at least "fairly useful" (54.8%), with 41.7% finding it "very useful". 9.5% of individuals found certain aspects of information unhelpful. These included the fact that commitment to treatment is required and the possibility that group work be undertaken. It is possible that participants misunderstood the question and may have meant that they found this information anxiety provoking. The wording of this question may have had an effect on these results.

Effect on Anxiety

Most individuals felt "a little anxious" about their appointment Reading the leaflet generally did not make prospective patients more anxious - a large percentage reported that it had not affected how anxious they felt (65.5%), with a smaller group maintaining that it had helped to reduce their anxiety (32.1%).

Table 1.2 shows the effect the leaflet had on individuals anxiety, detailing how they felt before and after reading it's contents.

Insert Table 1.2 here

It can be seen that the leaflet was most effective in reducing anxiety in those individuals who were a little anxious about attending a psychologist. However, in the majority of cases, the leaflet had no effect on anxiety levels. A very small percentage (2.4%) of individuals found that the leaflet actually increased their anxiety.

31% explained that they had very specific worries about their treatment. The most common worries were being able to express themselves adequately (n = 6) and talking about personal problems to a complete stranger (n = 8), (see Appendix 1.5*)*. Participants were asked an open-ended question about this matter, and the responses were then categorised into obvious themes.

One aspect of the leaflet, namely the possibility of being involved in group work as part of treatment, seemed to cause considerable anxiety. However, the leaflet does state that patients will be given the choice of whether they wish to participate in groups or not. Alternatively, certain parts of the leaflet made people feel more comfortable about coming to see a psychologist. The fact that the psychologist acts like a coach or guide rather than a "fixer" is an example of this. The explanation of confidentiality issues also helped to reduce anxiety.

Expectations

Most respondents had some idea of what to expect from attending a psychologist. However, reading the leaflet helped the vast majority know in more detail, what to expect from their visit to the department. Table 1.3 shows whether patients knew what to expect from coming to see a psychologist, and whether reading the leaflet changed their expectations in any way.

Insert Table 1.3 here

It can be seen that the leaflet has the most educating effect on those who already knew a little about what treatment would involve.

Additional Information

23.8% felt that they would prefer more information about certain issues mentioned in the leaflet, the most frequent of these again being the possibility of group work A small number of people (8.3%) felt that the leaflet had completely missed out information on certain issues. These tended to be practical pieces of information, such as working hours, the possibility of changing an appointment should patients be unable to attend, and whether patients have the choice of a male or female psychologist. These are important issues, which will be considered in the discussion.

Effect on Attendance

65.5% said that they would be more likely to attend their first appointment after reading the leaflet. No one said that the leaflet made it less likely that they would attend.

Discussion

In general, the leaflet met it's aims, however, there are certain issues which should be discussed and several possibilities for adaptations, which may increase it's usefulness. Although the Flesch Readability score indicated that the leaflet was "fairly difficult" to read, none of the respondents indicated this. This may mean that those who returned the questionnaire were of a high reading standard, while those who did not either found it difficult to read, or could not read it at all. The effect of this on the sample used and the results obtained should be acknowledged. Future information for patients should be as simple as possible, while still imparting the information required. However, it may be that the Flesch formula overestimated the level of reading difficulty, due to the fact that there were many polysyllabic words in the leaflet which would have been familiar to the reader i.e. "psychologist", "qualification", "university".

Most information gathered from the questionnaire has been positive in nature. This may indicate that the leaflet has indeed been successful, but may also show that people are reluctant to report negative information, for fear of the effect it may have on their future treatment. However, this issue *was* addressed in the covering letter sent with the questionnaire and participants were encouraged to report both positive and negative information.

The subject of group work seems to be an anxiety provoking issue for patients waiting for an appointment. This is despite the leaflet clearly explaining that patients will not be forced to join a group and will be given choice in this matter. It is possible that this last piece of information has not been read carefully, and that patients simply think the worst and expect to be offered group treatment without consultation. It is obvious that group work is anxiety provoking for many patients. This may be due to the fear of disclosing in front of many strangers, and other aspects of social anxiety. Patients may not realise the specific benefits of participating in a group and it may be useful to identify these and mention them in the leaflet, in addition to providing reassuring messages.

The additional issues which provoke anxiety (Appendix 1.5) should be acknowledged and included in any future revisions of the leaflet. In addition, it may be helpful to address these issues at the first appointment, in order to reduce subsequent non-attendance.

In retrospect, the issue of the leaflet affecting how likely people are to attend is unclear, and may have benefited from additional questioning. The leaflet can be seen to be successful if it clarifies an individual's decision about whether to attend or not. Individuals may decide that their problem does not require treatment, or that attending a psychologist is not what they expected it to be, and not the course of treatment they wish to pursue. This will effectively produce a more efficient service, as these individuals may contact the department to let them know they will not be attending *before* their appointment is sent out. This will obviously result in fewer missed appointments and more efficient use of clinicians' time. Alternatively, these patients may simply not attend their first appointment without notifying the department, resulting in high rates of non-attendance. In this case however, no one said that the leaflet made it less likely that they would attend. However, this group of people may have been contained in the 60% who did not respond to the questionnaire.

In a similar way, the fact that some individuals stated that the leaflet made no difference to the likelihood of their attendance may mean that the leaflet was unhelpful, or may mean that they would have come to the appointment regardless of whether they received the leaflet or not. Further questioning here would have been useful in clarifying this issue.

It may have been preferable to approach patients as they arrived in the department for their first appointment and asking them to complete the questionnaire then, in order to achieve a better response rate. This was considered but discarded, as the leaflet would have been read some time ago due to long waiting lists and the information may have been forgotten. Asking patients to complete a questionnaire directly before their first appointment may also prove extremely anxiety provoking for many. In addition, the process of simply being in the department may alter expectations.

It may be interesting to undertake the above in future, in order to ascertain how much of the information provided at the time of referral is remembered at the time of attendance. Asking patients after their appointment whether the information contained in the leaflet corresponded to their experience of attending may also be of use. This would indicate whether the leaflet is providing a realistic indication of the experience of psychological treatment or not. Even if the leaflet is beneficial to patients before they attend the department, if it does not prepare them for the actual experience of treatment then it's usefulness should be questioned.

Conclusion

The results of this survey indicate that the majority of patients found the leaflet useful. The leaflet also meets it's aims to a level acceptable to the department from which it is distributed.

Recommendations for Improvement

Several areas have been identified which should be considered in any future modification of the leaflet.

- The language used should be kept as simple as possible. There is evidence to suggest that the leaflet may be difficult to read, due to it's high Flesch score.
- Information should be included on topics such as working hours, whether patients have the choice of a male or female psychologist, and the possibility of changing appointment times should an appointment be unsuitable. It has been shown that these issues are anxiety provoking to some patients.
- The benefits of taking part in a group and the usual format of groups run by the department should be explained. It should be strongly emphasised that patients will not be forced to join a group if they do not wish to. The present level of emphasis on this point does not seem to be adequate.
- The leaflet should acknowledge that some people may find it difficult to explain their problem and that the psychologist will help them to do so. It may also be useful to

explain why it is sometimes advantageous to talk to a stranger rather than a friend about personal difficulties.

Although the leaflet has proven to be useful to patients, incorporating the above points may increase this usefulness. If the leaflet is modified in the future, a further evaluation should be carried out in order to ascertain whether this is the case.

References

1. Government White Paper "Working for Patients" (1989) Department of Health.

2. Morris, J.; Goddard, M. and Roger, D. (1989) The Benefits of Providing Information to Patients. University of York.

3. Matthews, A. and Ridgeway, V. (1981) Personality and Surgical Recovery: A Review. *British Journal of Clinical Psychology,* **20,** 243 - 260.

4. Myers, E.D. and Calvert, E.J. (1984) Information, Compliance and Side Effects. *British Journal of Clinical Pharmacology,* **17,** 221 - 225.

5. Baskerville, P.; Heddle, R. and Jarrett, P. (1985) Preparation for Surgery; Information Tapes for Patients. *The Practitioner,* **229,** 677 - 678.

6. Arthur, V.A.M. (1995) Written Patient Information: A Review of the Literature. *Journal of Advanced Nursing,* **21,** 1081 - 1086.

7. Sandler, D., Mitchell, J., Fellows, A. and Garner, S. (1989) Is an Information Booklet for Patients Leaving Hospital Useful? *British Medical Journal,* **298,** 870 - 874.

8. Miller, S.M., Brody, D.S. and Summeton, J. (1988) Styles of Coping with Threat; Implications for Health. *Journal of Personality and Social Psychology,* **54,** 142.

9. Larson, I. and Schumacher, H.R. (1992) Comparison of Literacy Levels of Patients in a VA Arthritis Centre with the Reading Level Required by Educational Materials. *Arthritis Care Research,* **5(1):** 13 - 16

10. Flesch, R. (1948) A New Readability Yardstick. *Journal of Applied Psychology,* **32(3),** 221 - 233.

11. Cureton, S. and Newnes, C. (1995) A Survey of the Practice of Psychological Therapies in an NHS Trust. *Clinical Psychology Forum,* **76,** 6 - 10.

12. Moser, C.A. and Kalton, G. (1971) Survey Methods in Social Investigation. Aldershot:Gower.

Tables

Table 1.1; Criteria required for relevant questions in order that the leaflet achieved it's aims.

Question	**Criterion**	**Actual Result**
How easy was it to understand the information in the leaflet?	Less than 10% to endorse "Difficult".	0% endorsed "Difficult".
What did you think of the length of the leaflet?	Over 60% to endorse "About right".	95.2% endorsed "About right".
How useful did you find the leaflet?	Less than 30% to endorse "Not useful".	3.6% endorsed "Not useful".
Has reading the leaflet made you feel....?	Less than 10% to endorse "More anxious".	2.4% endorsed "More anxious".
Has the leaflet helped you know what to expect from coming to see a psychologist?	Less than 40% to endorse "No, not at all."	1.2% endorsed "No, not at all."
Did the leaflet have any effect on how likely you were to attend once you have an appointment?	Less than 40% to endorse "The leaflet made no difference to whether I would attend or not."	34.5% endorsed "The leaflet made no difference to whether I would attend or not."

Table 1.2: Patient's anxiety before and after reading the leaflet (n = 84)

	Less anxious after reading	No different after reading	More anxious after reading	Total
Not anxious before reading	2	13	0	15
A little anxious before reading	24	39	2	65
Very anxious before reading	1	3	0	4.
Total	27	55	2	84

Table 1.3; Patients expectations about treatment, and whether the leaflet helped them know what to expect (n = 84)

	Leaflet definitely helped them know what to expect.	Leaflet helped a little bit in knowing what to expect.	Leaflet did not help at all in knowing what to expect.	Total
Definitely knew what to expect.	6	3	0	9
Knew a little bit what to expect.	23	32	1	56
Didn't know what to expect at all.	7	12	0	19
Total	36	47	1	84

Chapter 2 - Literature Review

THE ASSESSMENT OF DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY: A REVIEW HIGHLIGHTING THE NEED FOR VALIDATED SCALES

Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology.

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THE ASSESSMENT OF DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY - A REVIEW HIGHLIGHTING THE NEED FOR VALIDATED SCALES.

Abstract

Despite the high proportion of individuals with learning disabilities and mental health problems, research in this field has been scarce. In particular, studies concerning depression and learning disabilities are relatively limited. Models based on the general adult population have previously been assumed to be applicable to the learning disabled population. This is perhaps understandable given the fundamental difficulties in the assessment of depression in individuals with learning disabilities e.g. communication difficulties, subsequent reliance on third party reports, and the relatively heterogeneous population in question. This review considers the need for the development of a valid and reliable self-report measure of depression in learning disabled individuals. Measures such as these are widely available and used routinely in adult mental health fields for the purpose of monitoring treatment outcome, symptom screening and clarifying diagnosis. A measure developed specifically for learning disabled individuals would have equal value.

Prevalence, Symptomatology and Risk Factors

Although it has for long been recognised that people with learning disabilities also suffer from mental illness, research in this field has been limited (Eaton and Menolascino, 1982). Sovner and Hurley (1983) reported that learning disabled individuals experience the full range of mental health problems seen in the general population, while Gostason (1985) showed an increasing prevalence of mental illness with increasing levels of learning disability.

Several prevalence studies of depression have been completed with variable results (Campbell and Malone, 1991). Most estimates are in the range of between 1-5% (Wright, 1982). This range is due to the different populations which have been studied, differences in the diagnostic criteria used, and the procedures used for case detection. However, the phenomenon of "diagnostic overshadowing" often leads to underestimates, and Reiss (1990) reported that only one quarter of learning disabled individuals with a psychiatric disorder had received a diagnosis.

The point prevalence for Major Depressive Disorder in the general population is thought to be 5-9% for women and 2-3% for men, according to DSM-IV (American Psychiatric Association, 1994). In the general population, depression comprises depressed mood, tearfulness, diminished interest/pleasure in activities, appetite loss/gain, insomnia/hypersomnia, psychomotor agitation/retardation, fatigue, feelings of worthlessness, poor concentration, and recurrent thoughts of death or suicidal ideation. These can be measured by instruments such as the Beck Depression Inventory (Beck, Ward, Mendelson, Mock and Erbaugh, 1961), the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) and the Zung Depression Inventory (Zung, 1965). There is no such instrument in use in the learning disability field however, therefore symptom measurement can be problematic.

It is hardly surprising that mental illness is a common problem in individuals with a learning disability. In individuals with mild to moderate learning disabilities, social risk factors such as institutionalisation, stigmatisation, social isolation and rejection are likely to have a major influence. Depression particularly has been shown to be associated with a low level of social support (Meins, 1993) and a high level of stigmatisation (Reiss and Benson, 1985). Many people in the general population have stressful life circumstances which may contribute to the occurrence of mental health problems. This is also true for individuals with learning disabilities, who in addition, do not have compensating factors which make up for these difficulties. Individuals with learning disabilities may also be less able to conceptualise and express their feelings (Meins, 1995), therefore specific life events such as bereavement, may lead to an increased risk of developing mental health problems.

Organic factors may also play a role in the aetiology of mental illness in learning disabled individuals. There is a high prevalence of brain damage associated with learning disability, and Lund (1985) in a study of 300 individuals, reported that 52% of those with epilepsy had a psychiatric diagnosis compared with just 26% of those without epilepsy.

Conceptualisation of Depression in Learning Disabled Individuals

Sovner and Hurley (1983) maintain that mental illness in learning disabled individuals should not be regarded as fundamentally different from that occurring in non-learning disabled individuals. This may be the case for those with mild learning disabilities, but is unlikely for those with more severe and profound disabilities. However, it also depends on the theory of depression which is chosen to understand the illness in the general population.

Many theories of depression exist based on the general population, but it is unclear whether these are also applicable to the learning disabled population. There has been some discussion as to whether learning disabled people have the intellectual capacity necessary to experience depression. For example, Beck's (1976) cognitive theory maintains that depression occurs due to an individual holding a set of negative beliefs about themselves, life events and their future expectations. People with significant learning disabilities may find it difficult to conceptualise their lives in this way (Meins, 1995), and therefore it may not be possible to say that they suffer from depression according to a cognitive framework. In addition, problems follow from the way that cognition unfolds, and the developmental stage an individual is at. The capacity to produce and dismiss alternative hypotheses about future events is not thought to take place until formal operational stage in adolescence (Piaget, 2000), but these thought processes are thought to be the ones that directly contribute to feelings of hopelessness and despair according to cognitive theories of depression. Many non-learning disabled children do not reach this level of thinking (Wolfe, 2000), therefore it is unlikely that learning disabled individuals do either.

It is unlikely that learning disabled individuals experience depression in a psychodynamic way, simply due to the fact that Freud (1917) explains depression as anger turned against oneself after the loss of a loved object. This results in symptoms of withdrawal. Individuals with learning disabilities also exhibit withdrawal symptoms when depressed, however are more likely to express emotional distress in external ways, which can be seen by the presence of behavioural problems and aggression in those learning disabled individuals with depression.

Glick and Zigler (1995) have suggested a theoretical explanation for the differences in emotional expression between mildly and more severely learning disabled people. They maintain that there is a developmental advancement in the expression of emotional disturbance. In the early stages of development, behaviour is represented by "immediate, direct and unmodulated responses to stimuli", while later development uses "indirect, ideational and verbal or symbolic patterns". This means that those with significant learning disabilities will show their emotional disturbance through their actions rather than through their cognitions. They are also more likely to turn against others than turn against themselves. This may explain how the expression of emotional distress varies across levels of learning disability.

It is almost impossible to choose one theory of depression which will be appropriate for use through the entire range of learning disability. According to Meins (1995), consideration must be given to the level of learning disability. As the extent of learning disability increases, the presentation of depressive symptoms changes and becomes unlike that experienced by non-learning disabled and more mildly learning disabled people. Individuals with mild learning disabilities are more likely to exhibit symptomatology found in diagnostic criteria such as DSM-IV (A.P.A., 1994) and ICD-10 (World Health Organisation, 1994). This is clearly illustrated in Table 2.1. The theories and conceptualisations regarding depression in the general population may be true of those with mild learning disabilities, although this may not be the case for individuals with severe or profound learning disabilities.

Insert Table 2.1 here

Conceptualisations of depression in the learning disabled population have tended to focus on behavioural theories of reinforcement contingencies more than on cognitive theories. Depressive symptoms are seen as behaviours which can be produced due to reinforcers in the environment, and new behavioural responses to these reinforcers can be learnt. For example, Lewinsohn (1974) explained depression as occuring due to a lack of positive reinforcement which may result from poor social skills or less opportunity to obtain reinforcement from socially significant others. Depression in learning disabled individuals can be understood well in this way.

Another theory which may be applicable to individuals with learning disabilities is Seligman, Maier and Solomon's (1971) theory of Learned Helplessness. This is a non-cognitive mediational theory which shows that anxiety is the initial response to stress, but that it is replaced by depression if the individual comes to believe control is unavailable. This may be especially applicable to learning disabled individuals, many of whom have little control or choice in everyday life. In addition, this effect has also been shown in dogs, which lends support for its applicability to even profoundly disabled individuals, who have limited cognitive skills.

In recent years, more multidisciplinary ways of looking at depression have evolved, which consider cognition as well as simple behavioural responses. In addition, biological models should also be considered, with factors such as degree of brain damage (Lund, 1985), neurological abnormalities (Rutter, 1971), and genetics (Glue, 1989) providing useful alternatives to social and behavioural models. The limbic system has been shown to be overactive in individuals with depression, which points to a physiological cause of depression. This way of understanding depression can be applied to both learning disabled individuals and the general population, however, it may not be wise to state that this is the sole cause of depression. Psychological factors may also interact with physiological causes.

It is extremely difficult to choose one theory which will be applicable to the entire spectrum of learning disability, due to the heterogenity of the population in question. However, behavioural theories such as learned helplessness are perhaps the most appropriate. The assessment of depression should take into account the theories used to understand the illness, and practice may change depending on which theory is used. If depression is seen as purely a behavioural concept, then assessment should take into account behavioural factors and reinforcers in the environment rather than cognitive processes. However, as there is no clear viewpoint on this as yet, it would seem prudent to include both behavioural and cognitive factors in the assessment of depression. It is extremely difficult to make definitive statements about exactly how depression is experienced due to several areas of difficulty which will be discussed below.

