A Portfolio of Study, Practice and Research; Submitted for the Doctorate of Psychology (PsychD) in Clinical Psychology

including:

The Assessment of Mental Health Difficulties in Individuals with Learning Disabilities

Volume I

Elizabeth Crabtree
1999
Acknowledgements

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In particular, I would like to thank my parents who provided unending support.
This portfolio is dedicated to the memory of my sister, Belinda, who was an inspiration.
Statement of Anonymity

The information contained within this dossier is confidential. All identifying information for individuals detailed in the dossier has been changed to ensure client confidentiality.
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Introduction to the Portfolio

This portfolio contains a selection of work submitted as part of the PsychD in Clinical Psychology at the University of Surrey. Work included in the portfolio was undertaken over the three years of the course.

The portfolio is divided into three dossiers: academic, clinical and research. The clinical dossier in Volume I is an overview of the clinical work undertaken over the course. Further information is provided in Volume II, a confidential document, to protect the privacy of the clients seen.
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Academic Dossier
Discuss the Efficacy of Cognitive-Behavioural Interventions for Post Traumatic Stress Disorder

May 1997
Year I
Cognitive-behavioural psychology was initially applied to the conceptualisation and treatment of depression by Beck (1979). He suggested that the experience of events does not in itself result in difficulties but that it is the individual’s interpretations and thoughts about the incidents that can lead to psychological disturbance. Since Beck’s work on depression, a number of other client difficulties have benefited from being viewed in cognitive-behavioural terms (e.g. anxiety, marital problems, substance abuse) and interventions based on these models of functioning have been applied to the treatment of these difficulties (Scott, 1989). More recently, work within psychology has begun to investigate the application of cognitive-behavioural models to post-traumatic stress disorder (PTSD).

When investigating the literature on the efficacy of cognitive-behavioural interventions with PTSD, it is necessary to define what is meant by PTSD, discuss the diagnostic issues, identify the range of treatments currently available for PTSD and discuss the efficacy of treatments classified as cognitive-behavioural in contrast to the others identified.

**What is PTSD?**

It has been recognised for many years that people undergoing intensely traumatic experiences may suffer from long-lasting, post-traumatic effects. These symptoms were initially seen in relation to war veterans and classified in a variety of ways including shell-shock, war neurosis, combat exhaustion and flight fatigue (Scott and Stradling, 1992). Research has also found similar reactions in individuals who have experienced a number of other traumatic events including concentration camps (Trautman, 1964), rape (Steketee and Foa, 1987) and natural disasters (McFarlane, 1988).

Following sudden and unexpected traumatic incidents, many individuals undergo a set of normal stress reactions which last for a short period of time with recovery occurring spontaneously without the need for intervention. Some individuals
however, continue to experience intense and distressing reactions long after the initial event and can be identified as suffering from PTSD.

In 1980, the APA recognised PTSD as a diagnosable disorder that occurs following the experience of a traumatic event. DSM-IIIR (APA, 1987) defines this as:

"the development of certain characteristic symptoms following a psychologically distressing event which is outside the range of normal human experience"

DSM-IIIR (APA, 1987) contains criteria necessary for the diagnosis of PTSD. This requires that the individual has experienced or witnessed a traumatic event, that they are re-experiencing the event in some way, that they are avoiding stimuli associated with the trauma, that there is an increase in general levels of arousal and that symptoms have been experienced for a duration of a least one month (See Appendix I for full diagnostic criteria).

The recognition of PTSD as a disorder with standard diagnostic criteria has resulted from studies indicating that the experience of symptomatology following traumatic events is common, with a lifetime prevalence of 9.2% (Breslau et al., 1990). This high prevalence, greater than that of drug misuse and depression (Regier et al., 1988), indicates that there is a need to develop effective interventions.

**Cognitive-Behavioural Conceptualisation**

As mentioned above, cognitive-behavioural theory suggests that individual’s reactions to situations depends on their interpretation of the situation rather than the situation itself. It is suggested that people’s interpretation of events is influenced not only by environmental information but by information gained from others in the situation and from their own beliefs about themselves and the world. These beliefs held by the individual, schemata, are developed in early life and greatly affect individuals’ reactions to situations they encounter. The schemata, once activated, lead to the
production of automatic thoughts which influence individuals’ processing of information from the environment.

It is suggested in the literature that some individuals are more vulnerable to developing PTSD than others. Vulnerability factors include intensity of exposure, pre-existing personality and emotional disorder and family history of psychiatric disorder while protecting factors are adaptive coping style and effective support systems (Scott and Stradling, 1992).

Coping style is a particularly important factor in predicting response to trauma and Lazarus (1966) distinguishes between active and palliative coping where active coping is confronting the stressor and palliative coping is avoidance and management of emotional reactions. Research indicates that the use of active coping behaviours in traumatic experiences greatly decreases the probability of experiencing long-term distress (MacFarlane, 1988). Coping style is directly related to underlying assumptions or schemata and it appears that those prone to developing PTSD may share a number of characteristic schemata (e.g. I am worthless and bad, no-one can be trusted, nothing in the world is any good) (Scott and Stradling, 1992). Ellis (1994) also highlights a number of dysfunctional beliefs held by individuals vulnerable to developing PTSD - “.... they believe that they should be invulnerable to and not overreact to traumatic events, that they should have behaved better during these events, that a “just world” must exist, that life should be meaningful and comprehensible and that they should act well in practically all situations in order to accept themselves as “good” persons.”

**Interventions for PTSD**

A number of interventions are available for the treatment of PTSD including pharmacotherapy; psychotherapy (including cognitive and behavioural techniques, crisis intervention and psychodynamic counselling); group therapy (including self help and family therapy) (Solomon et al., 1992). These traditional interventions have been used for many years by therapists but recent developments in the field of PTSD
treatment have suggested more innovative therapies such as thought field therapy, visual-kinesthetic dissociation, eye-movement desensitisation and traumatic incident reduction which are referred to as “power therapies” or “efficient treatments” (Walsh, 1997).

**Pharmacotherapy**

The literature on the biological components of PTSD proposes that the experience of trauma may cause long-term biological changes including alterations to noradrenergic and serotonergic functioning and disruption of the sleep cycle which suggests that drug therapy would be a useful component of any therapeutic intervention (Solomon et al., 1992).

Davidson (1992) highlights six main aims of drug treatment for PTSD:

1) reduction of phasic intrusive symptoms  
2) improvement of avoidance symptoms  
3) reduction of tonic hyperarousal  
4) relief of depression, anhedonia  
5) improvement of impulse regulation  
6) control of acute dissociative and psychotic features

He reviewed the use of numerous drug interventions in the treatment of PTSD and concluded that tricyclic anti-depressants and MAOIs were effective in their treatment of PTSD when compared to a placebo. Solomon et al. (1992) reviewed the efficacy of drug therapy for PTSD and highlighted that the results of studies into treatment efficacy are mixed. Methodological difficulties are apparent in the studies reviewed with only five double-blind, placebo-controlled trials of drug therapy for PTSD, four of which investigate the use of anti-depressants. It was discussed that the varying efficacy was in part due to length of study but may also result from the presence of symptomatology of other psychiatric disorder including depression, anxiety, personality disorder and adjustment disorder which may be more resistant to change from medication alone.
Both Solomon et al. (1992) and Davidson (1992) conclude that drug therapy may be a useful part in the treatment of PTSD but that it is most useful when used in conjunction with psychotherapeutic intervention.

**Psychotherapy**

- **Crisis Intervention - Psychological Debriefing**
  As mentioned above, short-term emotional trauma is a natural consequence of the experiencing or witnessing of life-threatening events. These emotional difficulties may be transitory in nature and will not necessarily develop into symptoms that can be classified as fulfilling the diagnostic criteria for PTSD. Following traumatic incidents, it is useful for individuals to undergo psychological debriefing soon after the events to help overcome some of the cognitive confusion and distress they may be experiencing and to normalise their reactions (Hodgkinson and Stewart, 1991). This intervention is not intended as counselling but allows people the opportunity to discuss and share their thoughts and experiences about the incident that has occurred. This opportunity can help minimise the development of long-term psychological consequences of trauma while highlighting the routes by which individuals can access help should they develop symptoms of PTSD in the future. Debriefing should occur in a group setting within the first few days of an incident. Follow-up debriefing sessions should occur some time after the incident to check on progress and the possible development of pathological symptomatology.

- **Cognitive-behavioural Interventions**
  Cognitive-behavioural intervention with PTSD is a relatively new area of psychological research. The intervention can take a number of forms: exposure training, stress inoculation training (SIT) (a combination of muscular relaxation, thought stopping, breathing control, communication skills, guided self-instruction and stress inoculation), flooding and systematic desensitisation (Solomon et al., 1992). Behavioural techniques can be used in isolation but are believed to be most effective when used in conjunction with cognitive strategies. Behavioural components of the
intervention aim to activate fear and promote habituation while cognitive components aim to provide clients with the skills necessary to control their fear responses.

Given the influence that interpretations of events have on the long-term experience of PTSD symptomatology, it is necessary for therapeutic interventions to intervene to break the cycles of difficulties, address the experience of negative automatic thoughts that lower mood and encourage an active coping style. Cognitive-behavioural therapy seeks to help the client isolate negative automatic thoughts and thinking errors. It encourages them to question their thinking patterns and substitute more realistic thoughts for the automatic thoughts, using homework tasks to enable the client to experimentally test out their thinking patterns.

As with all forms of cognitive-behavioural intervention, sessions are short-term and structured making use of agenda setting for the sessions and the assigning of homework tasks for work between sessions. Scott and Stradling (1992) suggest a number of cognitive-behavioural strategies that should be employed within therapy to address both the issues of intrusive imagery and avoidant behaviours:

**Intrusive imagery / thoughts**

These are highly prevalent in clients experiencing PTSD and lead to considerable distress and feelings of loss of control. They can be related to sleep problems, flashbacks and the experience of nightmares. Four strategies may be employed to address these problems:

*Containment:* This is useful when clients spend time trying not to think about the experience of trauma but find this self-defeating ~ the more they try not to think about the incident, the more they seem to concentrate on it. Clients are encouraged to allocate a specific time of day to remember the incident for twenty minutes. When thoughts and images are experienced outside this time, clients are taught to use thought-stopping techniques with reminders that they will have time for these
thoughts later on. This serves to give the client control of their thoughts and can result in a reduction in the intrusive nature of the images.

*Desensitisation:* If containment is unsuccessful, it can be useful to use desensitisation procedures. It is important to ensure that a good therapeutic alliance has been constructed as clients may be reluctant to engage in this form of intervention. Clients are encouraged to make a 10 - 15 minute audio tape of the original event describing their thoughts, feelings and behaviours. The client should then play the tape on a daily basis on each occasion listening to the tape until they become more relaxed. The client then has the opportunity to think about and process the original trauma from a number of angles. This is particularly useful for single traumatic events and improvements can be observed within two to three weeks.

Clients can also be encouraged to write about the traumatic incident. This may help the client begin to engage with material of the trauma and can help reduce the intensity of the initial response to the material.

*Cognitive Restructuring:* When clients recount details of traumatic incidents, they tend to focus on negative details while discounting details where they made a positive impact on the situation. During therapeutic intervention, it is necessary to encourage the client to attend to the whole event experienced rather than selectively filtering information.

*Balancing out:* When clients are undergoing the experience of PTSD, they tend to attend mainly to negative experiences within their lives, finding it difficult to access more positive memories. An important aspect of intervention to PTSD is to help the client experience more positive memories with the vividness that they experience to memories of the trauma.
Avoidance reactions
People experiencing PTSD symptomatology engage in both behavioural and cognitive avoidance. Three strategies may be useful in addressing this:

Desensitisation to avoided situations: Therapeutic intervention should aim to enable the client to tolerate avoided situations which create discomfort due to providing reminders of the traumatic incident. A standard systematic desensitisation procedure (Wolpe, 1958) should be utilised looking at hierarchies of distress and encouraging the client to learn to tolerate the situations previously avoided.

Cognitive restructuring: As discussed above, the client experiencing PTSD symptomatology may be prone to thinking biases and selective filtering of information which will impact greatly on their emotions and behaviour. By addressing these thinking errors, the client can begin to realistically look at their avoidant behaviours and work through the problems they are encountering.

Task Orientation / Problem Solving: The overwhelming nature of many traumatic events may lead to the client disengaging from everyday situations. This may continue after the trauma has passed and the client may find themselves having difficulties making decisions about daily issues. It is important therefore, to help the client focus on their difficulties and this may be achieved through a problem solving approach. This is a practical, step-wise approach to enable people manage their difficulties based on the work of D’Zurilla and Goldfrid (1971). The therapist helps the client to define the problem, generate possible alternative solutions, evaluate the alternatives and isolate the steps required to carry out the preferred solution. The client then attempts to put the alternative agreed into practice and evaluates the outcomes.

Solomon et al. (1992) in their review of treatment efficacy for PTSD one again highlight that, as with studies into the efficacy of drug therapy, many studies have been conducted showing the efficacy of cognitive-behavioural interventions for PTSD
but few of these have been subject to systematic tests. Systematic desensitisation in conjunction with relaxation training (Peniston, 1986; Brom et al., 1989) and flooding (Keane et al., 1989; Cooper and Clum, 1989; Boudewyns and Hyer, 1990; Foa et al., 1991) were found to show improvements in client symptomatology compared to controls over either 3 or 6 month follow ups. Studies support the role of flooding as the most effective intervention for reduction of intrusive symptoms of PTSD. Flooding however, may result in complications (Pitman et al., 1991) and requires significant levels of client motivation to undergo such anxiety provoking exposure to the feared stimuli.

In the only randomised, controlled trial of cognitive-behavioural intervention, Foa et al. (1991), conducted research on interventions for forty-five rape victims assigned randomly to SIT, prolonged exposure (flooding), supportive counselling and waiting-list controls. They found that patients undertaking SIT improved more than those undertaking prolonged exposure with supportive counselling with waiting-list clients doing equally poorly. This effect was found at a three month follow-up suggesting that clients gained benefits from both SIT and prolonged exposure. Over time however, those in the flooding group maintained greater reduction in symptomatology than those in the SIT group. This was explained as the cognitive component providing short-term anxiety reduction with techniques not being continued by the clients after treatment had terminated.

- **Psychodynamic Psychotherapy**

The role of psychodynamic psychotherapy in the treatment of PTSD is to enable the individual to integrate the experience of trauma into their understanding of the meaning of life, self-concept and world image. Once again, only one controlled study is available looking at psychodynamic interventions with PTSD (Brom et al., 1989). This study highlighted the usefulness of this intervention for the reduction in avoidance symptomatology.
• **Power Therapies**

These interventions are recent developments in the field of treatment for PTSD and claim to promote change within one or two sessions. The relatively recent development of these interventions results in there being little evidence to support the claims in the literature. No controlled studies are available to provide information on the efficacy of these approaches. Walsh (1997) discusses the development of these forms of therapy and the possible rationale behind the reported high, fast success rates.

**Conclusion**

There is a wealth of literature available on the many treatment interventions available for individuals suffering from PTSD. However, there appears to be few studies which adhere to strict randomised, controlled experimental designs which results in difficulties when isolating the efficacy of different forms of treatment.

Studies show benefits of drug treatment, cognitive-behavioural interventions, psychodynamic psychotherapy and newer, more innovative forms of treatment such as eye-movement desensitisation. The limited rigorous research however, does point to treatments based on exposure to the feared information and situations as being the most effective intervention for reducing PTSD symptomatology. Problems arise with this form of intervention as it may cause clients to experience considerable distress and therefore they may be reluctant to continue with intervention. The use of cognitive and drug therapies can help reduce this anxiety and so enable the clients to comply with the therapeutic intervention.