Problems in Assessment of Depression in Individuals with Learning Disabilities

Difficulty expressing emotions verbally

The assessment and diagnosis of people with depression and learning disabilities can be difficult for several reasons. Firstly, people with a learning disability may find it hard to express how they are feeling verbally, and may do this in alternative ways, such as through aggressive behaviour or somatic complaints (Pawlarcyzk and Beckwith, 1987; Meins, 1995). However, there have also been some accounts of mild to moderately disabled individuals reporting their emotional states reliably when they are given the opportunity and assistance to do so, and are provided with the language and means required (Kazdin et al, 1983; Reiss and Benson, 1985). Many mild to moderately learning disabled people are also able to identify emotional states in others' speech and can infer emotion from situational cues (Reed and Clements, 1989).

Comprehension difficulties and verbal ability

Clinical interviews *can* be used for diagnosis if the individual concerned has adequate verbal ability. Lindsay, Michie, Baty and Smith (1994) for example, showed that people with a mild or moderate learning disability showed a high degree of consistency when reporting feelings of anxiety and depression. Learning disabled individuals are also able to tackle fairly complex propositions providing they are appropriately structured and the appropriate language is used (Moss et al, 1997). For example, people with learning disabilities may have a poor concept of time and find it difficult to give accurate information regarding the duration and frequency of their symptoms. Moss et al (1997) used a "time anchor" to overcome this problem, where the individual is asked to think of a certain event in the recent past and describe how they have felt since then.

Reliance on third party reports

It is difficult for clinicians to infer internal states and emotions purely by observational procedures. Communication difficulties often result in the clinician relying more heavily on third party reports or observations during the diagnostic process. The validity of diagnosis for non-verbal individuals is therefore unclear (Moss, 1995). Many individuals' mental health problems may remain undetected due to communication difficulties and the tendency of some clinicians to avoid asking them how they feel as they assume they will not be able to explain properly (Patel, Goldberg and Moss, 1993). However, a diagnosis cannot always be made from observations alone, and the reports of the individuals themselves are of paramount importance. Observation nevertheless is an important component of assessment and provides useful information. Observable symptoms commonly precipitate referral and a diagnosis of probable depression might be made on the basis of these symptoms alone. However, it is useful to gather additional information from the individual, if s/he has adequate verbal ability.

Moss, Prosser, Ibbotson and Goldberg (1996) recommended that interviewing respondents *and* informants leads to more accurate rates of detection when using the

Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD). Respondents may not always have insight into their condition, and in some cases their reports may be less adequate than the informant's or even absent altogether in the case of non-verbal individuals. They may lack detail on some information but may also be better at communicating their cognitions than an informant would be. Moss et al (1997) found that around one third of cases are missed if either interview is omitted.

Acquiescence and short attention span

Issues of acquiescence and short attention span should be acknowledged and addressed (Sigelman, Budd, Spanhel and Shoenrock, 1981). Acquiescence occurs when an individual answers in a positive manner to two contradictory prompts, i.e. "Are you happy?" and "Are you sad?" It is thought that this occurs especially in individuals with learning disabilities due to impaired cognitive development and as an attempt to increase social desirability (Shaw and Budd, 1982). These problems can be minimised by recapping and summarising what the respondent has said to give them the opportunity to accept or refute their answer.

Diagnostic overshadowing

Diagnostic overshadowing, which is the tendency to see the learning disability itself as more significant than any mental health problems which are apparent may also occur. This results in learning disabled individuals with mental illness not being identified and not being offered the required treatment (Levitan and Reiss, 1983). This can also lead to underestimates of the incidence and prevalence of mental health problems in this population (Reiss, 1990).

Assessment of Depression in Learning Disabled Individuals

Despite the above difficulties, several assessment tools have been developed for use with learning disabled individuals with depression and other mental health problems.

Diagnostic Schedules

Detailed description regarding these inventories and their psychometric properties can be found in Table 2.2. The Psychopathology Instrument for Mentally Retarded Adults (Matson, Kazdin and Senatore, 1984) was one of the first inventories and diagnoses psychiatric disturbance in general. It is a symptom inventory of 56 items derived directly from the DSM-III (American Psychiatric Association, 1980). Watson, Aman and Singh (1988) however, questioned the utility of developing measures for learning disabled individuals which are based on DSM criteria due to the aforementioned differences in presentation between the general population and learning disabled individuals. The Reiss Screen (Reiss 1987) is used for initial symptom identification and is valuable for screening purposes, but cannot provide the depth and level of detail necessary to make an accurate diagnosis (Moss, et al, 1993). The Psychiatric Assessment Schedule for Adults with a Developmental Disability (Moss et al, 1993, 1997) is a semi-structured interview, based on the ICD-10 clinical interview (WHO, 1994) which is useful for providing diagnoses, and helping staff recognise mental health problems and make informed referral decisions. A classificatory system for use with adults with learning disabilities has recently been developed by The Royal College of Psychiatrists (2001), entitled DC-LD (Diagnostic Criteria for use with Adults with Learning Disabilities/Mental Retardation). It is intended for use with adults with moderate to profound learning disabilities and can be used in conjunction with ICD-10 for those with mild learning disabilities. It is not an interviewing instrument however, but purely a classificatory system providing operationalised diagnostic criteria, therefore no data are available regarding its psychometric properties.

Insert Table 2.2 here

Rating Scales

Schedules also exist specifically for the quantification of depressive symptomatology, although Sturmey, Reed and Corbett (1991) reported a lack of important psychometric data in this area. Two of the most commonly used in the past in adult mental health fields are the Beck Depression Inventory (Beck, et al, 1961) and the Zung Self-Rating

Depression Scale (Zung, 1965). Both of these scales were adapted for use with learning disabled populations by Kazdin, Matson and Senatore (1983) primarily by simplifying language, using a pictorial response format and interviewing participants verbally. One hundred and ten participants completed the modified Beck Depression Inventory (Beck et al, 1961), the Zung Self Rating Depression Scale (Zung, 1965), the MMPI depression scale (Hathaway and McKinley, 1967), the Thematic Apperception Test (Riddle and Rapoport, 1976), and the Psychopathology Instrument for Mentally Retarded Adults (Matson, Kazdin and Senatore, 1984). Informants completed the Hamilton Rating Scale for Depression (Hamilton, 1960) and an informant version of the PIMRA. It was found that the BDI correlated with the Zung scale ($r=.59$, $p<.001$), the MMPI depression scale ($r=.25$, $p<.01$) and one informant measure, the Hamilton Rating Scale for Depression ($r=.24$, $p<.01$). The reported values of r however, are well below acceptability ($r=.70$; Gliner, 2000). The Zung scale correlated with fewer measures. All measures were related consistently to a diagnosis of depression. Results, however, were generally disappointing and largely inconsistent. The modified BDI has also been found to have an internal consistency of $\alpha = 0.59$ (Helsel and Matson, 1988) and is significantly lower than that of the original ($\alpha=0.86$) (Beck et al, 1961). Nunnally (1978) reported that values of α should lie between 0.70 and 0.90.

Lindsay et al (1994) also used a modified version of the Zung Depression Inventory with learning disabled individuals. Items were rephrased to ensure understanding and the response format was simplified to presence or absence of the symptom in question. A high degree of convergent validity was demonstrated between the modified Zung scale and the depression factor of the General Health Questionnaire ($r=.65$, $p<.05$), indicating the self-report of individuals with learning disabilities to be reliable and valid.

The validity of using schedules initially developed for the general population on a learning disabled population is questionable due to the aforementioned differences in presentation between the two populations. Furthermore, any problems with the original scale are also reproduced.

Rating scales originally developed for use with children have also been used with learning disabled individuals due to the similarity of problems in assessment in terms of limited verbal skills and dependence on information from third parties. The informant version of the Children's Depression Inventory has been used with adults who have learning disabilities and depression and convergent validity and high internal consistency (r=.83, when r refers to the point-biserial correlation of item-whole correlations) demonstrated (Benavidez and Matson, 1993). Meins (1993) demonstrated an internal consistency of α=.86, satisfactory inter-rater reliability and acceptable validity when the informant version was compared to DSM-III diagnosis of depressive disorder.

Recently, ICD-10 and DSM-IV *have* been used in learning disability research, although in most cases authors have had to modify or limit their application in some way in order to be used with this population (Sturmey, 1993). For example, presumed additional behavioural equivalents of depression such as onset of aggressive behaviour, screaming and reduction in communication were added to the existing DCR-10 criteria (WHO 1992) by Clarke and Gomez (1999). Doing this however, can produce substantial changes in the resulting diagnosis, and is therefore not an optimal situation (Zimmerman, Coryell, Corenthall and Wilson, 1986).

Furthermore, certain symptoms which commonly occur in depressed learning disabled individuals do not appear in DSM-IV, and other criteria in DSM-IV are never fulfilled by learning disabled people (Cooper and Collacott, 1994). For example, "feelings of worthlessness or guilt" and "suicidal ideation or attempts" are rarely reported (Meins, 1995) and symptoms such as self-injurious behaviour and aggression, common in learning disabled individuals are not included in DSM-IV (Moss, et al, 2000). Symptom checklists and rating scales are commonly derived from diagnostic schedules. It is apparent that if these scales are developed using diagnostic schedules appropriate for the general population, there is a risk of omitting crucial symptoms and therefore not having a valid symptom screening tool. Similarly, many of the symptoms contained in the checklist may be redundant.

There has yet to be a self-report depression questionnaire developed specifically for use with individuals with learning disabilities. This would be of use to clinicians working in the field for symptom screening, outcome measurement, and as an aid to diagnosis. Measures such as these are widely available in the adult mental health field and the development of a reliable and valid scale for people with learning disabilities is long overdue.

Conclusion

Although there are considerable difficulties involved in the development of a self report depression scale for use by learning disabled individuals, there is no question that it is needed. This paper has described the measures presently available for individuals with learning disabilities and depression, and the problems faced in the development of assessment tools for the learning disabled population. Depression scales have been successfully developed for use both with children and adults, therefore it is important that the issue be tackled in the field of learning disabilities also. In the general population, the use of reliable and valid symptom checklists for treatment evaluation procedures has led to more accurate monitoring of progress and outcome.

It is clear that there is a real need for a measure of depression which has been developed specifically for a learning disabled population. It is also clear that although observational and third party reports are valuable, the most pertinent information would be gained through asking the learning disabled individual as well as their carers. At present there are several instruments that diagnose psychiatric disturbance in general, but none that concentrate purely on quantifying depressive symptomatology. Most existing instruments also focus on the diagnosis of psychiatric disorder, but neglect the area of outcome measurement. A measure for learning disabled individuals similar to the Beck Depression Inventory (Beck, et al, 1961) but not simply a modified general population tool, would be of great use as it could be used for the purpose of screening and monitoring progress in treatment. Like the BDI, it should be quick and easy to use and should require no specialised training to administer, therefore it would be accessible to all health professionals. It should comprise cognitive and behavioural aspects of depressive symptoms, and should ideally include an informant measure to ensure the most accurate information is gathered (Moss et al , 1996) or to provide a measure for individuals who have difficulty communicating verbally. The development of a valid and reliable measure of depression may allow more extensive research to be undertaken in the area of depression and learning disabilities, especially its identification and treatment.

References

Aman, M.G., Watson, J.E., Singh, N.N., Turbott, S.H. and Wilsher, C.P. (1986) Psychometric and demographic characteristics of the Psychometric Instrument for Mentally Retarded Adults. *Pharmacology Bulletin,* **22,** 1972 - 1976.

American Psychiatric Association (1980) Diagnostic and Statistical Manual of Mental Disorders - Third Edition. Washington, DC, American Psychiatric Association, 1980.

American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition. Washington, DC, American Psychiatric Association, 1994.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J.E. and Erbaugh, J. (1961) An inventory for measuring depression. *Archives of General Psychiatry,* **4**, 561 - 571.

Beck, A.T. (1976) Cognitive therapy and emotional disorders. New York: International Universities Press.

Beck, A.T., Steer, R.A. and Brown, G.K. (1996) Manual for the Beck Depression Inventory - II. The Psychological Corporation. Harcourt Brace and Company, San Antonio.

Benavidez, D.A. and Matson, J.L. (1993) Assessment of depression in mentally retarded adolescents. *Research in Developmental Disabilities,* **14,** 179 - 188.

Campbell, M. and Malone, R.P. (1991) Mental retardation and psychiatric disorders. *Hospital and Community Psychiatry,* **42**, 374 - 379.

Clark and Gomez (1999) Utility of modified DCR-10 criteria in the diagnosis of depression associated with intellectual disability. *Journal of Intellectual Disability Research,* **43,** 413 - 420.

Cooper, S.A. and Collacott, R.A. (1994) Clinical features and diagnostic criteria of depression in Down's syndrome. *British Journal of Psychiatry*, **165,** 399 - 403.

Eaton, L.F. and Menolascino, F.J. (1982) Psychiatric disorders in the mentally retarded: Types, problems and challenges. *American Journal of Psychiatry,* **139**, 1297 - 1303.

Freud, S. (1917) *A general introduction to psychoanalysis.* Translated by Riviere, J. New York: Washington Square Press, 1952.

Lewinsohn, P.H. (1974) A behavioural approach to depression. In R.J. Friedman and M.M. Katz (Eds), *The psychology of deopression: Contemporary theory and research.* Washington D.C.: Winston-Wiley.

Gask, L. (1988) The Psychiatric Assessment Schedule (PAS) (revised) Manchester: Department of Psychiatry, Manchester University.

Glick, M. and Zigler, E. (1995) Developmental differences in the symptomatology of psychiatric inpatients with and without mild mental retardation. *American Journal of Mental Retardation,* **99**, 407 - 417.

Gliner, J.A. (2000) Single subject designs. *Journal of the American Academy of Child and Adolescent Psychiatry,* **39,** 1327 - 1329.

Glue, P. (1989) Rapid cycling affective disorders in the mentally retarded. *Biological Psychiatry,* **26,** 250 - 256.

Gostason, R. (1985) Psychiatric illness among the mentally retarded: A Swedish population study. *Acta Psychiatrica Scandinavica,* **Suppl 318,** 3 - 117.

Hamilton, M. (1960) A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry,* **23,** 56 - 61.

Hathaway, S.R. and McKinley, J.C. (1967) Minnesota Multiphasic Personality Inventory: Manual for Administration and Scoring. New York, Psychological Corporation.

Helsel, W.J. and Matson, J.L. (1988) The relationship of depression to social skills and intellectual functioning in mentally retarded adults. *Journal of Mental Deficiency Research,* **32,** 411 - 418.

Kazdin, A.E., Matson, J.L. and Senatore, V. (1983) Assessment of depression in mentally retarded adults. *American Journal of Psychiatry,* **140,** 1040 - 1043.

Levitan, G.W. and Reiss, S. (1983) Generality of diagnostic overshadowing across disciplines. *Applied Research in Mental Retardation,* **4,** 59 - 64.

Lindsay, W.R., Michie, A.M., Baty, F.J. and Smith, A.H.W. (1994) The consistency of reports about feelings and emotions from people with intellectual disability. *Journal of Intellectual Disability Research,* **38,** 61 - 66.

Lund, J. (1985) Epilepsy and psychiatric disorder in the mentally retarded adult. *Acta Psychiatrica Scandinavica,* **72,** 557 - 562.

Matson, J.L., Kazdin, A.E. and Senatore, V. (1984) Psychometric properties of the Psychopathology Instrument for Mentally Retarded Adults. *Applied Research in Mental Retardation,* **5,** 881 - 889.

Meins, W. (1993) Assessment of depression in mentally retarded adults. *Journal of Intellectual Disability Research,* **39,** 41 - 45.

Meins, W. (1995) Symptoms of depression in mentally retarded adults. *Journal of Intellectual Disability Research,* **39,** 41 - 45.

Moss, S.C., Patel, P., Prosser, H., Goldberg, D.P., Simpson, N., Roew, S. and Lucchino, R. (1993) Psychiatric morbidity in older people with moderate and severe learning disability (mental retardation). Part 1: development and reliability of the patient interview (the PAS-ADD). *British Journal of Psychiatry,* **163,** 471 - 480.

Moss, S.C. (1995) Methodological issues in the diagnosis of psychiatric disorders in adults with learning disability. *Thornfield Journal* (University of Dublin), **18,** 9 - 18.

Moss, S., Prosser, H., Ibbotson, B., and Goldberg, D. (1996) Respondent and informant accounts of psychiatric symptoms in a sample of patients with learning disability. *Journal of Intellectual Disability Research,* **40,** 457 - 465.

Moss, S.C., Ibbotson, B., Prosser, H., Goldberg, D.P., Patel, P. and Simpson, N. (1997) Validity of the PAS-ADD for detecting psychiatric symptoms in adults with learning disability. *Social Psychiatry and Psychiatric Epidemiology,* **32**, 344 - 354.

Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C. and Alborz, A. (2000) Psychiatric symptoms in adults with learning disability and challenging behaviour. *British Journal of Psychiatry,* **177,** 452 - 456.

Nunnally, J.C., Jr. (1978) *Psychometric Theory* (2nd edition) McGraw-Hill, New York.

Patel, P., Goldberg, D.P. and Moss, S.C. (1993) Psychiatric morbidity in older people with moderate and severe learning disability (mental retardation). Part II: The prevalence study. *British Journal of Psychiatry,* **163,** 481 - 491.

Pawlarcyzk and Beckwith (1987) Depressive symptoms displayed by persons with mental retardation: a review. *Mental Retardation,* **25,** 325 - 330.

Piaget, J. (2000) Piaget's Theory. In Lee, Kang (Ed) et al. Childhood cognitive development: The essential readings. Essential readings in development psychology. (pp 33-47) Malden, MA, US: Blackwell Publishers, Inc. xxi, 340 pp.

Reed, J. and Clements, J. (1989) Assessing the understanding of emotional states in a population of adolescents and young adults with mental handicaps. *Journal of Mental Deficiency Research,* **33,** 229 - 233.

Reiss, S. and Benson, B.A. (1985) Psychosocial correlates of depression in mentally retarded adults: I: Minimal social support and stigmatisation. *American Journal of Mental Deficiency,* **89,** 331 - 337.

Reiss, S. (1987) Reiss Screen for Maladaptive Behaviour. Chicago: International Diagnostic Systems, Inc.

Reiss, S. (1988) *Test Manual for the Reiss Screen for Maladaptive Behaviour.* Worthington, OH: International Diagnostic Systems, Inc.

Reiss, S. (1990) Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *American Journal on Mental Retardation,* **94,** 578 - 585.

Riddle, K.D. and Rapoport, J.L. (1976) A 2 year follow-up of 72 hyperactive boys. *Journal of Nervous and Mental Disease,* **162,** 126 - 134.