It seems therefore that the treatment of PTSD should follow an integrated pathway using techniques from both cognitive and behavioural theory while utilising medical intervention when appropriate to ameliorate client distress. The development of alternative “power therapies” should be observed with interest as these may prove to be more efficient, cost-effective ways of addressing PTSD symptomatology. These interventions should be subject to rigorous evaluation, however, to ensure they do in
fact produce long-term change before being used in preference to more standard intervention techniques.
REFERENCES


APPENDIX I

DIAGNOSTIC CRITERIA FOR POST-TRAUMATIC STRESS DISORDER
(DSM IV)

A. The person has been exposed to a traumatic event in which both of the following were present:

• the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others;

• the person’s response involved intense fear, helplessness or horror.

NOTE: In children, this may be expressed instead by disorganized or agitated behaviour.

B. The traumatic event is persistently re-experienced in one (or more) of the following ways:

• recurrent and intrusive distressing recollections of the event including images, thoughts, or perceptions;

NOTE: In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.

• recurrent distressing dreams of the event;

NOTE: In children, there may be frightening dreams without recognizable content.

• acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated);

NOTE: Young children may re-enact the trauma.

• intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event;

• physiological reactivity upon exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:

- efforts to avoid thoughts, feelings or conversations associated with the trauma;
- efforts to avoid activities, places, or people that arouse recollections of the trauma;
- inability to recall an important aspect of the trauma;
- markedly diminished interest or participation in significant activities;
- feelings of detachment or estrangement from others;
- restricted range of affect (e.g. unable to have loving feelings);
- sense of a foreshortened future (e.g. does not expect to have a career, marriage, children, or a normal life span).

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:

- difficulty falling or staying asleep;
- irritability or outbursts of anger;
- difficulty concentrating;
- hypervigilance;
- exaggerated startle response.

E. Duration of the disturbance (symptoms in Criteria B, C and D) is more than 1 month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
Specify if:

**Acute:** if duration of symptoms is less than 3 months.

**Chronic:** if duration of symptoms is 3 months or more.

**With delayed onset:** if onset of symptoms is at least 6 months after the stressor.
Discuss the role of the psychologist in a rehabilitation / continuing care multi-disciplinary team and the aspects of their involvement in a person's care.
Clinical psychologists have a significant role to fulfil in the care of people with long-term psychiatric disabilities. Their inclusion within the multi-disciplinary teams responsible for continuing care highlights that their role is developing. It has been suggested that their range of skills and approaches are distinct from other specialisms within the field to the extent that they should be considered as a specialism within their own right (Gentry, 1986). Clinical psychologists are currently assuming specialist roles within mental health teams and undertaking areas of work considered to be outside the skills of other team members. This development needs to be examined to assess whether clinical psychologists should be included in the teams, whether they have skills which are different from other team members and to which specific aspects of an individual's care they can contribute. When attempting to answer these questions, it is necessary to examine the general roles of a clinical psychologist, what is meant by long-term psychiatric rehabilitation and how these two areas interact.

What is Clinical Psychology?
Psychology can be described as the scientific study of mental processes and the application of this knowledge to the understanding and treatment of psychological problems such as depression, anxiety and schizophrenia using a wide range of therapeutic techniques. Many other professions within mental health teams can be seen to have skills which overlap with that of the clinical psychologist (e.g. social workers, psychiatrists, occupational therapists, psychiatric nurses) and use psychological intervention techniques such as counselling to address their clients' difficulties. It is important therefore, to investigate how the clinical psychologist can compliment the approaches used by other professionals and isolate what skills they hold exclusive to their profession.

Clinical psychology training equips the individual with specialist knowledge in psychological functioning enabling the undertaking of three main areas of work: psychological assessment, psychological treatment and evaluation of intervention (Hall and Marzillier, 1987) while functioning on three levels of intervention:
treatment and assessment (individual and with carers), staff training and support, and planning and prevention (Bender, 1979). Professional training also enables clinical psychologists to undertake roles in research, developing of organisational policies, administration and consultation.

**What is Rehabilitation?**

Rehabilitation can be described as the ongoing care and support of individuals with chronic or long-term disabilities. In rehabilitation services, attention is paid to how the psychological, social and physical environment impacts upon the level of disability experienced by an individual. In practice, rehabilitation is the provision of a service which helps individuals to correct, avoid or compensate for their handicapping conditions (Wright, 1980) while helping them to integrate with society as far as is possible.

People within continuing care services may have a number of difficulties which may cause challenges for the rehabilitation team e.g. altered perceptions, cognitive confusion, attentional deficits, motivational problems, impaired sense of identity, poor insight and fluctuating mental states which leave them feeling frightened, anxious and isolated (Perkins and Dilks, 1992). These problems can result in individuals displaying bizarre and unpredictable patterns of behaviour which need to be effectively managed by the service.

Wright (1980) suggests that a comprehensive rehabilitation service should provide a wide range of individualised services to facilitate the attainment of useful and satisfying lives for those with disabilities. He proposes that this should include assessment, counselling, planning, medical care, training (adjustment / occupational), financial assistance, employment opportunities and any other services considered appropriate.
**Clinical Psychology and Rehabilitation**

From the discussion above therefore, it is apparent that to provide a fully comprehensive rehabilitation service, it will be necessary to draw on a wide range of skills which cannot be covered by any one professional group. It is necessary, therefore, to address the area of rehabilitation from a multi-disciplinary approach to ensure that all problem areas can be effectively tackled in a way that meets the client's needs. The specific difficulties experienced by the individuals within rehabilitation services (Perkins and Dilks, 1992) would benefit from both assessment through functional analysis to identify the reasons behind behaviours and the provision of intervention plans to help manage some of the difficulties experienced. These are particular specialist skills of the clinical psychologist. In addition, the skills identified by Hall and Marzillier (1987) would also enhance the multi-disciplinary approach. These particular skills will be discussed in greater detail below.

**Assessment**

Assessment was highlighted by Wright (1980) as being a key component in the provision of a rehabilitation service. This process is undertaken at many levels by all members of the multi-disciplinary team. However, it can be proposed that the rigorous, scientific training of the clinical psychologist places them in a position of being able to effectively, systematically and thoroughly assess the rehabilitation client in a more comprehensive way than other team members. The clinical psychologist is able to use both clinical interview and observation, in conjunction with a number of psychological assessment tools, to formulate a model of the situation from which to develop an intervention plan. The formulation may also lead to the prediction of outcomes and may inform changes in therapeutic interventions if needed. The assessment of those with long-term psychiatric disabilities should occur on three levels: individual, environmental and service (Conning, 1991).

- Assessment of the individual

This assessment should address two main areas of the situation: the client's individual needs and the analysis of the problem area. To achieve the identification of the
client's needs, it is necessary to look systematically at all areas of the patient's life and functioning. Shepherd (1983) developed guidelines to help the therapist look at these issues but Conning (1991) highlights that, although these serve to aid the professional in the collection of relevant data, the information collected and needs identified are related, not to the client's views of the presenting problems, but more to the attitudes of the staff member undertaking the assessment. This assessment bias leads to the development of intervention programmes aimed at addressing the carer's view of the client's needs rather than the client's needs themselves. It is important that the clinical psychologist is aware of these problems in data collection and attempts to involve the client at all levels of need identification. They need to develop ways of facilitating the input of even the most severely disabled individuals to ensure that the client's needs are accurately identified.

The training of clinical psychologists in assessment techniques enables them to develop and apply measures that thoroughly assess specific problems areas. The training in observation and recording of information enables the provision of systematic measures which can be used by the clinical psychologist or passed to staff members to administer (e.g. the isolation of antecedents, behaviour and consequences by staff provide a greater understanding of problem situations and help in the accurate formulation of the problems and use of interventions.)

Clinical psychologists are also skilled in the administration of cognitive tests which can help isolate neuropsychological bases for problem behaviours e.g. attentional or memory deficits. Isolation of specific neurological deficits and difficulties can help in understanding the individual and aid the development of appropriate interventions to help deal with the consequences of cognitive impairments.

• Assessment of the environment

The impact of the changes in provision within the health service has highlighted the need to attend to environmental factors in the care on the individual with long-term psychiatric disabilities. Research has highlighted the impact of environmental factors
on the well-being of individuals and has looked at the role played by organisational and management practices, social interaction, staff attitudes and community involvement (Shepherd and Richardson, 1979; Garety and Morris, 1984). The assessment of the environment by the clinical psychologist should be used to guide intervention and planning and to overcome / ameliorate environmental problems to ensure the best possible provision of care for individuals.

- Assessment of the service
The changing ethos of the health service towards accountability has led to psychologists being involved in clinical audit. The move away from institutional care towards community based services for those with long-term mental health problems has led to development of many new care initiatives. The development of these new initiatives, and the focus on professional accountability, requires the evaluation of services to ensure that they are effective and efficient ways of caring for this population. It is believed that the training of psychologists in scientific methodology and evaluation leaves them well equipped to carry out this form of service evaluation.

**Therapy, Treatment, Counselling**
Approaches to the therapy and treatment of the individual may take place on an individual, one-to-one level with the client, on a consultancy level with staff and carers and on a higher level looking at organisational and ideological issues. The generic training of the clinical psychologist will enable them to address issues at all levels to help meet the needs of the long-term rehabilitation patient.

- Organisational
The changes in the mental health system have in part stemmed from the influential work of Wolfensberger (1972) on "normalisation". This work caused a change in the ideology and philosophy of continuing care which has required the input of clinical psychology in its implementation. The implementation of this philosophical stance throughout all areas of service provision has been problematic due to the tendency for misinterpretation of the underlying theories. It is necessary for clinical psychologists
to be aware of this tendency within continuing care systems and to work towards the practical application of the ideology.

Clinical psychologists possess skills in intervention at organisational levels to address the therapeutic needs of the individual client. Initial work in this area began with the implementation of token economies in hospital wards to address the behavioural problems of the client group (Hall et al., 1977). This developed through to the inclusion of clinical psychologists within the management structure of the health service which provided them with a role in the long-term planning and development of services. Of particular note, is the role of clinical psychologists in the planning and implementation of change in mental health services following the trend towards deinstitutionalisation, drawing on the skills and resources of the long-term care workers while recognising the benefits and pitfalls of previous ways of working.

• Work with staff
Much of the work undertaken by clinical psychologists regarding the care of people with long-term psychiatric disabilities is conducted through staff and care givers. It can be hypothesised that the carers and staff surrounding people with long-term disabilities are generally in the best position to monitor client well being and to provide therapeutic interventions; they are with the client on a regular basis, they have a relationship of trust and understanding with the client and, with the continuing pressure of time for clinical psychologists, they are able to devote more frequent and regular time to the client's individual needs. It is sensible therefore for clinical psychologists to work through these staff members to enable the implementation of packages of care (Whalan, 1987; Mitchell, 1988).

Psychological intervention implemented with staff can occur in a number of ways (Conning, 1991). The clinical psychologist may help staff to develop intervention programmes which can be implemented independently with little further support or they can train staff in psychological techniques to enable them to develop their own intervention programmes e.g. basic behavioural management. The psychologist can
conduct joint work with carers and team members who may have a more thorough knowledge of the client and may be able to highlight issues of importance that may otherwise be overlooked. They can help develop group programmes with staff and either co-run them or act as consultants for staff facilitators.

A further issue of importance in the care received by the long-term rehabilitation patient is the functioning of the staff team providing their care. If the team is fragmented, demoralised and "burnt-out", the client will not receive an optimal level of care. It should be the role of the clinical psychologist to attend to these issues, assess the functioning of the team and intervene in a diplomatic way to address these issues. The clinical psychologist will have skills in organisational functioning and be able to address issues of cohesiveness and team functioning in a way that impacts on staff attitudes, values and beliefs and creates the impetus for change within teams. Additionally, the psychologist tends to be seen as functioning independently from the management structure and may therefore be in an ideal position to assess and intervene in issues surrounding team functioning (Lavender, 1985).

- **Individual work**

The clinical psychologist is trained in a number of individual therapeutic techniques (e.g. cognitive therapy, behaviour therapy, psychotherapy) which may serve to help the client in long-term rehabilitation. The work with the client should follow a thorough assessment of client need. This ensures that an appropriate therapeutic intervention is undertaken based on a model that has direct relevance to the problem areas. Given the multi-disciplinary nature of the approach to rehabilitation, it is likely that the clinical psychologist will have to be flexible in their approach to individual work, liaising closely with other members of the team to ensure a consistent approach and to prevent duplication of work. It may be necessary for the clinical psychologist to attend to issues that are usually outside their remit but these can be approached in a therapeutic, goal directed way to enable the empowerment of the rehabilitation client.
Teaching
As mentioned above, clinical psychologists have a role to play in the training of care staff in therapeutic techniques. The knowledge gained through training in clinical psychology gives the psychologist a wide breadth of information which can be passed on to other professionals working within the field of rehabilitation. The transmission of knowledge to care staff can include basic principles of psychology, theory and practice of rehabilitation, and philosophy of service provision which can enable staff to provide a better quality of care for the patients and help them to develop and implement therapeutic programmes. This teaching can be on both a formal and informal level with the clinical psychologist becoming involved in lecturing, workshops, team days and team meetings as well as providing information during day to day contact with the staff group.

The inclusion of the psychologist within the multi-disciplinary team leads to staff being able to easily access this training while being able to obtain supervision and advice on finer points of the techniques discussed following the initial training.

Evaluation of interventions
The final area for discussion is the role of the psychologist in the evaluation of intervention measures. The changing face of the health service, and the increasing power of purchasers, requires that interventions are shown to be efficient and effective ways of promoting change. This requirement results in the need for therapeutic interventions to be evaluated to ensure they are effective ways of tackling client needs. The ethos underlying the training of clinical psychologists tends to be that of the scientist practitioner i.e. the application of scientific methodology and knowledge to clinical problems. This understanding of scientific methodology leaves the psychologist well versed in numerous evaluation techniques which would need to be undertaken to assess the efficacy of any intervention undertaken. Clinical psychology training highlights the importance of a rigorous scientific approach to the evaluation of intervention, including the use of statistical techniques to analyse the information attained. It provides information about the pitfalls of evaluation
techniques and the need to be aware of confounding variables which may result in change not directly related to the therapeutic intervention used. It would therefore seem that the clinical psychologist is the most appropriate member of the team to assess the utility of interventions.

Conclusion
The research into the main skills of the clinical psychologist stresses the areas of assessment, therapy, evaluation and teaching as being the main roles undertaken. These roles are undertaken from the basis of a solid foundation in scientific principles and theory. Psychology training provides knowledge of a wide range of theoretical approaches to many psychological problems and therefore the clinical psychologist can provide a model of situations from which formulations can be made and intervention plans developed. The training in scientific theory and practice enables the psychologist to apply formulations and hypotheses to the long-term rehabilitation client. The psychologist is able to continually evaluate the impact of the interventions, adapt formulations and alter interventions when necessary.

The role of the psychologist within the organisational structure enables them to observe team functioning and the impact this has on the service provided to the client. They can intervene on both individual and team levels to address issues within the team and work towards providing a more cohesive system of support for the individual in long-term rehabilitation.

It can be seen therefore, that the clinical psychologist has a range of skills and knowledge that will greatly contribute to the care of the long-term rehabilitation client. The skills of the clinical psychologist can be utilised at all stages of the rehabilitation process, from initial assessments looking at levels of functioning and client need, to the development of intervention programmes to overcome difficulties identified and to the evaluation of the intervention techniques utilised. The psychologist can work with staff to ensure the best care of the client, with the organisation as a whole to implement policy and procedure changes and with the
patient as an individual to overcome specific difficulties. These roles will compliment the work of other professions within the multi-disciplinary team and enable the provision of a comprehensive rehabilitation service.