Royal College of Psychiatrists. (2001) DC-LD (Diagnostic Criteria for Psychological Disorders for use with Adults with Learning Disabilities (Mental Retardation). Gaskell Press: London.

Rutter, M. (1971) Psychiatry. In Wortis, J. (ed) *Mental Retardation: An Annual Review,* Vol 3, pp. 186 - 221. New York: Grune and Stratton.

Seligman, M.E.P., Maier, S.F. and Solomon, R.L. (1971) Unpresictable and uncontrollable aversive events. In Brush, F.R. (Ed). *Aversive conditioning and learning.* New York: Academic Press.

Senatore, V., Matson, J.L. and Kazdin, A.E. (1985) An inventory to assess psychopathology in mentally retarded adults. *American Journal of Mental Retardation,* **89,** 459 - 466.

Shaw, J.A. and Budd, E. (1982) Determinants of acquiescence and nay saying of mentally retarded persons. *American Journal of Mental Deficiency,* **87,** 108 - 110.

Sigelman, C.K., Budd, E.C., Spanhel, C.L. and Schoenrock, C.J. (1981) When in doubt say yes: Acquiescence in interviews with mentally retarded persons. *Mental Retardation,* **19,** 53 - 58.

Sovner, R. and Hurley, D.A. (1983) Do the mentally retarded suffer from affective illness? *Archives of General Psychiatry,* **40,** 61 - 67.

Sturmey, P. (1993) The use of DSM and ICD diagnostic criteria in people with mental retardation. *Journal of Nervous and Mental Disease,* **181,** 38 - 41.

Sturmey, P. and Ley, T. (1990) The psychopathology instrument for mentally retarded adults. Internal consistencies and relationship to behaviour problems. *British Journal of Psychiatry,* **156,** 428 - 430.

Sturmey, P., Reed, R. and Corbett, J. (1991) Psychometric assessment of psychiatric disorders in people with learning difficulties (mental handicap): a review of measures. *Psychological Medicine,* **21,** 143 - 155.

Watson, J.E., Aman, M.G. and Singh, N.N. (1988) The Psychopathology Instrument for Mentally Retarded Adults: psychometric characteristics, factor structure and relationship to subject characteristics. *Research in Developmental Disabilities,* **9,** 277 - 290.

Wing, J., Nixon, J., Von-Cranach, M. and Strauss, A. (1977) Further developments of the present state examination and CATEGO system. *Arch-Psychiatr-Nervenkr,* **224,** 151 - 160.

Wolfe, F.E. (2000) Levels of Piagetian development among adult mathematics students. *Dissertation Abstracts International, A (Humanities and Social Sciences),* **60,** (9-A), Apr, US: Univ Microfilms International, 3239.

World Health Organisation (1992) *ICD-10: International Classification of Diseases,* 10th Revision. World Health Organisation, Geneva.

World Health Organisation (1994) *International Classification of Mental and Behavioural Disorders (ICD-10).* World Health Organisation, Geneva.

Wright, E.C. (1982) The presentation of mental illness in mentally retarded adults. *British Journal of Psychiatry,* **141,** 496 - 502.

Zigmond, A.S. and Snaith, R.P. (1983) The Hospital Anxiety and Depression Scale, *Acta Psychiatrica Scandinavica,* **67,** 361 - 370.

Zimmerman, M., Coryell, C., Corenthall, C. and Wilson, S. (1986) The research diagnostic criteria for endogenous depression and the dexamethosone suppression test: A discriminant function analysis. *Psychiatric Research,* **14,** 197 - 208.

Zung, W.W.K. (1965) A self rating scale for depression. *Archives of General Psychiatry,* **12,** 63 - 70.

Tables

Table 2.1 - Prevalence (%) of DSM-III criteria for major depression for two levels of learning disability (Meins, 1995)

Table 2.2 - Diagnostic schedules for measuring psychopathology in adults with learning disabilities

Table 2.1 - Prevalence (%) of DSM-III criteria for major depression for two levels of learning disability (Meins, 1995)

DSM-III Criteria	Mild LD	Severe LD
Mood disturbance	90	92
Depressed mood	65	8
Irritable mood	25	83
Decreased interest/pleasure	50	58
Appetite disturbance	45	25
Weight loss	35	25
Weight gain	10	0
Sleep disturbance	85	58
Insomnia	70	50
Hypersomnia	15	8
Motor disturbance	90	100
Agitation	60	92
Retardation	30	8
Low energy or fatigue	55	0
Feelings of worthlessness/guilt	25	17
Decreased concentration/indecisiveness	35	8
Suicidal ideation/attempts	30	8

Table 2.2 - Diagnostic schedules for measuring psychopathology in adults with learning disabilities

Diagnostic Schedule	**Description**
Psychiatric Assessment Schedule for Adults with a Developmental Disability (Moss et al, 1993, 1997).	Semi-structured interview. Modification of the Psychiatric Assessment Schedule (Gask, 1988). Based on the Present State Examination (Wing, et al, 1977). Patient and informant interviews included. Can detect symptoms and produce diagnoses. Can be used with non-verbal individuals as informant interview has shown reliable and valid diagnoses alone. Mean inter-rater reliability shown to be 0.8 (Moss, 1993). Mean kappa for all items was 0.72 Three components - the checklist, the Mini PAS-ADD and the diagnostic interview. Diagnostic interview is comprehensive but time consuming and impractical for treatment evaluation purposes. Mini PAS-ADD and the checklist take less time to administer but rely on carer information only.
Reiss Screen (Reiss, 1987)	Includes 36 items on a three point scale to indicate whether the symptom is "no problem, problem, or major problem". Includes psychiatric symptoms, but also aggressive, self injurious behaviour and items related to dependency and assertiveness. Cronbach's coefficient alpha estimated at .84 for the adult instrument (Reiss, 1988).
Psychopathology Instrument for Mentally Retarded Adults (Matson, Kazdin and Senatore, 1984)	Self-report and informant scales. Symptom inventory of 56 items derived directly from DSM-III. Median test-retest reliabilities were 0.58 for the self report version and 0.78 for the informant version (Senatore, et al, 1985). Internal consistencies were high, although several subsequent studies have reported more modest values than initially thought (Aman, et al, 1986, Sturmey and Ley, 1990).

Chapter 3 - Major Research Proposal

PSYCHOMETRIC PROPERTIES OF A NEW SCALE FOR MEASURING DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY: THE GLASGOW DEPRESSION SCALE FOR PEOPLE WITH A LEARNING DISABILITY

Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology.

Prepared in accordance with guidelines (Appendix 3.1)

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Summary

It is intended to develop a self-report scale which can be completed by individuals with mild to moderate learning disabilities in order to assess the presence of depressive symptomatology. A parallel scale will also be developed which can be completed by the carers of the learning disabled individual, for the same purpose. The psychometric properties of the scale will be evaluated and the scale modified as a result of this.

The study will be carried out in two areas - Renfrewshire and Greater Glasgow - and will recruit participants from Community Learning Disabilities Teams and Adult Mental Health Psychology Departments.

Introduction

For many years now, it has been recognised that people with learning disabilities also suffer from mental illness (Tredgold, 1908). Surprisingly though, the research in this field has been very limited (Eaton and Menolascino, 1982). There is now a growing recognition of the need to respond more adequately to mental health problems in this population.

Several studies have been completed detailing the prevalence rates of depression in people with a learning disability, however, different studies have reported different rates (Meins, 1993; Duncan, Penrose and Turnbull, 1936). This is due to the different populations which have been studied, differences in the diagnostic criteria used, and the procedures used for case detection. Most prevalence rates however, lie in the region of 1%-5% (Wright, 1982).

The fact that there are very few prevalence studies of depressive disorders in people with learning disabilities indicates the extent to which this area has previously been neglected. Models of depression are based on the general adult population and there has been little thought as to whether these models can also be used with the learning disabled population.

There are several areas of difficulty which can complicate the assessment and diagnosis of people with depression and learning disabilities. Firstly, people with a learning disability may find it hard to express how they are feeling verbally, and therefore do this in alternative ways, such as through aggressive behaviour or somatic complaints (Meins, 1995). In addition, communication difficulties often result in the clinician relying more heavily on third party reports or observations during the diagnostic process. The validity of diagnosis for non-verbal individuals is therefore unclear (Moss, 1995).

Furthermore, diagnostic criteria such as ICD-10 and DSM-IV, although helpful for use with non-learning disabled populations, are of limited use in this area. This is due to the fact that learning disabled people with depression may present differently from people without a learning disability. To complicate matters further, people with a severe or profound learning disability may present differently from those with a mild or moderate disability (Meins, 1995).

Several assessment instruments have been developed for use specifically with individuals with a learning disability. Examples of those intended to detect a wide range of disorders are the Psychopathology Instrument for Mentally Retarded Adults (Matson, Kazdin and Senatore, 1984) and the Psychiatric Assessment Schedule for Adults with a Developmental Disability (Moss et al, 1993;1997). The PAS-ADD is a semi-structured clinical interview, which is conducted both with the patient and an informant. The PIMRA is also conducted with the patient and an informant, and is a symptom inventory of 56 items derived directly from the DSM-III (American Psychiatric Association, 1980).

Self rating schedules also exist specifically for the diagnosis of depression. Two of the most common are The Beck Depression Inventory (Beck, Ward, Mendelson, Mock and Erbaugh, 1961) and the Zung Self-Rating Depression Scale (Zung 1965). The Zung Self Rating Depression Scale is a short, self administered scale which measures the frequency of affective, psychological and physiological concomitants of depression quantitatively.

For each item, the patient must indicate whether the symptom in question occurs "a little of the time, some of the time, a good part of the time, or most of the time". The Beck Depression Inventory also provides a quantitative assessment of the intensity of depression, and includes items regarding cognitive, behavioural and somatic symptomatology. The depressed individual must choose one of four statements for each item, according to which they feel applies best to them. These scales have been adapted for use with learning disabled individuals by means of simplifying language and response format (Kazdin, Matson, and Senatore, 1983), however, the validity of using a schedule developed for the general population on a learning disabled population is questionable.

This study proposes to develop a self-rating assessment tool which can be completed by individuals with a mild to moderate learning disability. It is unrealistic to attempt to develop a scale capable of assessing depressive symptomatology across the entire spectrum of learning disabilities, as presentations differ markedly depending on the level of disability.

It has been reported that interviewing of respondents *and* informants leads to more accurate rates of detection (Moss, et al, 1997). Respondents may not always have insight into their condition, and in some cases their reports may be less adequate than the informant's or even absent altogether. Moss, et al, (1997) have found that around a third of cases are missed if either interview is omitted. For this reason, a parallel scale will also be developed for completion by carers of the individual in question.

It can be argued that learning disabled individuals may have some difficulty in responding to a three point rating scale and this may result in less valid and reliable responses (Lindsay and Mitchie, 1988), however, it is thought necessary to use such a scale in this study. If a two point scale was used simply to indicate the presence or absence of depressive symptoms, this would give no information as to the intensity of these symptoms and the resulting severity of depression. It has also been shown that learning disabled individuals may experience more anxiety when answering questions requiring a "Yes" or "No" response, as they worry whether their answer is right or wrong (Sigelman, Budd, Spanhel, and Schoenrock, 1981). This does not occur with likert-type scales. In addition, questions requiring "Yes/No" answers may result in a higher level of acquiescence in learning disabled individuals. The ability of participants to respond to a three point scale will be investigated in the pilot study and the response format modified as a result. The difficulties involved in interviewing individuals with learning disabilities will be taking into consideration when developing the scale (Flynn, 1986; Antaki and Rapley, 1996; Dagnan, Dennis and Wood, 1994).

The scale will be of use to clinicians working in the learning disability field for symptom screening, outcome measurement and as an aid to diagnosis. Measures such as these are widely available in the adult mental health field and the development of a reliable and valid scale for people with learning disabilities is long overdue.

Aims and Hypothesis

The aim of this study is to develop and evaluate a self-report depression questionnaire specifically for people with a learning disability. It was also thought important to develop a measure which would correlate with other scales. As this is a psychometric scale development study, the primary goal is to establish reliability and validity of the new measure by answering the following questions:

- Is the questionnaire reliable and valid?
- Does the scale have content validity?
- Can the questionnaire differentiate between depressed individuals and non-depressed individuals? (Discriminant validity)
- Is the questionnaire concordant with results of the Beck Depression Inventory when completed by non learning disabled depressed individuals? (Criterion validity)
- Do carers have similar opinions as to the presentation of the individual in question? (Inter-rater reliability)
- Do carers agree with the learning disabled individual with regards to depressive symptomatology? (Inter-test reliability)
- Does the questionnaire show similar results when re-administered? (Test re-test reliability)

Plan of Investigation

Participants

Three groups of participants will be required. These are;

1. Learning disabled individuals with depression.

Inclusion Criteria -	Mild to moderate learning disability as indicated by case manager. Reasonable level of comprehension as shown by the results from the British Picture Vocabulary Scale (Short Form) (Dunn, Dunn, Whetton and Burley, 1997) Ability to communicate verbally to some extent. Currently diagnosed as depressed by consultant in charge of their treatment and results from the Mini-PAS-ADD (Prosser, Moss, Costello, Simpson and Patel, 1997)
Exclusion Criteria -	Diagnosis of autism or dementia.

2. Learning disabled individuals without depression.

Inclusion Criteria -	Mild to moderate learning disability as indicated by case manager. Reasonable level of comprehension as shown by results on the BPVS (Short Form). Ability to communicate verbally to some extent. Currently *not* depressed according to results on the Mini-PAS-ADD.
Exclusion Criteria -	Diagnosis of autism or dementia.

3. Non learning disabled individuals with depression.

Inclusion criteria -	Currently attending an Adult Mental Health Service with difficulties relating to depression.

Meet DSM-IV (American Psychiatric Association, 1994) criteria for depression according to the psychologist responsible for their treatment.

In addition, two carers of each learning disabled person will also be recruited. These carers will ideally be either both family members, or both paid carers.

All participants will be asked to give consent to participating in the study by signing a consent form after they have been provided with an information leaflet detailing the purpose of the study and the procedures involved. Learning disabled participants will be asked for verbal consent if unable to sign their name and will be given a verbal and written explanation of the study, written according to their level of comprehension.

According to Cohen (1992), a sample size of 21 would be required to predict a large effect size at power = 0.8, and a significance level of 0.05 for one-way ANOVA calculations.

Participants in each group will be matched as closely as possible for sex and age. This information will be provided by the consultant in charge of their care in the case of depressed participants, and either the named nurse or day centre manager in the case of non-depressed participants. Medical notes will not be accessed.

Design and Procedure

Stage 1 - Development of Item Pool (Carer Scale)

Items will be taken from the Diagnostic Criteria - Learning Disabilities (Royal College of Psychiatrists, 2001). These items are mostly somatic or behavioural in nature. As the DC-LD has been developed for use with individuals with moderate to profound learning disabilities, compared with mild to moderate learning disabilities in this study, additional somatic or behavioural items not yet included will be taken from ICD - 10 (World Health Organisation, 1994) and DSM - IV and included in an initial pool of items. These items will be converted into questions and a 3 point rating scale applied to each item ("Always, Sometimes, Never").

Client Scale

Cognitive and affective symptoms of depression will be extracted from ICD-10, DSM - IV and previously published depression scales. These items will be converted into questions and ideally, a 3 point rating scale ("Always, Sometimes, Never") applied to each question, if participants are able to respond in this way. This will be ascertained in the pilot study. This pool of questions will then be combined with the above pool of somatic and behavioural questions.

Stage 2 - Refining Items via Focus Groups

Focus group discussions will be held to generate the kind of language commonly used to describe depression by this group. The only criteria for inclusion in a focus group is that the individual has a mild to moderate learning disability and would like to be involved in helping with a study. Groups will consist of 4-6 participants identified through day centres, and one facilitator. They will be given pictorial and verbal presentations of emotional events and subsequent questioning as to how the people involved would feel. The scale will then be adapted if required, by simplifying questions or altering terminology used.

Stage 3 - Piloting of Draft Measure

3 people with learning disabilities and depression and 3 people with learning disabilities who do not have depression will then complete the scale in order to ascertain whether any questions are unclear or whether the response format is confusing. These individuals will meet inclusion criteria set out for the main study. The scale will be further revised in the light of this information. The scale will also be piloted on carers of learning disabled individuals, with and without depression.

Stage 4 - Administration of Questionnaire

Measures

Non learning disabled participants

Non-learning disabled individuals will complete the Beck Depression Inventory II (Beck, Steer, and Brown, 1996) and the GDS-LD (newly developed questionnaire). The BDI-II was chosen as it is the most widely used measure of depression in the general population today.

Carers

Carers will complete the carer version of the GDS-LD initially and also after a two day interval, in order to assess the test-retest reliability of the GDS-LD.

Learning Disabled Participants

All learning disabled participants will complete the client version of the GDS-LD, which will be re-administered after a delay for purposes of test-retest reliability.

Screening Measures

Before administering the questionnaire to learning disabled participants, their comprehension will be assessed by means of a vocabulary scale, such as the British Picture Vocabulary Scale (Short Form). The client's comprehension of the response format and their ability to respond in such a way will also be clarified before administering the scale, by means of screening questions.

All carers will complete the Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability (Mini-PAS-ADD) (Moss et al, 1997) in order to clarify the presence or absence of any mental health diagnosis.

Settings and Equipment

Learning disabled individuals will be seen individually by the researcher either in their home, the day centre they attend or the hospital in which they live. Carers will be seen in the location which is most convenient for them. Non learning disabled participants will be seen individually in the Psychology Department which they usually attend. They will be provided with a copy of the BDI-II and the GDS-LD and asked to complete them.

Data Analysis

Data will be obtained purely from responses on questionnaires. All questionnaires will be stored securely in a locked filing cabinet and will be anonymous, except for information such as; age, sex, and experimental or control group. Data will be analysed through the SPSS computer package by the following procedures.

- Content Validity - Items endorsed by few participants will be removed.
- Discriminant Validity - the ability of the scale to discriminate between groups will be investigated by means of a one way ANOVA and subsequent post hoc tests.
- Criterion Validity - Scores on the Beck Depression Inventory will be compared with non-learning disabled depressed participants scores on the GDS-LD. This will be done using the Pearson Product Moment Correlation, if data are parametric.
- Internal Consistency - this will be measured by Cronbach's coefficient alpha.
- Test-retest Reliability - this may be assessed by the Pearson product moment correlation.
- Inter-rater reliability - The degree of concordance between the two carers will be measured, as will the degree of concordance between carers and the learning disabled participant, using the Pearson Product Moment Correlation.

Practical Applications

The GDS-LD will be useful in both clinical and research work. It will enable clinicians to monitor treatment outcome and improvement over time. It is intended that the scale be short and easy to complete, so the administration need not be time consuming. It can be used as an aid to diagnosis and to indicate the presence of depressive symptomatology at a particular time. It will also indicate the specific pattern of symptoms experienced by the individual and may indicate areas to focus on in treatment. Most importantly, it will be a self-report measure which will have been developed on a learning disabled population, and will be reliable and valid for use with this population. Although the sample in this study will be small, further work could develop normative data in addition to re-validating the findings from the present study.