Team working requires flexibility and commitment from the psychologist and an ability to work creatively with some difficult issues. However, it is necessary for the clinical psychologist to be an integral part of the team to ensure that a comprehensive rehabilitation service is offered to all clients in the care of the rehabilitation team.
REFERENCES


Concern has been raised regarding a relationship between two clients of the same-sex but of differing levels of ability living in a staffed home. What are the areas that need to be considered when reflecting on this relationship with specific reference to consent and policy issues?
Over recent years there have been many changes in the provision of services for people with learning disabilities resulting from both the influence of the philosophy of normalisation (Wolfensberger, 1972) and the belief that these individuals have the right to receive the same life experiences as people without disabilities. This philosophical stance includes within it the right to sexual expression.

The issue of sexuality in individuals with learning disabilities has resulted in a number of difficulties for provider services at many levels including policy making, protection issues, views of carers and other professionals, views of parents and the views and beliefs of the individuals themselves. Craft (1994) highlights some of the historical perspectives leading to the reaction against the development of sexuality in people with learning disability. These include both the influence of the eugenics movement and the view that individuals with learning disability were “forever children” and therefore completely asexual.

It is against this negative history that the issue of sexual activity between individuals with learning disabilities is viewed. Policy making regarding sexual behaviour has to overcome a history of negative attitudes towards sexual activity between these individuals.

The dilemma faced in the case vignette, however, has yet another added issue steeped in a history of negativity, that of same-sex relationships. While many people (carers, parents and others) have a difficulty with the developing sexuality of people with learning disabilities, there are further deep-seated beliefs about the morality of homosexual behaviour in general.

Alongside these difficulties is the added issue of the legality of sexual relationships between people classified as having a learning disability.

Therefore, when reflecting on the issue of a sexual relationship between two same-sex clients, it is important to look at a number of issues. Services must tread the thin
line between the empowerment and protection of individuals within their care while recognising the influence of a number of factors. These include carer and parental perceptions (where relevant), the views and wishes of the individuals themselves and the legal implications of such a relationship. Particular attention should be paid to the understanding and intellectual abilities of the clients concerned and their capacity to consent to such a relationship.

Given the complexity of the issue of sexual activity between service users, it is important for provider services to develop a sexuality policy to provide guidelines and advice to ensure that the rights of the individuals are respected and that their safety is ensured. Such policies should be developed in consultation with service users, care staff and provider services (Cambridge and McCarthy, 1997). Cambridge and McCarthy (1997) discuss the development of a sexuality policy and indicate a number of main elements that should be included within it. These include: protection against abuse and exploitation, privacy and confidentiality, supporting the individual and their relatives, facilitating relationships, guidelines for the determination of consent, contraception, sex education and the provision of support in sexual health.

One of the first issues needing to be considered when reflecting on the development of same-sex relationships within a care home environment is that of consent, both with reference to legal constraints and the views of the individuals concerned.

**LEGAL ISSUES**

The legal system provides a number of limitations to sexual relationships both for people with and without learning disabilities. The law surrounding the sexual rights of people with learning disabilities is based on whether the individuals can be recognised to be “defective” or “severely learning disabled”, although there is little agreement on definitions. The Mental Health Act (1983) identifies the term “defective” as referring to “a state of arrested or incomplete development of the mind which includes severe impairment of both intelligence and social functioning”. Generally this term is accepted to be related to those individuals with IQ’s lower than
50 but this is by no means a clear cut definition and the assessment of the level of functioning of individuals can be subjective.

Many of these laws, however, are based on heterosexual relationships and aimed at the protection of women with learning disabilities. The 1959 Mental Health Act made it unlawful for a male staff member to have sexual intercourse with a female patient with mental disorder (including learning disability) with "woman" being changed to "person" in the 1983 act. Despite this change, the act still does not provide a relevant framework from which to view the development of relationships between service users particularly with reference to same-sex sexual behaviour. The 1956 Sexual Offences Act made it unlawful for a man to have sex with a woman identified as "defective" unless within a marital relationship, but once again this focuses on the protection of women within heterosexual contact.

There is very little legal framework from which to view the development of a same-sex relationship between individuals within a care home environment. The 1967 Sexual Offences Act states that a "defective" man cannot consent to homosexual activity (Gunn, 1987; Gunn, 1990) but same-sex relationships between women are not recognised within the law. It is unlikely however that prosecutions will be made if the relationship is thought to be meaningful or when both individuals concerned have learning disabilities (Gunn, 1987). It is therefore necessary for staff to assess whether the individuals concerned have both been able to consent to the sexual behaviour and ascertain whether the relationship is abusive.

SEXUAL ABUSE
Definitions of sexual abuse vary but can be considered to encompass both contact (touch, masturbation, penetration or attempted penetration) and non-contact (exposure to pornographic material, harassment, indecent exposure) abusive behaviour (Brown and Turk, 1994).
Brown and Turk (1992) suggest that sexual contact can be considered abusive if it falls within one of three general categories. These need to be considered when reflecting on such a relationship:

- the person withholds their consent.
- the person is unable to give consent due to their level of disability severely affecting their understanding of the elements and consequences of sexual behaviour.
- some other barrier to consent is present (including familial relationship, the presence of power imbalance or the use of threat).

**CONSENT**

When addressing the issues raised by Brown and Turk (1992), it is necessary to have an understanding of the components of consent. Sundram and Stavis (1994) describe three components of informed consent - knowledge of the important aspects, risks and benefits of the decision, an understanding of such knowledge and it's application to their own values and beliefs, and the voluntary nature of the decision (i.e. the individual is not subject to coercion). This competency to consent can be decided by a qualified professional (e.g. psychologist, psychiatrist) or by the judiciary based on evidence and expert opinion (Sundram and Stavis, 1994). Kaeser (1992) highlights the standard measures used to identify an individual’s capacity to consent include ability to read, write and tell the time, an understanding of the sexual act, its nature and possible consequences, and an ability to understand such behaviour in the context of the wider societal environment. Kaeser (1992) briefly discusses the shortcomings of such a framework by isolating the inability of even people with mild levels of learning disability to understand broad societal issues and their relation to sexual activity. It seems equally restricting however to use general abilities such as reading, writing and time telling, which are far outside the capacities of many individuals with learning disabilities, as indices by which to assess their ability to consent to sexual activity. These particular skills may be lacking in many individuals who are far more socially and functionally capable than assessments of these areas would suggest.
Kaeser (1992) discusses alternative methods of gaining an impression of consent. He proposes that decisions should be made based on knowledge of the individuals and the ways in which they are known to indicate their preference for engaging in activities e.g. do they appear to be happy or distressed, are they trying to escape from the activity, do they seek out the company of the other individual involved. This seems a much more valid method of recognising the likes and dislikes of the individuals concerned and relies on information gained from people who know them well and are able to interpret their methods of communicating their needs and desires. This reliance on third party interpretation will have its limitations as carers cannot be entirely objective in their assessments of their clients intentions and may impose their own moral viewpoints on their interpretation of client behaviour. Wherever possible therefore, the individuals concerned should be asked directly whether they are happy participating in the relationship.

It is important to recognise that for many individuals with learning disability the ability to withhold consent may be a difficult area. These individuals may have life experiences which leave them vulnerable to sexual abuse (Caffrey, 1991; McCormack, 1991). However, some of these individuals do experience environments which promote assertiveness and provide education of a sufficient standard to enable individuals to communicate their decisions through verbal or non-verbal means.

When assessing whether both of the individuals in the relationship are providing consent, it is vital to assess accurately their ability to withhold consent and attend to any behavioural indications that may indicate distress whilst in each other’s company. If at any stage it is considered that either individual is not providing consent to the relationship, every effort must be made to protect them.