Timescales

It is intended to begin the preliminary development of the questionnaire and recruitment of subjects as soon as ethical approval has been received. Ideally this would be in April - June 2000. The project will be piloted during July 2000. Data collection will be undertaken during August 200 - March 2001. Statistical analysis will be done in April 2001 and report of experiment and results will be undertaken in May-July 2001.

Ethical Approval

Ethical approval is required for this study, however, it has not been obtained as yet. Ethical applications will be submitted to Greater Glasgow Community and Mental Health Services NHS Trust and Argyll and Clyde Health Board. Dates for submissions to Greater Glasgow are as yet unknown, however, I would aim to submit to Argyll and Clyde by one of the following dates - March 17th or April 14th.

<u>**References**</u>

American Psychiatric Association (1980) Diagnostic and Statistical Manual of Mental Disorders. Third Edition. American Psychiatric Association. Washington, DC. 1980.

American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders. Fourth Edition. American Psychiatric Association, Washington, DC. 1994.

Antaki, C. and Rapley, M. (1996) Questions and answers to psychological assessment schedules: hidden troubles in “quality of life” interviews. *Journal of Intellectual Disability Research,* **40,** 421 - 437.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J.E., and Erbaugh, J. (1961) An inventory for measuring depression. *Archives of General Psychiatry,* **4,** 561 - 571.

Beck, A.T., Steer, R.A. and Brown, G.K. (1996) *Beck Depression Inventory - II.* The Psychological Corporation, Harcourt Brace and Company, San Antonio.

Cohen, J. (1992) A power primer. *Psychological Bulletin,* **112,** 155 - 159.

Dagnan, D., Dennis, S. and Wood, H. (1994) A pilot study of the satisfaction of people with learning disabilities with the services they receive from community psychology services. *The British Journal of Developmental Disabilities,* **XL,** 38 - 44.

Duncan, A.G., Penrose, L.S. and Turnbull, R.C. (1936) A survey of the patients of a large mental hospital. *Journal of Neurological Psychopathology* **16,** 225 - 38.

Dunn, Ll. Dunn, L. Whetton, C. and Burley, J. (1997) The British Picture Vocabulary Scale: Second Edition. NFER-NELSON, Berkshire.

Eaton, L.F. and Menolascino, F.J. (1982) Psychiatric disorders in the mentally retarded: types, problems, and challenges. *American Journal of Psychiatry,* **139,** 1297 - 1303.

Flynn, M.C. (1986) Adults who are mentally handicapped as consumers: issues and guidelines for interviewing. *Journal of Mental Deficiency Research,* **30,** 369 - 377.

Kazdin, A.E., Matson, J.L., and Senatore, V. (1983) Assessment of depression in mentally retarded adults. *American Journal of Psychiatry,* **140**, 1040 - 1043.

Lindsay, W.R. and Michie, A.M. (1988) Adaptation of the Zung self rating anxiety scale for people with a mental handicap. *Journal of Mental Deficiency Research,* **32,** 485 - 490.

Matson, J.L., Kazdin, A.E. and Senatore, V. (1984) Psychometric properties of the Psychopathology Instrument for Mentally Retarded Adults. *Applied Research in Mental Retardation,* **5**, 881 - 889.

Meins, W. (1993) Assessment of depression in mentally retarded adults: Reliability and validity of the Children's Depression Inventory (CDI). *Research in Developmental Disabilities* Aug, **14**, 299 - 12.

Meins, W. (1995) Symptoms of major depression in mentally retarded adults. *Journal of Intellectual Disability Research,* **39**, 41 - 45.

Moss. S.C., Patel, P., Prosser, H., Goldberg, D.P., Simpson, N., Rowe, S. and Lucchino, R. (1993) Psychiatric morbidity in older people with moderate and severe learning disability (mental retardation). Part 1: Development and reliability of the patient interview (the PAS-ADD). *British Journal of Psychiatry,* **163,** 471 - 480.

Moss, S.C. (1995) Methodological issues in the diagnosis of psychiatric disorders in adults with learning disability. *Thornfield Journal* (University of Dublin), **18**, 9 - 18.

Moss, S.C., Ibbotson, B., Prosser, H., Goldberg, D.P., Patel, P. and Simpson, N. (1997) Validity of the PAS-ADD for detecting psychiatric symptoms in adults with learning disability. *Social Psychiatry and Psychiatric Epidemiology,* **32,** 344 - 354.

Prosser, H., Moss, S.C., Costello, H., Simpson, N. and Patel, P. (1997) The Mini-PAS-ADD: an assessment schedule for the detection of mental health needs in adults with learning disability (mental retardation). Hester Adrian Research Centre, University of Manchester, Manchester.

Royal College of Psychiatrists (2001) DC-LD (Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation). Gaskell Press: London.

Sigelman, C.K., Budd, E.C., Spanhel, C.L. and Schoenrock, C.J. (1981) Asking questions of retarded persons; a comparison of yes/no and either/or formats. *Applied Research in Mental Retardation,* **2,** 347 - 357.

Tredgold, A.F. (1908) *A textbook of mental deficiency.* Balliere, Tindall, and Cox: London.

World Health Organisation (1994) ICD-10 Classification of Mental and Behavioural Disorders. Geneva.

Wright, E.C. (1982) The presentation of mental illness in mentally retarded adults. *British Journal of Psychiatry,* **141,** 496 - 502.

Zung, W.W.K. (1965) A self-rating scale for depression. *Archives of General Psychiatry,* **12,** 63 - 70.

Chapter 4 - Major Paper

PSYCHOMETRIC PROPERTIES OF A NEW SCALE FOR MEASURING DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY: THE GLASGOW DEPRESSION SCALE FOR PEOPLE WITH A LEARNING DISABILITY (GDS-LD)

Submitted in partial fulfilment of the requirements for degree of Doctor of Clinical Psychology.

Prepared in accordance with the requirements for submission to The British Journal of Psychiatry (Appendix 4.1)

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Structured Summary

Background

There is a shortage of reliable and valid tools in the field of learning disabilities for assessing depression and other types of psychopathology. This may be due, in part, to problems in measurement.

Aims

The purpose of this study was to develop and evaluate a self-report scale, which could be completed by individuals with mild to moderate learning disabilities, to assess depressive symptomatology. A supplementary scale was also developed for completion by carers.

Method

An item pool was generated from the Diagnostic Criteria - Learning Disabilities (Royal College of Psychiatrists, 2001) and several other published depression scales, and modified by use of focus groups with learning disabled people. A pilot study was then carried out to assess whether the scale was easily understood and further modifications were undertaken. The GDS-LD was then administered to 19 people with learning disabilities and depression and their carers, and 19 learning disabled people without depression and their carers for evaluation of reliability and validity. It was also given to 27 non-learning disabled people with depression who also completed the Beck Depression Inventory II (Beck, Steer, and Brown, 1996) for criterion validity purposes.

Results

The GDS-LD and Carer Supplement successfully differentiated between depressed and non-depressed groups. The GDS-LD correlated highly with the BDI-II ($r=.95$, $p<.001$) and had good test-retest reliability ($r=.97$, $p<.001$) and internal consistency ($\alpha=.90$). Test-retest reliability of the Carer Supplement was high ($r=.98$, $p<.001$), as was inter-test reliability between the Carer Supplement and the GDS-LD ($r=.93$, $p<.001$). Internal consistency of the Carer Supplement was reported as $\alpha=.88$.

Conclusion

In light of these promising results, it is hoped that the GDS-LD and carer supplement may become useful tools for further clinical and research practice, and may contribute to our understanding of psychopathology in people with a learning disability.

Introduction

Despite the recognised co-morbidity of learning disability and mental disorder (Eaton and Menolascino, 1982; Sovner and Hurley, 1983) and the reported prevalence of depression in this population (Campbell and Malone, 1991; Wright, 1982), few studies have systematically investigated these inter-relationships. In part, this may be because of problems in measurement. Previous diagnostic systems have been criticised (Watson, Aman and Singh, 1988) but there have been recent improvements (Royal College of Psychiatrists, 2001). Similarly, adapted symptom rating scales for depression (Kazdin, Matson and Senatore, 1983) have been forwarded, but these may not have population-specific, ecological validity. The aim of this paper is to develop and evaluate a self-report depression assessment tool for use with individuals with mild to moderate learning disabilities and their carers. It will be used primarily as a treatment outcome tool, but may also be of use for symptom screening purposes. It is hoped that the development of the GDS-LD will allow more extensive research to be undertaken in the area of depression and learning disabilities.

Method and Results

This study aimed to develop and evaluate a measure of depressive symptomatology in individuals with a learning disability. It was also felt to be important to develop a supplementary measure which could be completed by carers of a learning disabled person. The methodology and results will be integrated for purposes of clarity. This is primarily a psychometric study concerning issues of validity, reliability and scale sensitivity. The experimental design followed a series of developmental stages (Appendix 4.2).

Development of an Item Pool for the GDS-LD

Twenty-seven items comprised the initial item pool. Seventeen items were taken from the depression subscale of the Diagnostic Criteria - Learning Disabilities (DC-LD), recently developed by the Royal College of Psychiatrists (2001). This schedule has been specifically developed for use with moderate to severely learning disabled individuals and comprises items not included in measures developed for the general population. An additional four items were taken from ICD-10 (World Health Organisation, 1994) and DSM-IV (American Psychiatric Association, 1994). Several previously published depression scales were also reviewed; the Beck Depression Inventory-II (Beck, Steer and Brown, 1996), The Hamilton Depression Inventory (Hamilton, 1960), and the Zung Depression Rating Scale (Zung, 1965), and six further items were added to the pool. The initial pool of items can be found in Appendix 4.3.

Development of Response Format

Several response options were considered. Lindsay and Michie (1988) found a 2 choice format between presence or absence of symptoms to have higher test-retest reliability than a 4 choice format in this population. However, a 2 choice format was felt by the author to be too insensitive to changes of symptoms over time, and may also lead learning disabled individuals to respond perseveratively or in an acquiescent manner (Flynn, 1986), while a 4 choice format was thought to be too difficult for participants to comprehend. A 3 choice format therefore, was selected for the present study, comprising the following; never/no (0), sometimes (1), a lot/always (2). However, responses were presented in two stages; firstly requiring a Yes/No answer indicating presence or absence of the symptom in question, and subsequently requiring an answer indicating the severity of the symptom if present from a choice of two responses (sometimes and a lot/always). In order to reduce acquiescence, symbols were used to represent each answer, and the participants were encouraged to point to the one which best described how they felt.

Furthermore, a screening process was developed before the individual completed the questionnaire in order to assess their understanding of the words "never/no, sometimes and always/a lot/yes", and rule out perseveration and acquiescence. Participants who persistently responded in an acquiescent or perseverative manner were not included in the study. This process also provided information as to the ease of responding according to a 2-stage process, and the appropriateness of this, and provided the opportunity for the individual to practice responding in the manner required by the questionnaire, before it was administered. Further details of its content can be found in Appendix 4.4.

Refinement of Items

Two focus group discussions, each including 6 people with a mild to moderate learning disability were held in order to observe the type of language commonly used by learning disabled people to describe depression. In total, 6 males and 6 females participated, with ages ranging from 26 - 60 years (mean=42.25 yrs, s.d.=10.31yrs). Participants were given pictorial presentations of emotional events and facial expressions and asked to discuss how the people involved would feel. Facial expressions were taken from the Boardmaker computer programme (Mayer Johnson, 1997) and pictorial images were taken from the Life Horizons slides (Kempton, 1988), and the situations then discussed. Each focus group was audio-taped and transcribed. Every word used to describe an emotion was logged and frequency counts were made. The most frequent words generated in the focus groups were subsequently used to compose the questions contained in the GDS-LD. Examples of words generated to describe depression included "sad, crying, upset, and depressed". Further examples can be found in Appendix 4.5. Alternative phrasings of questions were also provided, which were available for use if the initial question was misunderstood. Each participant was asked to answer each question according to how they had felt "in the last week".

Piloting of Draft Measure

Three individuals with learning disabilities and depression and three with learning disabilities without depression completed the GDS-LD in order to clarify whether each question was clear and easily understood. The author administered the GDS-LD to each participant by reading each question aloud. No psychometric evaluation was completed on the pilot study results. Participants views on the ease of responding according to a 3 choice response format were gathered, and all participants stated they found this fairly easy. All participants were able to answer according to the 2 stage procedure previously described and there was no evidence of high rates of perseveration or acquiescence. The response process was made clearer by using pictorial representations of each response, taken from the Boardmaker computer programme (Mayer-Johnson, 1997). No symbols could be found which exactly matched the responses required, but participants stated that it was clear what the symbols meant. These symbols can be found in Appendix 4.6. Several participants did not require these aids however, and spontaneously answered in terms of never/sometimes/a lot before the response options were presented to them. Their answers were subsequently clarified using the 2 stage procedure. In addition, the British Picture Vocabulary Scale (Dunn, Dunn, Whetton and Burley, 1997) was completed with each learning disabled participant in order to provide a descriptive measure of their level of comprehension (Table 4.1). Mean age equivalent score was 8.95 years, with a range of 6-11.2 years and a standard deviation of 1.9 years.

Eight items were consequently removed from the GDS-LD for a variety of reasons. Details of this are included in Appendix 4.7. Any items or words which were unclear or confusing to participants were altered, and the scale was then administered to the experimental groups.

Field-testing and Psychometric Development

Method

Three experimental groups were included in this part of the study; learning disabled individuals with depression plus two of their carers, learning disabled individuals without depression plus two of their carers, and non-learning disabled individuals with depression. A non-depressed learning disabled group was included in order to ascertain whether the GDS-LD would be able to discriminate between depressed and non-depressed individuals. A non-learning disabled depressed group was included in order to provide a criterion measure against which to validate the GDS-LD. Two carers were required in order to evaluate the inter-rater reliability of the GDS-LD (Carer Supplement). By means of a power calculation (Cohen, 1992), it was estimated that 21 participants per group would be required to predict a medium effect size at power = 0.8, and a significance level of 0.05 for one-way ANOVA calcuations. A post-hoc power calculation stated that 6 participants per group would have been sufficient. Learning disability psychiatrists identified depressed participants, and day centre managers identified non-depressed controls. The non-learning disabled depressed group was recruited through clinical psychology Adult Mental Health services. The referring clinicians and day centre staff were provided with guidelines detailing the inclusion criteria for participants. For the learning disabled depressed participants, inclusion criteria comprised mild to moderate learning disability, reasonable level of comprehension, ability to communicate verbally and a current diagnosis of depression. Criteria for non-depressed learning disabled groups were similar, although to be included individuals were required not to have a current diagnosis of depression. Individuals were excluded if they had a diagnosis of autism or dementia. Criteria for inclusion in the non-learning disabled depressed group consisted of current attendance at an Adult Mental Health Service regarding difficulties relating to depression, and a diagnosis of depression of any type according to DSM-IV criteria. These criteria can be found in full in Appendix 4.8. Participants were then invited to take part in the study and were told that it was about how people feel, and especially about feeling sad or down. Consent forms were approved by the appropriate local research ethics committee, and participants were advised that they were free to decline to take part, or to withdraw at any time.

Once participants had been identified and had consented to take part, carers of each learning disabled individual were interviewed by the author and completed the Mini-PAS-ADD with the assistance of the author (Mini-Psychiatric Assessment Schedule for Adults with a Developmental Disability; Prosser et al, 1996), a standard assessment for evaluation of psychiatric disorder in people with a learning disability. This was done to clarify that individuals had been allocated to the correct groups - depressed, or non-depressed. No individuals in the non-depressed group met criteria for depression on the Mini-PAS-ADD, while all depressed individuals did. Of the 40 learning disabled people approached to take part, two of their carers refused to let the researcher meet with them, and gave no reason for this. No one dropped out of the study once they had agreed to take part.

The recruitment procedure for this part of the study identified 67 people, of whom 65 agreed to participate (depressed learning disabilities = 19, non-depressed learning disabilities = 19, non-learning disabled depressed = 27). The mean age of participants was 41.42 yrs (range = 20-76 yrs: standard deviation = 12.00) (Table 4.1). The male to female ratio was 32:33. Twenty-eight participants had a mild level of learning disability and ten had moderate learning disabilities. There were no significant differences between the learning disability groups in terms of age, gender, degree of disability or BPVS results.

Insert Table 4.1 here

Validity

Content Validity

The method described so far provides support for the content validity of the scale. In addition, items given a score of "0" by more than 50% of learning disabled depressed participants were removed in order to further clarify the content validity. No items met this criteria and required to be removed. The final questionnaire, which comprised 20 items can be found in Appendix 4.9.

Discriminant Validity

Preliminary checks of skewness and kurtosis were undertaken which verified that data was suitable for parametric analysis. The ability of the GDS-LD to discriminate between the 3 experimental groups is illustrated in Figure 4.1. Inspection of these data suggests that the scale appeared to discriminate between the depressed and non-depressed groups in terms of levels of depression reported. This was confirmed by a one-way ANOVA (F=44.446; df = 2; p<.001) and Scheffe post hoc tests demonstrated that there was a significant difference between each of the two depressed groups and the non-depressed group (both p<.05). There was no significant difference between the two depressed groups.

Insert Figure 4.1 here

Criterion Validity

In order to investigate criterion validity, twenty-seven non-learning disabled depressed individuals completed both the GDS-LD and the Beck Depression Inventory-II (Beck, Steer and Brown, 1996). A scatterplot of the relationship between scores on these two measures can be found in Figure 4.2. Data were analysed using Pearson's Product Moment Correlation. This analysis revealed r=.946, (p<.001, two tailed), signifying good criterion validity.

Insert Figure 4.2 here

Reliability

Test-retest reliability

Test-retest reliability was measured by administering the GDS-LD at the beginning and the end of assessment sessions with all learning disabled participants, after an interval of approximately one hour. This was done primarily to measure the ease of comprehension of the GDS-LD rather than its stability. The test-retest reliability of the questionnaire, measured by the Pearson product moment correlation was r=.97, (p<.001, two tailed), indicating high test-retest reliability. When calculated using only participants with depression and learning disabilities, r=.94, (n=19, p<.001).

Internal Consistency

Internal consistency was assessed by calculation of coefficient α, which revealed satisfactory values. A value of $\alpha=0.7$ or above is considered to be acceptable (Nunnally, 1978). Alpha was .90 for the total scale (n=38), with the range in internal consistency as measured by α if item deleted being .89 and .91, and mean $\alpha=.90$ (Appendix 4.10). These results indicate that the GDS-LD has good internal consistency. When n=19 (learning disabled depressed individuals only), alpha was .81, with a range of .77 and .82, and a mean $\alpha=.80$.