**SEXUAL KNOWLEDGE**

In conjunction with the issue of consent to sexual activity, it is necessary to consider the level of sexual knowledge held by both individuals. Once it has been established that the individuals concerned wish to participate in a relationship, it is important to
assess the knowledge base on which they are making this decision. Many surveys of people with learning disability show that they do not have extensive knowledge of sexual activity in comparison to their non-disabled peers (Gillies and McEwen, 1981; Brantlinger, 1985; McCabe and Cummins, 1996). However, the growing recognition of the rights to sexual expression of people with learning disability is leading many authors in the field to highlight the need for appropriate sex education for people with learning disability. This will empower them to make informed choices about their sexuality and help them to protect themselves from unwanted sexual experiences (Kaeser, 1992; Sundram and Stavis, 1994; McCabe and Cummins, 1996; Cambridge and McCarthy, 1997).

In conjunction with knowledge about sexual activity, it is important to ascertain the extent of knowledge about safe sexual practices to reduce the risk of sexually transmitted disease and, in the case of heterosexual relationships, unwanted pregnancy.

**SAME-SEX RELATIONSHIPS**

If it is considered that the individuals concerned are making a decision to consent to sexual contact without coercion, and that this consent is informed to the extent that it is based on a solid knowledge base, then it is also necessary to consider the basis of the same-sex relationship. While it is recognised that it is common for learning disabled individuals to engage in same-sex relationships, (Monat-Haller, 1992; McCarthy and Thompson, 1994; McCabe and Cummins, 1996; Cambridge, 1997) it can sometimes be unclear whether this is a result of genuine sexual preference or the result of a number of other factors.

Monat-Haller (1992) discusses that there are limited opportunities for these individuals to engage in sexual relationships with a partner of choice and therefore many individuals become involved in sexual relationships with any available partner. She distinguishes between homosexual relationships and same-sex relationships on this basis. Same-sex relationships refer to sexual activity with an available partner for
sexual exploration. She considers that homosexuality refers to the choice of a same-sex partner when there are opportunities and freedoms to engage in sexual activity with either same-sex or opposite-sex sexual partners. If individuals are restricted to same-sex environments, where contact with members of the opposite sex is discouraged, it is unsurprising if they choose to participate in sexual activity with same-sex partners who they know and understand.

It is necessary to assess the extent to which the same-sex relationship is the result of preference for homosexual relationships or the result of lack of opportunity to develop secure and trusting relationships with opposite sex partners. If the individuals concerned live in a same-sex environment with little access to day services or environments which would allow access to other individuals of the opposite sex, it would be necessary to establish whether this could be incorporated into their general care plans to allow them extended opportunities. If other opportunities are available, and it is considered that the relationship is based on definite preference for a homosexual relationship, then opportunities should be made available for the individuals to spend time together developing their relationship.

ATTITUDES OF OTHERS
Once it has been established that the individuals under discussion both can, and do, consent to the relationship, and that their behaviour is based on general preference as opposed to lack of alternative opportunities, it will be necessary for the service providers to respond to this relationship in a way that promotes dignity and privacy to enable its development. It is helpful if guidelines to carers are included in a policy document so that all staff can respond to the development of the relationship in a consistent manner.

Staff attitudes to the development of sexual relationships of those in their care vary widely. While staff may feel that their behaviour is supportive of the sexuality of the service users, the individuals themselves tend to feel that the opposite is true and that staff may be instrumental in providing obstacles to the development of close and
intimate relationships (Johnson and Davies, 1989). In their research, Johnson and Davies (1989) found that the reluctance of staff to encourage the sexual behaviour of their clients may be related to a lack of knowledge and experience of these issues, leading to feelings of inadequacy. They found that many care environments contained a small but influential “restrictive minority” characterised by older carers with little formal training, who had strong religious values and actively sought to restrict the opportunities for sexual expression of the service users. Other authors also highlight that staff viewpoints are important factors in determining the likelihood of service users being actively encouraged to develop intimate relationships and found that more liberal views were held by younger, professional staff members with no particular religious affiliation (Trudel and Desjardins, 1992; Murray and Minnes, 1994). The older staff members tended to be direct care staff and would therefore exert a large influence on the opportunities available for individuals to develop satisfying intimate relationships. A further, unsurprising finding was that homosexual behaviour was viewed less tolerably than heterosexual relationships (Trudel and Desjardins, 1992).

It would be necessary therefore, to provide a firm set of guidelines for staff to ensure that personal viewpoints and morality do not result in undue restrictions being placed upon the development of close, intimate relationships between service users. The provision of sexuality policies containing these guidelines removes responsibility from such carers and ensures that the rights of the service users are protected. Staff should receive training in the policies to help them understand the underlying rationale behind the guidelines. This will enable them to recognise the need to balance protection of the service users with risk taking to enable the development of close relationships.

In the same way, the views of parents of service users can be important factors in the development of same-sex relationships for people with learning disability. While it is important to inform parents of the sexuality policies, it is also important to recognise the need for a confidential service for people with learning disabilities and that it may
not be appropriate to involve the parents in decisions made about relationships without the consent of the individuals concerned.

**PRIVACY**

One final issue that needs to be considered when addressing the development of intimate relationships between service users, is the issue of privacy and access to facilities that enable people to experience intimate behaviours away from others. Many care home environments and day service facilities do not have space to allow service users privacy for any length of time. Many people with learning disabilities share bedrooms and living facilities which results in inappropriate sexual behaviour being displayed in public. Once it has been established that the individuals wish to develop intimate relationships and this has been assessed through the sexuality policy, attempts should be made to allow the individuals privacy to explore their relationship further. The boundaries for engaging in sexual activity should be explicitly explained to the individuals to ensure that they do not exhibit such behaviour in inappropriate, public settings.

**CONCLUSION**

The discovery of a same-sex relationship between service users leaves providers, carers and the individuals themselves with a number of questions that need to be answered to ensure the safety and protection of the individuals, while enabling them to develop their relationship if these questions can be answered appropriately. Initially, it must be ensured that both parties consent to the relationship and that neither is being exploited. This is of particular relevance if the individuals have differing levels of ability but each should be given equal consideration when investigating and assessing the issue of consent. Time should be spent in discussion with the individuals to assess this information and attention should be paid to their level of social functioning and known behaviours indicating consent. Once it has been established that both individuals consent, attention should be paid to the availability of opportunities to meet other individuals to ensure that the relationship is not developing only as a result of a restrictive environment. Policies and procedures
should be developed to protect the rights of the service users and ensure that they are provided the opportunities and privacy necessary to develop meaningful, intimate relationships and so allow them access to this aspect of human experience.
REFERENCES


Discuss the Utility of the Diagnostic Classification of Attention Deficit Disorder

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Year II
**Issues of Definition**

When addressing the utility of a diagnosis of attention deficit disorder (ADD), it is first necessary to spend some time discussing what is actually meant by the term ADD. ADD as a diagnostic category has evolved over a number of years and is a general psychiatric label that refers to “developmentally inappropriate levels of motor activity, attention and/or impulsivity.” (Maag and Reid, 1994). Erk (1995a, 1995b) describes the evolution of this terminology over time from the initial use of the term Hyperkinetic Reaction in Children in DSM II (APA, 1968) to the current use of Attention Deficit / Hyperactivity Disorder (AD/HD) with the predominant features being either inattention or hyperactivity as described in DSM IV (APA, 1994).

ADD as a discrete diagnostic category was seen within DSM III (APA, 1980) with subcategories being provided for ADD with and without hyperactivity. The revised edition, DSM III-R (APA, 1987), however reverted to emphasising the importance of hyperactivity while DSM IV (APA, 1994) allows the subdivision of ADHD into three separate categories (Maag and Reid, 1994).

A difficulty encountered when reviewing the literature in the field of diagnosis of ADD is the differing usage of terminology by authors. Some authors refer to ADHD within their articles and seek to concentrate primarily on the particular category of ADD where hyperactivity is the predominant feature, others choose to use ADD as an all encompassing label under which all of the various subtypes are subsumed, while yet other authors do not definitively state the definitions they are using when discussing their viewpoints.