Specificity and Sensitivity of the GDS-LD

Specificity and sensitivity values for each cut-off point of the GDS-LD were also calculated (Table 4.2). Specificity refers to the likelihood of people without depression being wrongly identified as depressed and sensitivity refers to the ability of the scale to identify correctly all those who were indeed depressed. It is apparent that if a score above 15 on the GDS-LD is considered to be indicative of a diagnosis of depression, the specificity values are optimal, i.e. 100%. Using 15 as the cut-off in this study ensures that no individuals without depression are wrongly identified as depressed, and 89.5% of those with depression are correctly identified. However, it may be clinically more important to identify all those who might be depressed, rather than to avoid making false positives. Therefore, using 13 as the cut-off point will increase the percentage of depressed individuals identified to 95.7%, although the number of false positives will also increase. If the value of 10 is used to ensure 100% sensitivity, specificity decreases substantially, to an unacceptable level of 68.4%. In light of the importance of detecting those who are indeed depressed, without wrongly identifying those who are not depressed, 13 should be advised as the cut-off point for clinically significant symptoms of depression.

Insert Table 4.2 here

Development of Supplementary Carer Scale

As previously mentioned, a supplementary carer scale was also developed as an adjunct to the main aim of the study. Clearly, the principal contribution that a carer can make to the assessment of depression is to report on their observations. The development of the GDS-LD Carer Supplement was an attempt to do this in a systematic way. It was developed as follows;

Items which may be easily observed by a carer were extracted from the item pool, and included in the supplementary carer scale (GDS-LD Carer Supplement). This was done by asking three clinical psychologists working in the area of learning disabilities to indicate which items they felt were overtly observable. Those items which were unanimously chosen were included in the carer scale and can be found in Appendix 4.3. A 2 stage response process was used for both carer and client scales. The GDS-LD (Carer Supplement) was piloted using 6 carers - 3 of a learning disabled individual with depression, and 3 of a learning disabled individual without depression. Two were paid carers and four were family members. They were asked to give their opinion regarding the ease of completing the scale, and all found it to be easily understandable and clear. No items required to be altered. The carer supplement was then administered independently to two carers of learning disabled participants in both groups (n=76). Carers were either both paid carers or both family members.

Items given a score of "0" by more than 50% of carers of learning disabled depressed participants were removed for purposes of content validity. No items met this criteria however. The Carer Supplement, comprising 16 items, can be found in Appendix 4.11.

Test-retest reliability after a delay of approximately two days was computed using the primary carer of each learning disabled participant, and found to be high (r=.98, p<.001, two tailed) for the total group and similarly high for the depressed group alone (r=.94, p<.001). Inter-test reliability between the GDS-LD and the carer supplement was found to be r=.93 (p,.001, two tailed) and for the depressed learning disabled participants group alone was r=.87 (p<.001, two tailed). These results indicate good inter-rater reliability, and provide evidence for the potential usefulness of the carer supplement even in the absence of a result from a learning disabled participant themselves. Inter-rater reliability between carers was measured at r=.98 (p<.001, two tailed), showing a high level of agreement between carers. Carers of learning disabled depressed individuals only yielded r=.93, p<.001.

Internal consistency was assessed using coefficient alpha, which revealed satisfactory values. Alpha was .88 for the total scale (n=38), with the range in internal consistency as measured by α if item deleted being .86 and .90. These results indicate that the supplementary carer scale also has good internal consistency. When n=19 (carers of learning disabled depressed individuals only), alpha was somewhat lower at .66, with a range of .58 and .72 (Appendix 4.12).

Discussion

The purpose of this study was to develop and psychometrically evaluate a self-report questionnaire to quantify depressive symptomatology in individuals with mild to moderate learning disabilities. The outcome of this is the GDS-LD and its Carer Supplement, both of which have been shown to be potentially useful.

It was felt that there was a need for a measure specifically designed for learning disabled individuals, instead of using a modified form of a general population measure. The GDS-LD has been developed using the Diagnostic Criteria - Learning Disabilities (Royal College of Psychiatrists, 2001), a diagnostic schedule specifically for learning disabled individuals, along with reference to supplementary literature, previously published depression scales and diagnostic schedules used with the general population, and direct work with learning disabled people with and without depression. In carrying out this study, it has not simply been accepted that the construct of depression is identical to that in the general population.

Because of the methodological procedure involved in their development, content and face validity of the GDS-LD and the Carer Supplement were high. They were also able to discriminate between depressed and non-depressed groups of learning disabled individuals, allocated on the basis of Mini-PAS-ADD results and consultant psychiatrist's clinical judgement. The GDS-LD correlated highly with the BDI-II completed by a non-learning disabled depressed group, which suggests that the same construct was being measured.

The findings of this study also show that the GDS-LD and the Carer Supplement have good internal consistency and test-retest reliability. Inter-test reliability between the client and carer scales is also high, indicating that the Carer Supplement may be used with non-verbal learning disabled individuals if required. Inter-rater reliability between carers was also high, although this may not have been the case had carers not been either both paid carers or both family members.

If the psychometric evaluation of the GDS-LD were to be extended further, it would be interesting to consider the issue of "inter-administrator reliability". The GDS-LD was administered to all participants in this study by the author, except in the case of the non-learning disabled depressed participants, who self-administered the questionnaire. Another issue which could be given further investigation is whether the reliability of the GDS-LD would remain high if it was used with individuals with a more severe learning disability.

The GDS-LD normally took 10-15 minutes to administer, depending on the ability and to some extent, co-operation, of the respondent. It is simple to administer and does not require any special training, indicating that it may be of use within clinical sessions, for screening purposes, and in research studies. The three point response format was easy to use. However, some participants spontaneously answered in term of "never/no, sometimes and always/a lot", signifying that such concepts were well-known to them and comprehensible. This is demonstrated by the good test-retest reliability values, as had the response format been poorly understood or confusing, the resulting test-retest reliability would have been lower. The screening procedure was important in familiarising participants with the response format and providing an opportunity for them to practice responding before the GDS-LD was administered.

Limitations

There were a number of limitations in this study:

1. The conceptual basis of the scale has limited validity due to the fact that the development of a well validated conceptualisation of depression in learning disabled individuals was beyond the scope of the study . However, the results suggest that the scale has strong clinical validity.
2. The majority of participants had a mild level of disability. It would be interesting to evaluate the scale more fully using individuals with more severe levels of disability. It may be the case that certain questions may have to be re-written for this purpose and become more concrete, or the response format may have to be altered.
3. The scale was not evaluated in terms of its ability to distinguish symptoms of depression from symptoms of other mental health problems such as anxiety. This would be a useful development in future studies.
4. Test-retest reliability of the GDS-LD was assessed in a preliminary manner, due to time constraints. This should be repeated with a larger interval between testing sessions e.g. several weeks instead of approximately one hour. Nevertheless, the high test-retest reliability values obtained after one hour illustrates that

individuals with a learning disability are able to give consistent, accurate representations of their feelings and not simply respond in a random manner.

5. The study was an exploratory investigation and hence would require to be repeated on a much larger scale in order to clarify whether the reliability and validity of the GDS-LD would remain high.
6. With regards to the Carer Supplement, although it has been shown to be a useful adjunct to the GDS-LD, the information it provided was obviously limited to overtly observable symptoms of depression. It would be important not to overlook the many additional cognitive symptoms of depression which may be present in addition.

Clinical Implications - GDS-LD

The development of the GDS-LD has several implications for both clinical and research work within the field of learning disabilities.

1. The GDS-LD is quick and easy to use, and requires no special training, making it accessible to all professionals working with learning disabled people with mental health problems.
2. It takes between 10-15 minutes to complete, therefore can be used during clinical sessions, and repeatedly, as an indication of treatment outcome.
3. It may also be suitable for use in research work.
4. The GDS-LD may be a useful screening tool for depressive symptomatology, and be used to aid further referral decisions.

GDS-LD Carer Supplement

1. The GDS-LD Carer Supplement may be a reliable and valid measure for use with non-verbal individuals with learning disabilities or those who are unable to accurately self-report their symptoms, as it shows high inter-test reliability with the GDS-LD.
2. It may be especially relevant for use with those with more severe learning disabilities, who may have verbal communication difficulties but also tend to display more behavioural symptoms of depression than those with milder disabilities.
3. It is quick and easy to complete, requiring no training or prior experience of mental health issues and terminology.
4. It may be administered verbally or simply given to the carer to complete without the required presence of the administrator.
5. The Carer Supplement may also be used as a screening tool to guide staff in further referral decisions.

The development of the GDS-LD has provided promising results in terms of the scale's reliability and validity. It is hoped that it will become a useful measure for both clinical and research practice in the future, although it does require further evaluation on a larger scale.

References

American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition. Washington, DC, American Psyciatric Association, 1994.

Beck, A.T., Steer, R.A. and Brown, G.K. (1996) *Beck Depression Inventory - II.* The Psychological Corporation, Harcourt Brace and Company, San Antonio.

Boardmaker ™ (1997) Mayer Johnson Inc. California, USA.

Campbell, M. and Malone, R.P. (1991) Mental retardation and psychiatric disorders. *Hospital and Community Psychiatry,* **42,** 374 - 379.

Cohen (1992) A power primer. *Psychological Bulletin,* **112,** 155 - 159.

Dunn, Ll., Dunn, L., Whetton, C. and Burley, J. (1997) *British Picture Vocabulary Scale: Second Edition.* NFER-NELSON, Berkshire.

Eaton, L.F. and Menolascino, F.J. (1982) Psychiatric disorders in the mentally retarded: Types, problems, and challenges. *American Journal of Psychiatry,* **139,** 1297 - 1303.

Flynn, M.C. (1986) Adults who are mentally handicapped as consumers: issues and guidelines for interviewing. *Journal of Mental Deficiency Research,* **30,** 369 - 377.

Hamilton, M. (1960) A rating scale for depression. *Journal of Neurology, Neurosurgery and Psychiatry,* **23,** 56 - 61.

Kazdin, A.E., Matson, J.L. and Senatore, V. (1983) Assessment of depression in mentally retarded adults. *American Journal of Psychiatry,* **140,** 1040 - 1043.

Kempton, W. (1988) *Life Horizons. Physiological and Emotional Aspects of Being Male/Female. (Sex Education for People with Special Needs).* James Stanfield and Co.

Lindsay, W.R. and Michie, A.M. (1988) Adaptation of the Zung self-rating anxiety scale for people with a mental handicap. *Journal of Mental Deficiency Research,* **32,** 485 - 490.

Nunnally, J.C., Jr. (1978) *Psychometric Theory* (2nd edition) McGraw-Hill, New York.

Prosser, H., Moss, S.C., Costello, H., Simpson, N. and Patel, P. (1996) *The Mini-PAS-ADD: A Preliminary Assessment Schedule for the Detection of Mental Health Needs in Adults with Learning Disabilities.* Hester Adrian Research Centre, University of Manchester: Manchester.

Royal College of Psychiatrists (2001) *DC-LD: Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation.* Gaskell Press, London.

Sovner, R. and Hurley, D.A. (1983) Do the mentally retarded suffer from affective illness? *Archives of General Psychiatry,* **40,** 61 - 67.

Watson, J.E., Aman, M.G. and Singh, N.N. (1988) The Psychopathology Instrument for Mentally Retarded Adults; psychometric characteristics, factor structure and relationship to subject characteristics. *Research in Developmental Disabilities,* **9,** 277 - 290.

World Health Organisation (1994) *International Classification of Mental and Behavioural Disorders (ICD-10).* World Health Organisation. Geneva.

Wright, E.C. (1982) The presentation of mental illness in mentally retarded adults. *British Journal of Psychiatry,* **141,** 496 - 502.

Zung, W.W.K. (1965) A self-rating scale for depression. *Archives of General Psychiatry,* **12,** 63 - 70.

Tables

Table 4.1 - Descriptive characteristics of participants by experimental group (total n=65). Information is also provided on focus group participants.

Group	**No. of participants**	**Age (mean)**	**Gender male:female**	**Degree of disability mild:mod**	**BPVS age equivalent (mean)**
Depressed learning disabled	19	40.21 (21 - 60; s.d.=12.20)	10:9	15:4	9.28 yrs (6 - 12.6yrs) s.d.=1.80
Non-depressed learning disabled	19	39.11 (25 - 59; s.d.=9.31)	10:9	13:6	9.18 yrs (5.9 - 12.5 yrs) s.d.=2.06
Depressed non-learning disabled	27	43.89 (20 - 76; s.d.=13.41)	12:15	N/A	N/A
Focus group	12	42.25 (26 - 60; s.d.=10.31)	6:6	8:4	8.95 yrs (6 - 11.2 yrs) s.d.=1.90

(all $p>.05$)

Table 4.2 - Sensitivity and specificity values of the GDS-LD according to total score cut-off points (n=38)

Cut-off point	Sensitivity (%)	Specificity (%)
1	100	0
2	100	0
3	100	0
4	100	0
5	100	15.8
6	100	15.8
7	100	26.3
8	100	47.4
9	100	52.6
10	100	68.4
11	95.7	78.9
12	95.7	84.2
13	95.7	89.5
14	89.5	94.7
15	89.5	100
16	84.2	100
17	78.9	100
18	73.7	100
19	73.7	100
20	68.4	100

21	57.9	100
22	57.9	100
23	47.4	100
24	47.4	100
25	47.4	100
26	36.8	100
27	31.6	100
28	26.3	100
29	15.8	100
30	10.5	100
31	5.3	100
32	5.3	100
33	5.3	100
34	0	100
35	0	100
36	0	100
37	0	100
38	0	100
39	0	100
40	0	100

Figures

Figure 4.1: Comparison of the three participant groups in terms of GDS-LD total scores. Error bars are added.

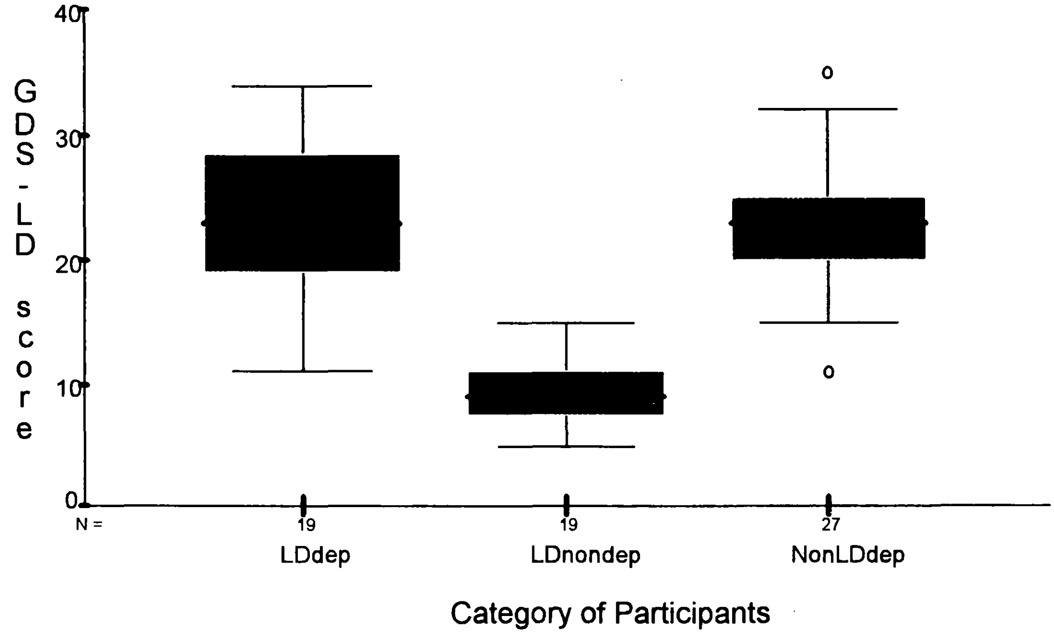
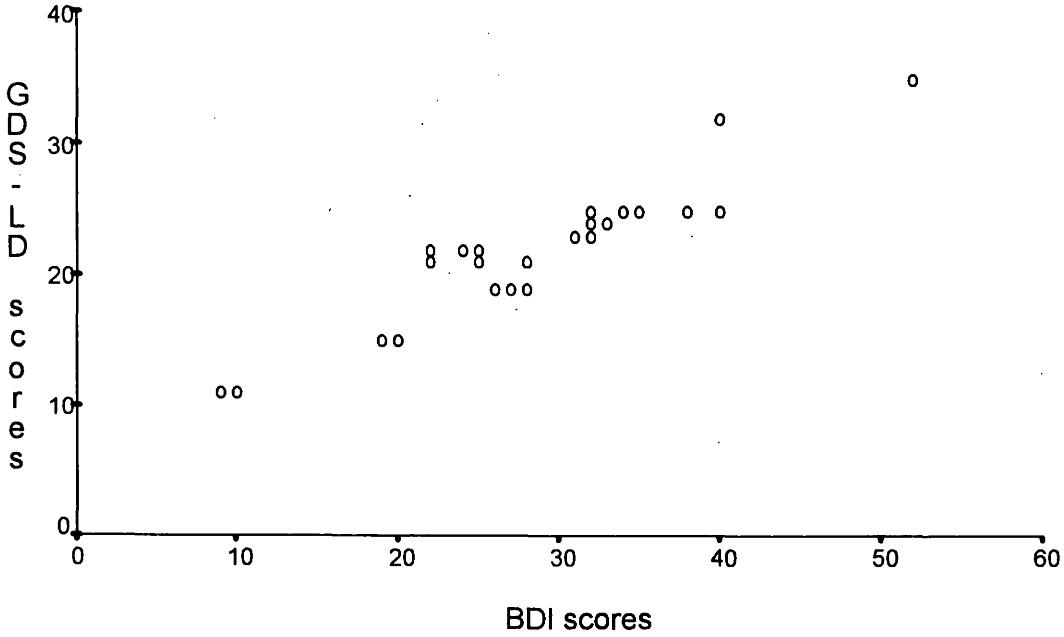


Figure 4.2 - Scatterplot of scores on GDS-LD and BDI-II for the non-learning disabled group (n=27).



Chapter 5 - Clinical Research Case Study

THE EFFECTIVENESS OF DIFFERENTIAL REINFORCEMENT OF OTHER BEHAVIOUR (DRO) AND EXTINCTION ON KICKING BEHAVIOUR IN A MODERATELY LEARNING DISABLED MAN

Submitted in partial fulfilment of the requirement for the degree of Doctor of Clinical Psychology

Prepared in accordance with the requirements for submission to Journal of Applied Research in Intellectual Disabilities. (Appendix 5.1)

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Running Title: Effectiveness of DRO and Extinction on Kicking

Abstract

The present study was designed to determine the effects of extinction and differential reinforcement of other behaviour (DRO) on the reduction of kicking behaviour in a moderately learning disabled man (C.C.), in the presence of continual positive reinforcement from peers. In order to determine the effectiveness of the intervention, an ABAB design was implemented (Kazdin, 1982). DRO and extinction were delivered by one staff member in a discussion group consisting of 8 adults with learning disabilities. This led to an increase in the amount of time C.C. spent engaged in appropriate, non-disruptive activities, and a subsequent decrease in the kicking behaviour. This may indicate that the attention of the staff member was the critical aspect in the maintenance of kicking and that the kicking behaviour may have been due to understimulation.

Appendix 1 - Small Scale Service Evaluation

Appendix 1.1: Notes for Contributors (Health Bulletin)

Appendix 1.2: Questionnaire

Appendix 1.3: Information Leaflet

Appendix 1.4: Covering Letter enclosed with Questionnaire

Appendix 1.5: Patient's responses when asked whether they had any worries or fears regarding their appointment.

Appendix 1.1

Notes for Contributors

Papers, articles and other contributions should be sent to the Editor, *Health Bulletin*, Scottish Office Department of Health, Room 143, St Andrew's House, Edinburgh EH1 3DE. They must be submitted exclusively for *Health Bulletin*. Acceptance is on the understanding that editorial revision may be necessary. All papers are reviewed by the Editor and by peer review, referees being drawn from a panel of appropriate professionals. No correspondence can be entered into in relation to articles found to be unsuitable and returned to authors.

Material submitted for publication must be typewritten on one side of the paper only, in double spacing and with adequate margins, and each page should be numbered. The top typed copy should be submitted, with four other copies. All papers should be prefaced by a structured Abstract, of about 250 words in length. It should normally contain six clearly headed sections entitled Objective, Design, Setting, Subjects, Results and Conclusion. The name, appointment and place of work of the authors should be supplied on a separate title page. This same page should include the full postal address of one author, to whom correspondence and reprints will be directed. There should be adequate references to any relevant previous work on the subject; these references should appear at the end of the material on a separate page or pages, using the Vancouver style, which in the case of papers in journals includes:

Surname and initials of author(s)
Title of paper
Full name of Journal
Year published
Volume number
Opening and closing page numbers

Reference to books should similarly include author's name and initials, full title, edition (if necessary), place of publication, publisher's name, year and, if required, volume number, chapter number or page number.

Short Communications. *Health Bulletin* publishes short communications (not exceeding three pages in length) as a separate section, and we aim to offer speedier publication for these. Material intended for this section should be submitted in the above form, and the covering letter should state the intention.

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Proofs

Contributors will receive one set of proofs. It should be read carefully for printer's errors, and any tables, figures and legends should be checked. Alterations should be kept to a minimum, and the proofs should be promptly returned.

Reprints

One hundred reprints will be supplied free of charge. A limited extra number (for which a charge will be made) may be ordered from the Editor when the proofs are returned.

Appendix 1.2

DEPARTMENT OF CLINICAL PSYCHOLOGY

HOSPITAL

PATIENT SURVEY

In order to improve our service we would appreciate your views on the information leaflet you have just received. Please complete the following short questionnaire by *circling* the answer which best represents your view.

1. Have you read the enclosed information leaflet?

   Yes No

(If "No", please read the leaflet before filling in this form.)

2. Have you ever had an appointment with a psychologist in the past?

   Yes No

3. How easy was it to understand the information in the leaflet?

   East Average Difficult

4. What did you think about the length of the leaflet?

   Too short About right Too long

5. How useful did you find the leaflet?

   Very useful Fairly useful Not useful

6. Was there any information in the leaflet which you did not find useful?

   Yes No

(If "Yes", please specify below by underlining the relevant options).

You will take an active role in your treatment, working jointly with the psychologist.
There will be no quick "magic" cures. Treatment may take some time.
Be prepared to accept setbacks in treatment.
The psychologist is more like a coach or guide, rather than a "fixer" - they will help you to help yourself.
You will need to show a real commitment to treatment.
There is a possibility of group work in your treatment.

Practicalities of treatment - how long appointments last, how many appointments you will be expected to have etc.
Other
(please specify)____

7. Having read the leaflet, how do you now feel about coming to see a psychologist?

Not anxious at all A little anxious Very anxious

8. Has reading the leaflet made you feel.....

Less anxious No different More anxious

9. Did any specific part of the leaflet make you feel especially anxious?

Yes No

If "Yes", which part was this? Please underline the options below).

You will take an active role in your treatment, working jointly with the psychologist.
There will be no quick "magic" cures. Treatment may take some time.
Be prepared to accept setbacks in treatment.
The psychologist is more like a coach or guide, rather than a "fixer" - they will help you to help yourself.
You will need to show a real commitment to treatment.
There is a possibility of group work in your treatment.
Practicalities of treatment - how long appointments last, how many appointments you will be expected to have etc.
Other
(please specify)____

10. Did any specific part of the leaflet make you feel more comfortable about coming to see a psychologist?

Yes No

(If "Yes", which part was this? Please underline the options below).

You will take an active role in your treatment, working jointly with the psychologist.
There will be no quick "magic" cures. Treatment may take some time.
Be prepared to accept setbacks in treatment.
The psychologist is more like a coach or guide, rather than a "fixer" - they will help you to help yourself.
You will need to show a real commitment to treatment.
There is a possibility of group work in your treatment.

Practicalities of treatment - how long appointments last, how many appointments you will be expected to have etc.
Other
(please specify)____

11. Before you read the leaflet, did you know what to expect from coming to see a psychologist?

Yes, definitely A little bit No, not at all

12. Has the leaflet helped you to know what to expect from coming to see a psychologist?

Yes, definitely A little bit No, not at all

13. Is there anything mentioned in the leaflet that you would prefer to know more about?

Yes No

(If "Yes", please specify below by underlining the relevant options).

You will take an active role in your treatment, working jointly with the psychologist.
There will be no quick "magic" cures. Treatment may take some time.
Be prepared to accept setbacks in treatment.
The psychologist is more like a coach or guide, rather than a "fixer" - they will help you to help yourself.
You will need to show a real commitment to treatment.
There is a possibility of group work in your treatment.
Practicalities of treatment - how long appointments last, how many appointments you will be expected to have etc.
Other
(please specify)____

14. Is there anything that you feel the leaflet has missed out altogether?

Yes No

(If "Yes", please specify below)

____
____
____
____

15. Do you have any worries or fears about your appointment and/or treatment?

Yes No

(If "Yes", please specify below).

____

____

____

____

16. Did the leaflet have any effect on how likely you were to attend once you have been sent an appointment?

I am more likely to attend I am less likely to attend

The leaflet made no difference to whether I would attend or not

Thank you for taking the time to fill in this questionnaire. Please now place it in the stamped addressed envelope supplied, and return it to the Department of Psychology.

Appendix 1.3

Introduction to the Clinical Psychology Service

The department of clinical psychology is staffed by clinical psychologists, assistant psychologists and a counsellor. We offer a wide range of assessment and therapy services aimed at helping patients deal with their mental health problems effectively.

What is a clinical psychologist?

A clinical psychologist is a fully independent healthcare professional with six to eight years of university level training prior to qualification. Qualification involves obtaining a university degree in psychology (the study of how people think, feel and behave) and then a post-graduate degree in clinical psychology (the psychological study of clinical problems and their treatment).

What is an assistant psychologist?

An assistant psychologist is someone who has obtained a university degree in psychology, but has not yet taken further training to qualify as a clinical psychologist. An assistant psychologist always works under the supervision of a qualified clinical psychologist.

What is a counsellor?

A counsellor is someone who has obtained a recognised qualification in counselling, and has the skill of helping people in emotional distress to talk about their problems and learn to deal with them in a resourceful manner. Our counsellor works under the supervision of a clinical psychologist.

What is the difference between a psychologist and a psychiatrist?

Psychologists are not medically trained doctors, whereas psychiatrists are. Therefore, psychologists do not prescribe medication or use other forms of physical treatment, but rather rely exclusively on psychological methods to help patients deal with their problems.

Who can benefit from our services?

Our department offers help to people with a wide range of problems, including:

- anxiety and panic attacks
- fear and phobias
- obsessions and compulsions
- depression
- stress problems
- alcohol and drug dependence
- eating problems
- relationship difficulties
- bereavement problems
- sexual abuse
- after-effects of traumatic experiences

What happens after you are referred?

With this leaflet you will receive a letter informing you of how long you will have to wait for your first appointment. If you feel your problem is sufficiently urgent that it requires more prompt attention you can speak to your doctor and ask him/her to contact us for an earlier appointment.

What kind of help is on offer?

Naturally the type of help offered to you depends on the nature of your problems. However, generally speaking you will be expected to play an active role in the therapy process - you will work with your psychologist or counsellor in arriving at an understanding of your difficulties and in finding and implementing ways of overcoming these.

The aim of therapy is not necessarily to provide an immediate 'cure' for your problems or symptoms, but to help you develop better ways of dealing with them, which over the course of time may lead to a complete cessation of the problems. There might be set-backs along the way but hopefully you will learn skills to cope with the set-backs effectively.

Your psychologist or counsellor will be like a coach or guide, helping you to help yourself. Therefore, if you have decided to undertake therapy at our department, it is important that you make a serious commitment to it. This means attending your appointments reliably, and putting effort into carrying out the various "homework" tasks that your psychologist or counsellor suggests to you.

Therapy may be on an individual basis or in a group setting. You will of course have a say in whether you would like to take part in group therapy. Sometimes a person might benefit more from a therapy group than from individual therapy. But in any case you will not be made to attend group therapy if you really do not want to. In some cases an assistant psychologist may be asked to support and assist you with a programme to overcome your problems. If so, this will be explained to you at the time.

How long will therapy last?

Your first appointment will most likely be an assessment session which last between 45 minutes and 1 hour. The assessment might take more than 1 appointment to complete. It is only when the assessment is complete that various therapy options will be discussed with you.

The number of therapy sessions required varies from person to person. We have found that on average, people do not often require more that 10 appointments, but occasionally up to 20 or more are necessary.

Each individual therapy sessions will last about 45 minutes, while a therapy group session will be about an hour to an hour and a half.

What about confidentiality?

Your psychologist or counsellor is bound by a strict code of confidentiality. This means that no one other than your own GP or another doctor who may have referred you will be told anything of what you have spoken about without your express permission. If you feel there are things you do not want even your doctor to know, it is important that you discuss this with your psychologist or counsellor.

You should also be aware that your psychologist/counsellor may if necessary discuss your case with another psychologist in supervision.

Where will you be seen?

Your appointment will be at the psychology department in Hospital or in one of the many local health centres. Please check your appointment letter when you receive it to make sure that you go to the right place.

Appendix 1.4

Department of Psychology
Hospital

INFORMATION LEAFLET SURVEY

As you know, you will shortly receive an appointment with a clinical psychologist. Many people are unsure what to expect when they visit the psychology department, and this may cause them to worry about their appointment. We realise that attending a psychologist may be difficult for various reasons, and believe that the more information you have about what is likely to happen, the easier you will find it to attend.

For this reason, we have enclosed an information leaflet with the letter you will receive indicating how soon you will receive an appointment. This leaflet explains a bit about the psychology department and what you can expect to happen when you attend. We are interested to find out whether this leaflet is helpful to those who have just been referred to the department, and if it can be improved in any way. This is important to us, as we obviously want people to arrive for an appointment knowing roughly what will happen, and feeling relaxed.

In order for us to gather this information we would like to ask your views on the leaflet you should have already received. It would be extremely helpful if you could take 5 minutes to complete the attached questionnaire. Although it may look lengthy, it mostly requires you to simply circle your chosen answer. We are interested in you opinions, and your participation I this survey would enable us to improve the service in the future. We are looking for positive AND negative feedback, but most importantly, we are looking for honest feedback. All questionnaires are completely anonymous. Whether you choose to complete the questionnaire or not will have no effect on the treatment you will be offered in the future.

We have enclosed a pre-paid envelope to enable you to return the questionnaire promptly. You do not need a stamp.

Thank you for your assistance.

Appendix 1.5

Patient's responses when asked whether they had any worries or fears regarding their appointment.

Will my friends or family look at me in a different light?

What if I meet someone I know in the waiting room?

Will the psychologist think my problem is very minor? - I don't want to be seen to be wasting precious appointment time.

I won't know how to express myself.

Will I get on with the therapist?

Should I have done any preparation, or should I bring anything?

I do not enjoy talking to strangers usually, especially about personal problems.

I am concerned about having to have a lot of time off work for my appointments.

I am worried about attending on my own.

Appendix 2 - Literature Review

Appendix 2.1 - Notes for Contributors (British Journal of Clinical Psychology).

Appendix 2.1

NOTES FOR CONTRIBUTORS

1. The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour, e.g. neuropsychology, age associated CNS changes and pharmacological (in the later case an explicit psychological analysis is also required), through studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis. The general focus of studies is an abnormal behaviour such as that described and classified by current diagnostic systems (ICD-10, DSM-IV) but it is not bound by the exclusive use of such diagnostic systems. The Journal is catholic with respect to the range of theories and methods used to answer substantive scientific problems. Studies of samples with no current psychological disorder will only be considered if they have a direct bearing on clinical theory or practice.

2. The following types of paper are invited:

(a) Papers reporting original empirical investigations.

(b) Theoretical papers, provided that these are sufficiently related to empirical data.

(c) Review articles which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications.

(d) Brief Reports and Comments (see paragraph 6).

Case studies are normally published only as Brief Reports. Papers are evaluated in terms of their theoretical importance, contributions to knowledge, relevance to the concerns of practising clinical psychologists, and readability. Papers generally appear in order of acceptance, except for the priority given to Brief Reports and Comments.

3. The circulation of the Journal is worldwide, and papers are reviewed by colleagues in many countries. There is no restriction to British authors, and papers are invited from authors throughout the world.

4. The editors will reject papers which evidence discriminatory, unethical or unprofessional practices.

5. Papers should be prepared in accordance with The British Psychological Society's *Style Guide*, available at £3.50 per copy from The British Psychological Society, St. Andrews House, 48 Princess Road East, Leicester LE1 7DR, England. Contributions should be kept as concise as clarity permits, and illustrations kept as few as possible. Papers should not normally exceed 5000 words. A structured abstract of up to 250 words should be provided (see Volume 35(2), pp. 323 (1996) for details). The title should indicate exactly, but as briefly as possible the subject of the article, bearing in mind its use in abstracting and indexing systems.

(a) Contributions should be typed in double spacing with wide margins and only on one side of each sheet. Sheets should be numbered. The top copy and at least three good duplicates should be submitted and a copy should be retained by the author.

(b) This journal operates a policy of blind peer review. Papers will normally be scrutinized and commented on by at least two independent expert referees as well as by the editor or by an associate editor. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page and the text should be free of such clues as indentifiable self-citations ('In our earlier work ...'). The paper's title should be repeated on the first page of the text.

(c) Tables should be typed in double spacing on separate sheets. Each should have a self-explanatory title and should be comprehensible without reference to the text. They should be referred to in the text by arabic numerals. Data given should be checked for accuracy and must agree with mentions in the text.

(d) Figures, i.e. diagrams, graphs or other illustrations should be on separate sheets numbered sequentially 'Fig. 1', etc., and each identified on the back with the title of the paper. They should be carefully drawn, larger than their intended size, suitable for photographic reproduction and clear when reduced in size. Special care is needed with symbols: correction at proof stage may not be possible. Lettering must not be put on the original drawing but upon a copy to guide the printer. Captions should be listed on a separate sheet.

(e) Bibliographical references in the text should quote the author's name and the date of publication thus: Hunt (1993). They should be listed alphabetically by author at the end of the article according to the following format:

Moore, R. G. & Blackburn, I.-M. (1993). Sociotrophy, autonomy and personal memories in depression. *British Journal of Clinical Psychology*, 32, 460–462.

Steptoe, A. & Wardle, J. Cognitive predictors of health behaviour in contrasting regions of Europe. In C. R. Brewin, A. Steptoe & J. Wardle (Eds), *European Perspectives in Clinical and Health Psychology*, pp. 101–118. Leicester: The British Psychological Society.

Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

(f) SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses (see BPS *Style Guide*).

(g) Authors are requested to avoid the use of sexist language.

(h) Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The materials should be submitted to the Editor together with the article, for simultaneous refereeing.

6. Brief Reports and Comments are limited to two printed pages. These are subject to an accelerated review process to afford rapid publication of research studies, and theoretical, critical or review comments whose essential contribution can be made within a small space. They also include research studies whose importance or breadth of interest is insufficient to warrant publication as full articles, and case reports making a distinctive contribution to theory or method. Authors are encouraged to append an extended report to assist in the evaluation of the submission and to be made available to interested readers on request to the author. To ensure that the two-page limit is not exceeded, set typewriter *margins to 66 characters maximum* per line and limit the text, including references and a 100-word abstract, to 150 lines. Figures and tables should be avoided. Title, author and name and address for reprints and date of receipt are not included in the allowance. However deduct three lines from the text each and every time any of the following occur

(a) title longer than 70 characters,

(b) author names longer than 70 characters,

(c) each address after the first address,

(d) each text heading (these should normally be avoided).

A character is a letter or space. A punctuation mark counts as two characters (character plus space) and a space must be allowed on each side of a mathematical operator.

7. Proofs are sent to authors for correction of print, but not for introduction of new or different material. They should be returned to the Journals Manager as soon as possible. Fifty complimentary copies of each paper are supplied to the senior author on request: further copies may be ordered on a form supplied with the proofs.

8. Authors should consult the Journal editor concerning prior publication in any form or in any language of all or part of their article.

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Appendix 3 - Proposal for Major Research Paper

Appendix 3.1 - Guidelines from Course Handbook

Appendix 3.2 - Letters from relevant ethics committees

Appendix 3.1

1.1 Applicants - names and addresses including the names of co-workers and supervisor(s) if known.

1.2 Title - no more than 15 words.

1.3 Summary - No more than 300 words, including a reference to where the study will be carried out.

1.4 Introduction - of less than 600 words summarising previous work in the field, drawing attention to gaps in present knowledge and stating how the project will add to knowledge and understanding.

1.5 Aims and hypothesis to be tested - these should wherever possible be stated as a list of questions to which answers will be sought.

1.6 Plan of investigation - consisting of a statement of the practical details of how it is proposed to obtain answers to the questions posed. The proposal should contain information on Research Methods and Design i.e.

1.6.1 Subjects - a brief statement of inclusion and exclusion criteria and anticipated number of participants.

1.6.2 Measures - a brief explanation of interviews/observations/ rating scales etc. to be employed, including references where appropriate.

1.6.3 Design and Procedure - a brief explanation of the overall experimental design with reference to comparisons to be made, control populations, timing of measurements, etc. A summary chart may be helpful to explain the research process.

1.6.4 Settings and equipment - a statement on the location(s) to be used and resources or equipment which will be employed (if any).

1.6.5 Data analysis - a brief explanation of how data will be collated, stored and analysed.

1.7 Practical applications - the applicants should state the practical use to which the research findings could be put.

1.8 Timescales - the proposed starting date and duration of the project.

1.9 Ethical approval - stating whether this is necessary and, if so, whether it has been obtained.

Appendix 3.2

GREATER GLASGOW
PRIMARY CARE
NHS TRUST

Ref: AmcM/0015

1 August, 2000

Ms Fiona Cuthill
Academic Department
Gartnavel Royal Hospital
1055 Gt Western Road
Glasgow
G12 0XH

Dear Ms Cuthill

PROJECT: Psychometric properties of a new scale for measuring depression in people with a learning disability: The Glasgow Depression Scale for people with learning disability

Many thanks for sending the amendments to the above named submission to the Research Ethics Committee - it was formally discussed at our meeting on Thursday, 13 July 2000. I am pleased to be able to tell you that the Committee has no objections from an ethical point of view, to this project proceeding and ethical approval is formally granted.