As stated above the most recent diagnostic criteria is presented in DSM IV which provides criteria for Attention Deficit / Hyperactivity Disorder enabling the practitioner to categorise the individual into subtypes of either predominantly inattentive type, predominantly hyperactive-impulsive type or combined type dependant on the pattern of symptomatology displayed. The diagnosis of AD/HD using this criteria requires the identification of six behavioural symptoms out of a
total of nine. As stated, the pattern of symptom presentation effects the diagnostic subtype given. It has been suggested that the behavioural disturbance displayed by the two distinct subtypes (as opposed to those children diagnosed with combined AD/HD) are quite different. Children with primarily hyperactivity and impulse control problems will often exhibit conduct disorder while those with primarily attention deficits will more likely display difficulties resulting from anxiety, depression and shyness (Sabatino and Vance, 1994).

Consequently, it is difficult to isolate what exactly is meant by the label ADD as definitions vary so widely and have evolved over time. For the purposes of this discussion, the term ADD will be used to refer generically to attention deficit disorders thus including those children diagnosed within any of the subtypes isolated by DSM IV criteria.

**The use of diagnostic criteria in general**

The definition of ADD therefore, requires that the behaviour exhibited by the individual presenting to services fulfils the diagnostic criteria as defined by either DSM IV or ICD-10. The use of diagnostic criteria is well established within general psychiatric practice but reliance on this approach, in itself, has inherent difficulties. Scotti et al. (1996) discuss the utility of the approach to diagnosis used by DSM IV. They suggest that the usefulness of a classification scheme, such as DSM IV, is based on three main considerations: providing accurate diagnosis to enable the receipt of financial support from health care services and other agencies; the need for clinicians and researchers to share a common language and communicate without ambiguity and therefore be consistent in their understanding of the issues under discussion; to enable accurate prognosis which can be used to appropriately inform the development of intervention programmes.

However, Scotti et al. (1996) believe that the use of such a diagnostic system should only be viewed as a starting point from which to develop formulations of, and treatment approaches to, clinical problems. They believe that classification systems
focus only on what constitutes the behaviours indicative of the diagnosis and not on what function these behaviours serve. They highlight that DSM IV, as with all other standard diagnostic criteria, focus primarily on behavioural excesses and deficits and does not allow for the identification of skills and assets which may be necessary for the development of appropriate intervention programmes. It is suggested that the use of diagnostic criteria requires supplementary functional analysis of behaviours exhibited by individuals to ensure that treatment approaches are correctly tailored to respond to the differing needs of individuals’ difficulties.

The use of diagnostic criteria for ADD

For many years, ADD has unquestioningly been viewed as a psychiatric disorder but consideration needs to be given to whether it should be seen as is a valid psychiatric condition. Reid, Maag and Vasa (1994) suggest that there are three basic assumptions that are held which result in the view of ADD as a valid psychiatric disorder. These include the belief that the diagnostic criteria provided enable the correct classification of ADD and its differentiation from other disorders, the belief that ADD can be diagnosed accurately and reliably using available assessment tools such as behaviour rating scales and the view that there is ample evidence available to confirm an organic etiology for ADD. Reid et al. (1994) challenge these basic assumptions and suggest that caution should be used when viewing ADD as a separate diagnostic category.

- Differential diagnosis

The first issue to be considered is whether it is possible to accurately differentially diagnose ADD from other psychiatric disorders. As discussed above, diagnosis of ADD requires the identification of a number of behavioural indicators in children relating to attentional deficits, impulsivity and hyperactivity. Reid et al. (1994) contend that the behaviours identified as indicative of ADD are not based on firm empirical evidence and that ADD cannot be reliably differentiated from other similar disorders (e.g. conduct disorder, oppositional defiant disorder) in relation to etiology, course or response to treatment. Yelich and Salamone (1994) also question the
empirical basis on which the criteria are developed stating "the diagnostic classification system . . . . reflects an eclectic theoretical position . . . . on a consensus of common behaviours thought to be symptomatic of ADHD."

Even if it can be established that the behaviour identified within the criteria do accurately reflect a valid psychiatric condition, a fundamental difficulty with the dependence on these criteria is the reliance on socially constructed views of "deviance" and "normality". This factor is reflected in differential rates of diagnosis seen between America and Europe. The American psychiatric community appears to view ADD as a primarily medical condition intrinsic to the child and does not consider the social construction of disorder as an issue in diagnosis. This results in ADD being 50 times more likely to be diagnosed in America than in England or France and being increasingly likely to be treated with methylphenidate medication as opposed to behaviourally based interventions (Reid, Maag and Vasa, 1994). The huge discrepancy between rates of diagnosis suggests that ADD cannot be considered to be a definitive entity with discrete behavioural indicators but that interpretation of diagnostic criteria is hugely influenced by cultural factors.

A further problem which increases the likelihood that use of the criteria will be influenced by cultural and social factors is that the behavioural indicators necessary for diagnosis of ADD are childhood behaviours that fall at the extreme end of a "normal" distribution. This therefore, relates to how beliefs about "normality" are socially constructed and it needs to be considered whether deviance from normality can be accurately assessed.

- **Assessment measures**

The diagnostic criteria suggest a range of behaviours which, if present, would indicate that a diagnosis of ADD is appropriate. For accurate diagnosis, it is important that the clinician attends to the whole range of behaviours required for diagnosis and undertakes a full assessment of the child. Difficulties arise because the target behaviours identified by DSM IV do not contain operational definitions or
behavioural anchors to guide the clinician in deciding whether they are present in a sufficiently severe form to contribute to diagnosis (Reid, Maag and Vasa, 1994). Behaviours identified as indicative of ADD include fidgeting, interrupting and talking excessively but it is not clear what form these behaviours should take or at what level their presence would be considered excessive.

A number of assessment tools are available to aid the clinician in the recording of information necessary to make a diagnosis of ADD. These include the Conners Scales for both teachers and parents (Conners, 1989) and the Child Behaviour Checklist (Edelbrock and Achenbach, 1984). Difficulties arise as many tools used for identification of ADD are based on Likert scales requiring observers to rate the behaviours of children. Once again, behavioural anchors and operational definitions are rarely provided resulting in little agreement between raters regarding the child’s behaviour (Reid, Maag and Vasa, 1994). Furthermore, personal attitudes and beliefs regarding childhood behaviour may have an impact on rater tolerance of certain behaviours used in diagnosis and therefore be reflected in the type of problem identified and the extent to which the raters consider it necessary for intervention to be provided (Reid, Maag and Vasa, 1994).

- **Etiology**

Many authors discuss the fact that ADD is currently based firmly within the medical model and is considered to have neurological and genetic components (Maag and Reid, 1994; Erk, 1995b; Reid and Maag, 1997). Erk (1995b) states that “Fundamentally, ……… (ADD) can be thought of as a neurobiological disorder” and quotes a number of studies upholding the claim that ADD has genetic components and is caused by physical anomalies within the brain. However Reid and Maag (1994, 1997) highlight the methodological flaws intrinsic in many of the research designs undertaken and the lack of scientific rigour employed when making far reaching conclusions from the research.
The belief in ADD as a psychiatric disorder is based on the unquestioning belief in these three assumptions regarding differential diagnosis, assessment measures and etiology, which leads to the medicalisation of a group of behavioural phenomena. The difficulty with viewing ADD as a purely medical phenomenon is that the problems experienced by the child are then seen as intrinsic to the child and tend to lead to treatment approaches based primarily on pharmacological intervention.

Diagnostic criteria for ADD require that the child exhibits a number of specific behaviours reflecting difficulties with social functioning while treatment focuses on the administration of medication (Maag and Reid, 1994). This reliance on a medical model of ADD results in little attention being given to other external factors which may influence the child's behaviour and therefore other alternative approaches, tailored to address particular problems encountered by the child, are rarely considered. It needs to be recognised that children do not behave in isolation from their social world and that some behaviours used as indicators for ADD may well be understandable reactions to their social environment. It would seem unreasonable therefore to view the exhibition of difficult behaviours as purely intrinsic to the child without taking a full account of the larger system within which the child exists.