Before your project commences you will also require to obtain management approval via the Research & Development Directorate, Gartnavel Royal Hospital.

I would also like to take this opportunity to remind you that you should notify the Committee if there are any changes, or untoward developments, connected with the study – the Committee would then require to further reconsider your application for approval. The Committee expect to receive a brief regular update every 6 months, and then a brief final report on your project when the study reaches its conclusion. (Failure to keep the Committee abreast of the status of the project can eventually lead to ethical approval being withdrawn)

May I wish you every success with your study.

Yours sincerely

Aw mc Mahon

A W McMAHON
Administrator – Research Ethics Committee

cc B Rae

ARGYLL AND CLYDE HEALTH BOARD • ACTION HEALTH

Direct Line: 0141 842 7266
Karen Harkins
Direct Fax: 0141 842 7308

Your Ref:
Our Ref: LREC 25/00
Date: 12th April 2000

Ms Fiona Cuthill
Trainee Clinical Psychologist
Dept. of Psychological Medicine
University of Glasgpw
Gartnavel Royal Hospital
1055 Great Western Road
GLASGOW
G12

Dear Ms Cuthill

PSYCHOMETRIC PROPERITIES OF A NEW SCALE FOR MEASURING DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY; THE GLASGOW DEPRESSION SCALE FOR PEOPLE WITH A LEARNING DISABILITY

The Argyll and Clyde Local Research Ethics Committee considered your request at its meeting on 5th April 2000. I can confirm that there is no objection on ethical grounds to the proposed study but before granting approval, we would be grateful if you could make the following amendments:-

a. For completeness, please include patients with severe learning difficulties in the exclusion criteria for the study.

b. We would be grateful for clarification on whether or not patients detained under the Mental Health (Scotland) Act will be included in the study.

c. We note that you do not intend to advise the patients GP of their involvement in the study. In view of the vulnerable patients involved, it is felt that this information may be useful and therefore request that you advise the patients GP of their involvement in the audit.

d. Please amend the Consent Form (1) to include a countersignature.

e. Please forward a copy of the new scale you plan to use for measuring depression in people with a learning disability.

When this is submitted the Chairman's approval will be granted.

Yours sincerely

J.J. Morrice F.R.C.S.
Chairman

LOCAL RESEARCH ETHICS COMMITTEE
\\ARGYLL\VOL2\COMMON\NURSING\KHARKINS\ETHICS\LETTERS\[illegible]
Ross House, Hawkhead Road, Paisley PA2 7BN
Tel 0141 842 7200 Fax 0141 848 1414

Appendix 4 - Major Research Paper

Appendix 4.1 - Notes for Contributors (British Journal of Psychiatry)

Appendix 4.2 - Flowchart of experimental design for the development of the GDS-LD

Appendix 4.3: Initial pool of items used to develop the GDS-LD

Appendix 4.4: Screening process

Appendix 4.5: Examples of words generated in focus groups

Appendix 4.6: Symbolic representations of response format

Appendix 4.7: Items removed from initial pool and reasons for their removal.

Appendix 4.8: Inclusion and exclusion criteria

Appendix 4.9: GDS-LD Final Draft

Appendix 4.10: Table of alpha when item deleted from the GDS-LD

Appendix 4.11: Carer version of GDS-LD

Appendix 4.12 : Table of alpha when item deleted from the Carer Supplement

Appendix 4.1

Instructions to authors

The *British Journal of Psychiatry* is published monthly by the Royal College of Psychiatrists. The *BJP* publishes original work in all fields of psychiatry. Manuscripts for publication should be sent to The Editor, The British Journal of Psychiatry, 17 Belgrave Square, London SW1X 8PG.

All published articles are peer reviewed. A decision will be made on a paper within three months of its receipt.

Contributions are accepted for publication on the condition that their substance has not been published or submitted for publication elsewhere. Authors submitting papers to the *BJP* (serially or otherwise) with a common theme or using data derived from the same sample (or a subset thereof) must send details of all relevant previous publications, simultaneous submissions, and papers in preparation.

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Manuscripts accepted for publication are copy-edited to improve readability and to ensure conformity with house style.

We regret that manuscripts and figures unsuitable for publication will not normally be returned.

MANUSCRIPTS

Three high-quality manuscript copies together with an electronic copy on floppy disk (IBM formatted) should be submitted, and authors should keep one copy for reference. Articles should be 3000-5000 words long, must be typed on one side of the paper only, double-spaced throughout (including tables and references) and with wide margins (at least 4 cm); all the pages, including the title page, must be numbered.

TITLE AND AUTHORS

The title should be brief and relevant. If necessary, a subtitle may be used to amplify the main title.

All authors must sign the covering letter; one of the authors should be designated to receive correspondence and proofs, and the appropriate address indicated. This author must take responsibility for keeping all other named authors informed of the paper's progress.

All authors should clearly state their involvement in the work presented, and any conflict of interest arising, in the accompanying letter.

If authors wish to have their work peer reviewed anonymously, they must submit their work without personal identification; names and addresses of all authors should be given in the covering letter. Otherwise, the names of the authors should appear on the title page in the form that is wished for publication, and the names, degrees, affiliations and full addresses at the time the work described in the paper was carried out given at the end of the paper.

STRUCTURE OF MANUSCRIPTS

A structured summary should be given at the beginning of the article, incorporating the following headings: Background; Aims; Method; Results; Conclusions; Declaration of interest. The latter should list fees and grants from, employment by, consultancy for, shared ownership in, or any close relationship with, an organisation whose interests, financial or otherwise, may be affected by the publication of your paper. This pertains to all the authors of the study. The summary should be no more than 150 words. Editorials do not require summaries.

Introductions should be only one paragraph (up to 150 words). Use of subheadings is encouraged, particularly in the Discussion. Three clinical implications and three limitations of the study should be provided. A separate Conclusions section is not required.

REFERENCES

References should be listed alphabetically at the end of the paper, the titles of journals being given in full. Reference lists not in *BJP* style will be returned to the author for correction.

Authors should check that the text references and list are in agreement as regards dates and spelling of names. The text reference should be in the form '(Smith, 1971)' or 'Smith (1971) showed that . . .'. The reference list should follow the style example below (note that *et al* is used after three authors have been listed for a work by four or more).

Alderson, M. R. (1974) Self poisoning: what is the future? *Lancet*, *i*, 104–113.

American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders* (3rd edn) (DSM-III). Washington, DC: APA.

Aylard, P. R., Gooding, J. H., McKenna, P. S., *et al* (1987) A validation study of three anxiety and depression self assessment scales. *Psychosomatic Research*, **1**, 261–268.

De Rougemont, D. (1950) *Passion and Society* (trans. M. Belgion). London: Faber and Faber.

Fisher, M. (1990) *Personal Love*. London: Duckworth.

Flynn, C. H. (1987) Defoe's idea of conduct: ideological fictions and fictional reality. In *Ideology of Conduct* (eds N. Armstrong & L. Tennehouse), pp. 73–95. London: Methuen.

Jones, E. (1937) Jealousy. In *Papers on Psychoanalysis*, pp. 469–485. London: Baillière, Tindall.

Mullen, P. E. (1990*a*) Morbid jealousy and the delusion of infidelity. In *Principles and Practice of Forensic Psychiatry* (eds R. Bluglass & P. Bowden), pp. 823–834. London: Churchill Livingstone.

— **(1990*b*)** A phenomenology of jealousy. *Australian and New Zealand Journal of Psychiatry*, **24**, 17–28.

Personal communications need written authorisation; they should not be included in the reference list. No other citation of unpublished work, including unpublished conference presentations, is permissible.

TABLES

Each table should be submitted on a separate sheet. They should be numbered and have an appropriate heading. The tables should be mentioned in the text but must not duplicate information in the text. The heading of the table, together with any footnotes or comments, should be self-explanatory. The desired position of the table in the manuscript should be indicated. Do not tabulate lists, which should be incorporated into the text, where, if necessary, they may be displayed.

Authors must obtain permission if they intend to use tables from other sources, and due acknowledgement should be made in a footnote to the table.

FIGURES

Figures should be individual glossy photographs, or other camera-ready prints, or good-quality output from a computer, not photocopies, clearly numbered and captioned below. Avoid cluttering figures with explanatory text, which is better incorporated succinctly in the legend. Lettering should be parallel to the axes. Units must be clearly indicated and should be presented in the form quantity:unit (note: 'litre' should be spelled out in full unless modified to ml, dl, etc.).

Authors must obtain permission if they intend to use figures from other sources, and due acknowledgement should be made in the legend.

Colour figures may be reproduced if authors are able to cover the costs.

STATISTICS

Not all papers require statistical analysis. Case histories and studies with very small numbers are examples. In larger studies where statistical analyses are included it is necessary to describe these in language that is comprehensible to the numerate psychiatrist as well as the medical statistician. Particular attention should be paid to clear description of study designs and objectives, and evidence that the statistical procedures used were both appropriate for the hypotheses tested and correctly interpreted. The statistical analyses should be planned before data are collected and full explanations given for any *post-hoc* analyses carried out. The value of test statistics used (e.g. χ^2, t, F-ratio) should be given as well as their significance levels so that their derivation can be understood. Standard deviations and errors should not be reported as ±, but should be specified and referred to in parentheses.

Trends should not be reported unless they have been supported by appropriate statistical analyses for trends.

The use of percentages to report results from small samples is discouraged, other than where this facilitates comparisons. The number of decimal places to which numbers are given should reflect the accuracy of the determination, and estimates of error should be given for statistics.

A brief and useful introduction to the place of confidence intervals is given by Gardner & Altman (1990, ***British Journal of Psychiatry***, **156**, 472–474). Use of these is encouraged but not mandatory.

Authors are encouraged to include estimates of statistical power where appropriate. To report a difference as being statistically significant is generally insufficient, and comment should be made about the magnitude and direction of change.

GENERAL

All abbreviations must be spelt out on first usage.

The generic names of drugs should be used, and the source of any compounds not yet available on general prescription should be indicated.

Generally, SI units should be used; where they are not, the SI equivalent should be included in parentheses. Units should not use indices: i.e. report g/ml, not g ml^{-1}.

The use of notes separate to the text should generally be avoided, whether they be footnotes or a separate section at the end of a paper. A footnote to the first page may, however, be included to give some general information concerning the paper.

If an individual patient is described, his or her consent should be obtained and submitted with the manuscript. The patient should read the report before submission. Where the patient is not able to give informed consent, it should be obtained from an authorised person. Where the patient refuses to give consent, the case study can only be written up if personal details and dates and other information which identifies the patient is omitted to ensure that there is no breach of confidentiality. Contributors should be aware of the risk of complaint by patients in respect of defamation and breach of confidentiality, and where concerned should seek advice.

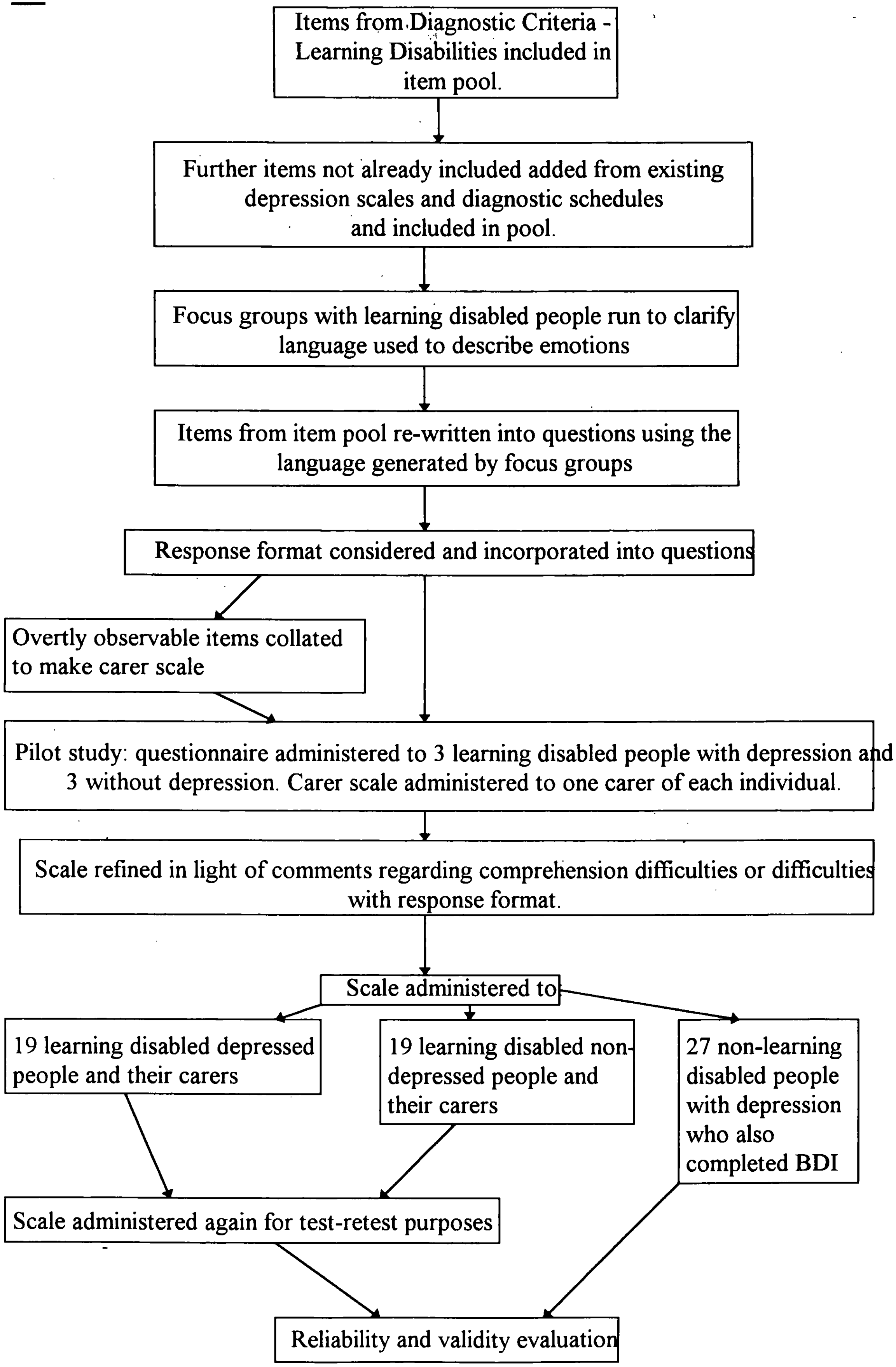
PROOFS

A proof will be sent to the corresponding author of an article. Offprints, which are prepared at the same time as the *BJP*, should be ordered when the proof is returned to the Editor. Offprints are despatched up to six weeks after publication. The form assigning copyright to the College must be returned with the proof.

LETTERS TO THE EDITOR

Letters must be double spaced and should not exceed 350 words. They will be edited for clarity and conformity with *BJP* style and may be shortened. There should be no more than five references. Proofs will not be sent to authors.

Appendix 4.2 - Flowchart of experimental design for the development of the GDS-LD



Appendix 4.3: Initial pool of items used to develop the GDS-LD

Items taken from the Diagnostic Criteria - Learning Disabilities (Royal College of Psychiatrists (2001)

* Depressed mood
* Irritable mood
* Loss of interest or pleasure in activities
* Social withdrawal
* Reduction of self-care
* Reduction in quantity of speech/communication
# Loss of energy/increased lethargy
Onset or increase in anxiety or fearfulness
* Tearfulness
Reduced ability to concentrate
Distractibility
* Increased motor agitation
* Onset of or increase in appetite disturbance
* Onset or increase in sleep disturbance.
\# Increase in reassurance seeking behaviour
\# Onset or increase in somatic symptoms/physical health concerns
\# Increase in specific problem behaviour

Items taken from DSM-IV or ICD-10

* Recurrent thoughts of death
Lack of emotional reactions to events or activities that normally produce an emotional response.
Delusions or hallucinations (severe depression with psychotic symptoms)
Unreasonable feelings of self-reproach

Items taken from previously published depression scales

Self dislike (BDI - II)
Pessimism (BDI-II, Zung)
Past failure (BDI-II)
Guilty feelings (BDI-II, Hamilton)
Punishment feelings (BDI-II)
Worthlessness (BDI-II, Zung)

Items marked with a * also are included in the supplementary carer scale.

Items marked with a # are included in the supplementary carer scale only - not the client scale.

Appendix 4.4: Screening process

Hello, my name is .... What is your name?.....................
I would like to ask you a few questions about yourself to find out a bit about you.
Show symbols for "Yes", "No", "Sometimes", A Lot/Always" and explain what they mean.
I am going to ask you some questions and I would like you to point to the picture which best explains what your answer is.

Yes/No questions - use only Yes/No symbols.

1.	Is your name Bob? (use different name if client called Bob)	Yes	No
2.	Is your name *(insert real name)?*	Yes	No
3.	Do you live in Scotland?	Yes	No
4.	Do you live in America?	Yes	No

(Participant must answer all four questions correctly to be included in study.)

Sometimes/Always questions - use only Sometimes/Always symbols

1.	Do you get out of bed in the morning?	Sometimes	Always
2.	Do you go to the shops?	Sometimes	Always
3.	Do you have fish for tea?	Sometimes	Always
4.	Do you go to bed at night?	Sometimes	Always
5.	Does it rain here?	Sometimes	Always

(Participant must answer all 5 questions correctly to be included in study.)

Using three envelopes of different sizes, place them in front of the participant in ascending order of size and ask the following questions:

1.	Point to the smallest envelope.	Smallest	Middle sized	Biggest
2.	Point to the smallest envelope.	Smallest	Middle sized	Biggest
3.	Point to the 2nd biggest envelope.	Smallest	Middle sized	Biggest

(Participant must answer all 3 questions correctly to be included in study.)

Screening of Understanding

Equipment: cup, spoon, toothbrush.

1. Show me the cup. Correct Incorrect
2. Show me the spoon. Correct Incorrect
3. Show me the toothbrush. Correct Incorrect

(Participant must answer all 3 questions correctly to be included in study.)

Equipment: toothbrush, spoon, comb, box, plate, cup.

1. Put the spoon in the cup. Correct Incorrect
2. Put the toothbrush on the plate. Correct Incorrect
3. Put the comb in the box. Correct Incorrect

(Participant must answer all 3 questions correctly to be included in study.)

Equipment: as above, plus a pen.

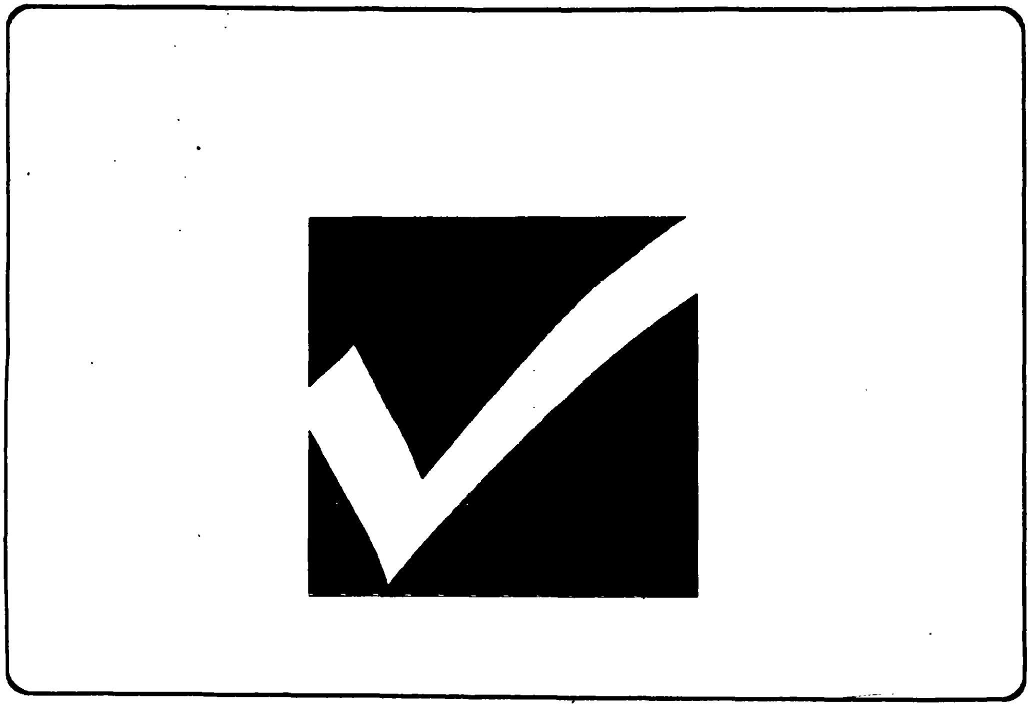
1. Put the spoon and knife on the plate. Correct Incorrect
2. Give me the cup, the box and the comb. Correct Incorrect
3. Put the pen in the box and the knife in the cup. Correct Incorrect

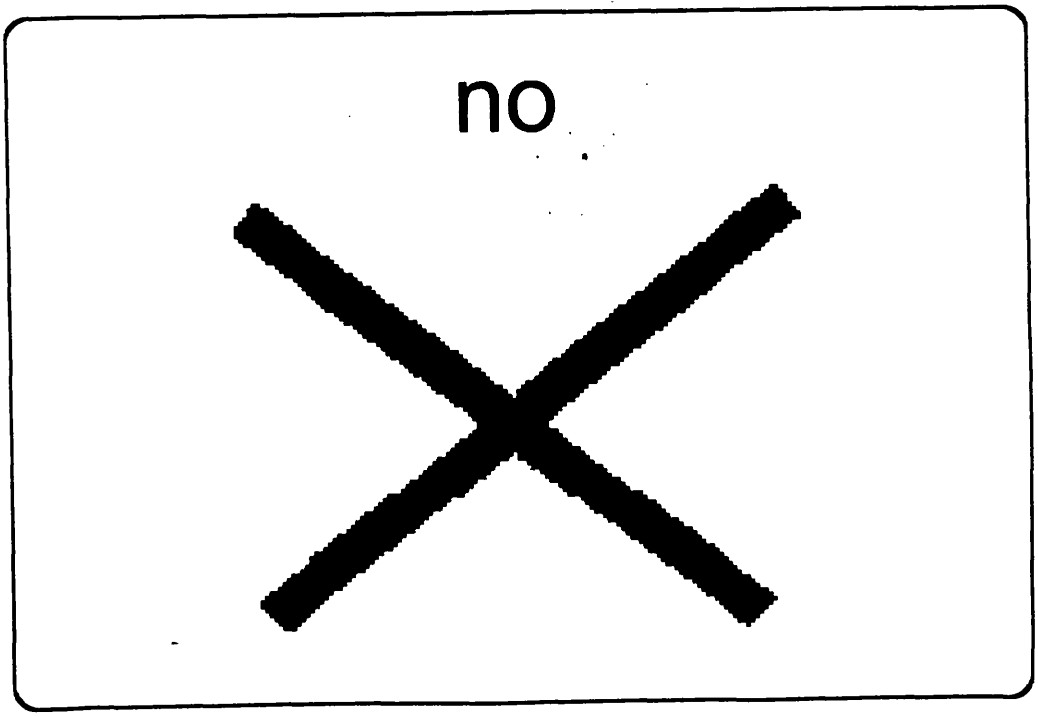
(Participant must answer all 3 questions correctly to be included in study.)

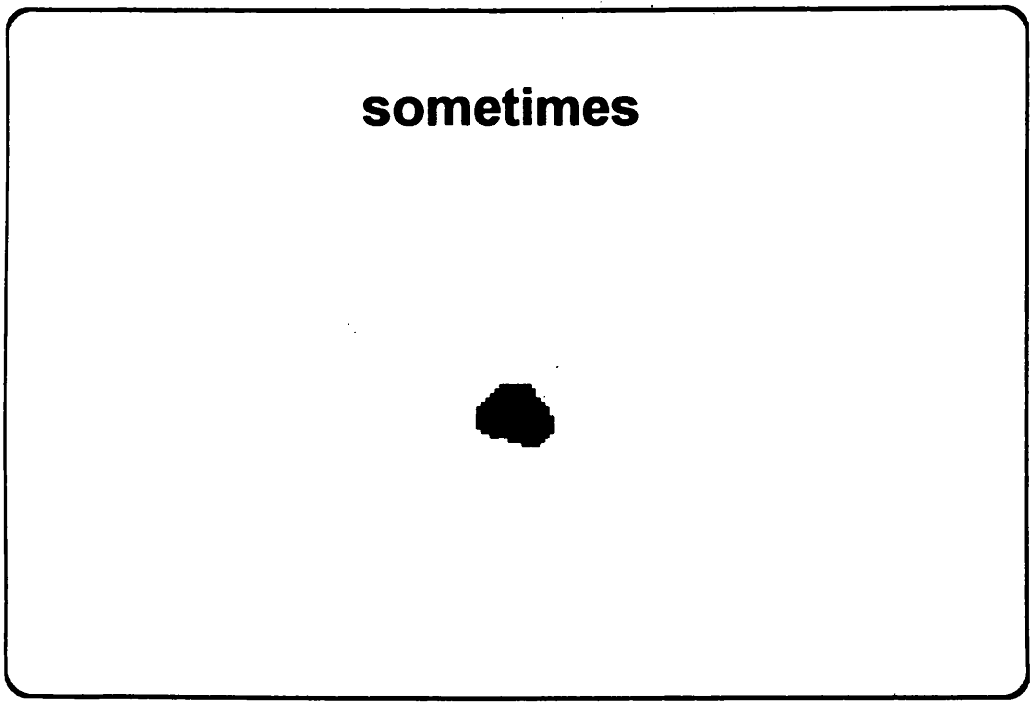
Appendix 4.5: Examples of words generated in focus groups

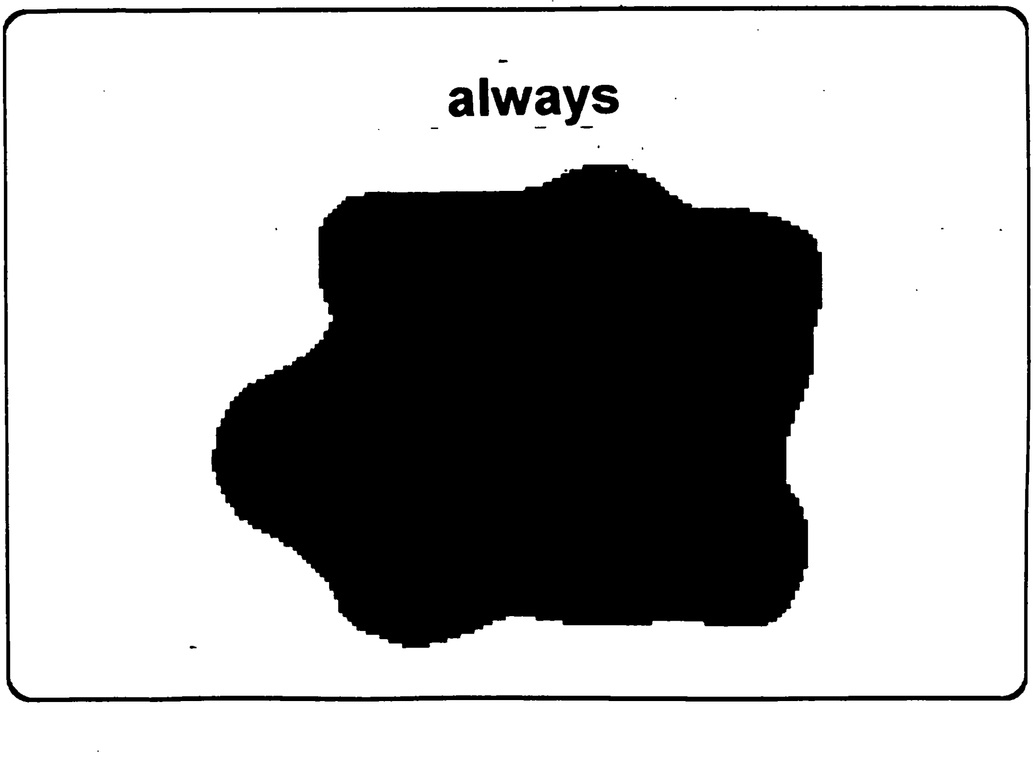
Type of emotion	Generated words to describe that emotion
Happy	Happy, pleased, smiling, in a good mood.
Sad	Sad, crying, upset, down, miserable, low, depressed, hurt feelings, disappointed, sulky.
Angry	In a bad mood, mad, angry, shouting, upset,
Anxious	Scared, frightened, worried, nervous, tense
Tired	Tired, no energy, lazy, sleepy.

Appendix 4.6: Symbolic representations of response format






sometimes


always

Appendix 4.7: Items removed from initial pool and reasons for their removal.

I feel as if I have failed/not done well.

I have felt guilty/that things happen because of me.

I have felt as if I am being punished/as if I deserve to feel sad.

I have felt as if I am worthless/as if I am not worth bothering about.

I ask other people whether I am doing things properly/right.

All above items were removed due to participants requiring extensive explanation of their meaning in order for them to be understood. In some cases, items remained misunderstood even after explanation, with 50% of participants stating that they did not understand the question.

I shout at other people or hit other people.

This item was removed as participants in the pilot study reacted negatively to it, and reported feeling as if they had done something wrong. They were reluctant to answer the question in the affirmative.

I have had a headache or other aches and pains.

This item was removed as all participants in the pilot study responded by saying they sometimes have headaches. It was felt that this question would not discriminate between depressed and non-depressed groups.

I have felt tired or weak.

This question was misunderstood by some participants and could not be distinguished from questions regarding sleep difficulties.

Appendix 4.8: Inclusion and exclusion criteria

Learning disabled participants with depression

Inclusion criteria - Mild to moderate learning disability as indicated by case manager.
Reasonable level of comprehension as shown by the result from the BPVS (Short Form).
Ability to communicate verbally to some extent.
Currently diagnosed as depressed by consultant in charge of their treatment and results from Mini PAS-ADD.
Is cared for by two individuals willing to take part in the study.

Exclusion criteria - Diagnosis of autism or dementia.

Learning disabled participants without depression

Inclusion criteria - Mild to moderate learning disability as indicated by case manager.
Reasonable level of comprehension as shown by results from the BPVS (Short Form).
Ability to communicate verbally to some extent.
Currently *not* depressed according to results on the Mini PAS-ADD.
Is cared for by two individuals willing to take part in the study.

Exclusion criteria - Diagnosis of autism or dementia.

Non-learning disabled participants with depression

Inclusion criteria - Currently attending an Adult Mental Health Service with difficulties relating to depression.
Meet DSM-IV criteria for depression according to psychologist responsible for their treatment.

Appendix 4.9: GDS-LD Final Draft

Hello. My name is .... I would like to talk to you about how you have been feeling recently and what kind of things you like doing. Can you tell me about something you did last week that you enjoyed? (Provide prompts if necessary). I am now going to ask you about how you have been feeling since .... (anchor event last week). There is not a right and wrong answer - I just want to know how you feel. If I have not explained things well enough, please ask me to tell you what I mean. We will be using the pictures we looked at before. (Recap on the meanings of these).

Each question should be asked in two parts. Firstly the participant is asked to choose between a "Yes" and "No" answer using the symbols provided. If their answer would score 0 according to the scoring key, no further action is required and a score of 0 is marked. If their answer would score 1 or 2 points according to the scoring key, they should then be presented with two more symbols and asked to choose between "Sometimes" and "Always". The questions in italics are to be used if the questions in normal print are not understood. If a response is unclear, ask for concrete examples of what the participant means or talk in general with them about their answer until you are able to allocate it to a response.

	In the last week....	**Never/No**	**Sometimes**	**Always/A lot**
1.	Have you felt sad? *Have you felt upset?* *Have you felt miserable?* *Have you felt depressed?*	0	1	2
2.	Have you felt as if you are in a bad mood? *Have you felt bad tempered?* *Have you felt as if you want to shout at people?*	0	1	2
3.	Have you enjoyed the things you have done? *Have you had fun?* *Have you enjoyed yourself?*	2	1	0
4.	Have you enjoyed talking to people and being with other people? *Have you liked having people around you?* *Have you enjoyed other people's company?*	2	1	0
5.	Have you made sure you have washed yourself, worn clean clothes, brushed your teeth and	2	1	0

		Never/No	**Sometimes**	**Always/A Lot**
	combed your hair? *Have you taken care of the way you look?* *Have you looked after your appearance?*			
6.	Have you felt tired during the day? *Have you gone to sleep during the day?* *Have you found it hard to stay awake during the day?*	0	1	2
7.	Have you cried?	0	1	2
8.	Have you felt you are a horrible person? *Have you felt others don't like you?*	0	1	2
9.	Have you been able to pay attention to things such as watching TV? *Have you been able to concentrate on things like TV programmes? What is your favourite TV programme? Are you able to watch it from start to finish?*	2	1	0
10.	Have you found it hard to make decisions? For example, have you found it hard to decide what to wear in the morning, or what you would like to eat, or do? *Have you found it hard to choose between 2 things? Give concrete example if required.*	0	1	2
11.	Have you found it hard to sit still? *Have you fidgeted when you are sitting down?* *Have you been moving about a lot?*	0	1	2
12.	Have you been eating too little? Have you been eating too much? *Do people tell you you should*	0	1	2

		Never/No	**Sometimes**	**Always/A Lot**
	eat more/less? (Positive response for eating too much OR too little is scored:)			
13.	Have you found it hard to get a good night's sleep? (Ask all following questions to clarify response or for information. If a positive response given to one of the following questions, score positively). *Have you found it hard to fall asleep at night?* *Have you woken up in the middle of the night and found it hard to get back to sleep?* *Have you woken up too early in the morning? (Clarify time)*	0	1	2
14.	Have you felt that life is not worth living? *Have you ever wished you could die?* *Have you felt you do not want to go on living?*	0	1	2
15.	Have you felt as if everything is your fault? *Have you felt as if people blame you for things?* *Have you felt that bad things happen because of you?*	0	1	2
16.	Have you felt that other people are looking at you, talking about you, or laughing at you? *Have you worried about what other people think of you?*	0	1	2
17.	Have you become very upset if someone tells you you have done something wrong/you have made a mistake? *Do you feel sad if someone tells you........?/gives you a row?* *Do you feel like crying if someone tells you.........?/gives you a row?*	0	1	2

		Never/No	**Sometimes**	**Always/A Lot**
18.	Have you felt worried? *Have you felt nervous?* *Have you felt tense/wound up/ on edge?*	0	1	2
19.	Have you thought that bad things keep happening to you? *Have you felt that nothing nice ever happens to you any more?*	0	1	2
20.	Have you felt happy when something good happened? *If nothing good has happened in the past week - If someone gave you a nice present, would that make you happy?*	2	1	0

Thank you for answering these questions. It was very helpful. What are you going to do now? Have you any plans for the rest of the day?

Appendix 4.10

Table of Alpha if item deleted for each question in GDS-LD

Question Number	n=38 (all learning disabled participants)	n=19 (learning disabled depressed only)
1	.8923	.7920
2	.8990	.8108
3	.8980	.8053
4	.8973	.7899
5	.9018	.8069
6	.9019	.8205
7	.9008	.8006
8	.8947	.7938
9	.8957	.8083
10	.8955	.7878
11	.9127	.8118
12	.9108	.8183
13	.9016	.8010
14	.8952	.7916
15	.9026	.8095
16	.9012	.7832
17	.8977	.7805
18	.9010	.8180
19	.8962	.7716
20	.9041	.8094

Appendix 4.11: Carer version of GDS-LD

What is the name of the person you look after?..
(x in questions denoted their name).
Are you a family member or a paid carer?..

The following questions ask about how x has been feeling in the last week. There is no right or wrong answer. Please circle the answer you feel best describes x in the last week.

	Never	**Sometimes**	**Always/A Lot**
1. Has x appeared depressed?	0	1	2
2. Has x been physically or verbally aggressive *more than they usually are?*	0	1	2
3. Has x avoided company or social contact?	0	1	2
4. Has x looked after his/her appearance?	2	1	0
5. Has x spoken or communicated as much as he/she used to?	2	1	0
6. Has x cried?	0	1	2
7. Has x complained of headaches or other aches and pains?	0	1	2
8. Has x still taken part in activities which used to interest him/her?	2	1	0
9. Has x appeared restless or fidgety?	0	1	2
10. Has x appeared lethargic or sluggish?	0	1	2
11. Has x eaten too little? If no.... Has x eaten too much? If no, score 0. (A positive answer to either question means it should be scored. Please tick which response is relevant, beside the question).	0	1	2
12. Has x found it hard to get a good night's sleep? Please tick which one of the following	0	1	2

	Never	**Sometimes**	**Always/A Lot**
options is relevant. Has x had difficulty falling asleep when they go to bed at night? Has x been waking up in the middle of the night and finding it hard to get back to sleep again? Has x been waking up very early in the morning and finding it hard to get back to sleep?			
13. Has x been sleeping during the day?	0	1	2
14. Has x said that he/she does not want to go on living?	0	1	2
15. Has x asked you for reassurance?	0	1	2
16. Have you noticed any change in x recently?	No 0	Little 1	Lot 2

Please explain what changes you have noticed, either in his/her mood or behaviour.

....

....

....

....

Thank you for answering these questions.

Appendix 4.12

Table of Alpha if item deleted for each question of the Carer Supplement

Question Number	n=38 (carer 1 of all learning disabled participants)	n=19 (carer 1 of learning disabled depressed participants only)
1	.8657	.6262
2	.8728	.6317
3	.8715	.5916
4	.8801	.6272
5	.8723	.6372
6	.8788	.6581
7	.8856	.6976
8	.8652	.5854
9	.8988	.6790
10	.8765	.6528
11	.8909	.7159
12	.8673	.6093
13	.8850	.6817
14	.8759	.6374
15	.8791	.6266
16	.8593	.5880