**The usefulness of diagnostic criteria**

The use of diagnostic criteria, therefore provides a picture of a child with a medical condition that is subject to change primarily through medication. Is this useful? It would seem that this approach to the diagnosis of ADD provides an illusory view of a child who cannot be expected to change and function within societal norms without medical intervention. It fails to account for the function served by the behaviour, the impact of the wider environmental system on behaviour or the utility of interventions based on system change. The diagnostic criteria which suggests that there is a distinct diagnostic entity of ADD is not fully upheld by the research literature but this creates an image of uniformity across all children with ADD. It is likely however, that these children are not a homogeneous group and therefore does anyone benefit from a diagnostic process which creates this image of uniformity? Admittedly, the issues of
diagnosis being necessary for access to services and funding exist although, the presence of behavioural problems alone, without a diagnostic label, would probably be sufficient to gain health service intervention. However, communication and the provision of prognoses are not necessarily enhanced by the use of the global term ADD as this use of a diagnostic label does not reflect the large heterogeneity of the client group nor the varying need for differing therapeutic intervention or the probable outcomes that can be expected.

**A functional approach to assessment**

The view that diagnostic criteria require further, supplementary information to enable the development of informed treatment packages as highlighted by Scotti et al. (1996) is also discussed within the ADD literature. This area of growth appears to be in response to the recognition of the limitations inherent in the reliance on a medical model of ADD and the belief that attention needs to be paid to environmental contingencies external to the child which may be affecting the behavioural repertoire exhibited.

Maag and Reid (1994) comment that the use of functional analysis in the assessment of ADD has been widely ignored by the literature. They suggest that it is important to look both at the skills and deficits within the child and the ecological variables which may influence the child’s choice of behaviour.

Maag and Reid (1994) discuss the child based deficits with reference to the diagnostic criteria related to difficulties in waiting for turns in group situations. They highlight a number of reasons why this could be difficult for a child, including a lack of knowledge of the rules of turn taking, anxiety resulting from negative attributions, and failure to monitor social situations accurately. It is apparent that the intervention approach adopted to address difficulties in turn taking would vary enormously depending on the outcome of functional analysis of this behaviour. For any intervention to be successful, it must directly address the reason for the behavioural
deficit and the matching of assessment information to intervention approaches is necessary to enable the development of appropriate interventions.

The ecological variables highlighted by Maag and Reid (1994) include task demands, expectations of parents and teachers and responses of others to the difficult behaviours. Many of the behavioural criteria necessary for diagnosis of ADD can be displayed by children in response to a number of differing environmental contingencies including the receiving of attention (from parents, teachers or peers) or the avoidance of task demands. It is vital that the role of environmental variables is fully considered during assessment so that other, more appropriate ways of gaining the desired contingencies can be developed by the child.

The functional approach to the diagnosis of ADD has the added benefit of removing attention away from the child as the victim of a medical condition and more towards the view of a child responding to his or her larger environment. This enables a collaborative approach to be developed whereby all members of the larger system are involved in developing more appropriate coping mechanisms aimed at alleviating the difficulties being experienced.

The use of a diagnostic label alongside this approach may also have beneficial functions (Reid and Maag, 1997). It can help by removing blame from the child and enabling parents and other caregivers to separate the child from their difficult behaviour (White and Epston, 1990). The diagnostic label also serves to legitimise parental concerns and remove from them the stigma of the child's behaviour resulting from poor parenting (Reid and Maag, 1997).

Conclusion
Reid and Maag (1997) propose that the development of constructs and diagnostic labels are only useful if their development informs treatment. Their discussion of the diagnostic criteria indicates that this is not the case for ADD and that diagnosis using
purely DSM IV criteria provides little useful guidance for treatment or prognosis due to the problems inherent in its development.

For a diagnosis of ADD to have clinical utility therefore, it is necessary to look beyond the general diagnostic criteria as described by DSM IV towards isolating factors which are individual to the child and his/her environment. This more individualised approach will enable the development of a fuller understanding of the reasons for, and consequences of, the child's difficult behaviours which will in turn inform the development of the therapeutic intervention. This more individual approach to assessment and treatment will enable practitioners to develop more effective approaches to the care of their clients.
REFERENCES


Describe the Theoretical Models that have Underpinned the Development of Group Therapy for Older People. What are the Special Considerations that Need to be Addressed? Discuss Appropriate Methods for Evaluating its Effectiveness for this Client Group
INTRODUCTION

In answering the question posed, the essay initially focuses on models of group therapy developed for older adults followed by discussion on special considerations needing to be addressed when working with older people in group settings. Finally, attention is paid to the difficulties encountered when evaluating effectiveness of group intervention with this population.

Group therapy for older people is a relatively new area within the provision of services. The growth in therapeutic services for older adults is a reflection of population changes whereby the older adult population is a fast growing section of the population as a whole. Advances in medical knowledge and available treatment, alongside a general rise in standards of living, has resulted in the tendency for people to live longer. Population estimates suggest that by the year 2050, 20% of the American population will be over the age of 60 years with particular increases being seen in the proportion of people over the age of 85 years (Myers, Poidevant and Dean, 1991). Population projections in the UK show a similar trend with estimates showing that by 2030, 29% of the population will be over the age of 60 with 13% being over the age of 75 (Kendrick and Warnes, 1997). Alongside this population increase, has been a decline in the relative number of people in the 45 - 65 year age bracket. Historically, these individuals were care-givers to their ageing relatives and friends. A decrease in family sizes has resulted in fewer individuals being available to care for their older relatives, leaving this responsibility primarily to the state. This change in population distribution has led to an increased need for the provision of therapeutic interventions to address the mental health needs of older adults. Myers, Poidevant and Dean (1991) suggest that between 15 - 20% of older adults experience mental or physical health problems that impinge on their quality of life while Kendrick and Warnes (1997) summarise a number of studies which indicate that older adults are prone to experiencing dementia, depression and anxiety disorders.

Group therapy has been a general treatment modality for many years and is considered to be a cost effective, efficient and efficacious way of providing a range of
therapeutic interventions. It has been hypothesised that this is an appropriate medium through which to provide therapeutic input for older adults.

O’Leary (1996) suggests that group approaches are particularly relevant with an older adult population. She considers that the nature of general problems in older adults (e.g. social isolation, loneliness, role loss and bereavement) can be addressed through group intervention which provides opportunities to gain support and develop new relationships with peers who have undergone similar experiences. She believes that the participation in groups allows for the sharing of difficulties and the opportunity to develop problem solving skills. Capuzzi and Gross (1980) also consider the role of loneliness, isolation and rejection in the experience of depression and the increased risk of suicide during the ageing process. They suggest that group therapy leads to reductions in loneliness and isolation and that the opportunity for social contact helps to counteract feelings of rejection.

GROUPS FOR OLDER ADULTS
Having established the reasons for undertaking group interventions with older people, it is necessary to consider the variety of therapeutic groups available and the psychological models on which they are based. Burnside (1984) suggests that there are four distinct types of groupwork used with older adults: reality orientation, remotivation therapy, group psychotherapy and reminiscence. These approaches will be described in more detail below along with one further approach not highlighted by Burnside, that of validation therapy.

- **Reality Orientation Groups**
Reality orientation was one of the first groups developed specifically for use with older adults and provides a group approach for those individuals who are beginning to become disorientated in time and place. It was developed from the work of Dr James Folsen who worked with elderly war veterans on the USA during the 1950’s (Miller and Morris, 1993). The group approach to reality orientation suggests that 3 to 5 clients meet for hourly sessions at least twice weekly to help with orientation of the
person to their environment. At a most basic level, the session provides information on the day, date and time alongside the current environmental situation (e.g. weather). The groups spend time looking at individuals’ personal psychosocial situation, self care skills and the differences between their past and present experiences. It is expected that participation in such groups helps increase overall functioning and levels of self-awareness and so prevents further psychological deterioration (Capuzzi, Gross and Friel, 1990). The benefits gained through the participation in these groups can be enhanced by the care team surrounding the individual. The care staff are encouraged to ensure the environment is structured in a way that promotes ease of orientation (e.g. clear signs to rooms, accurate clocks and calendars providing clear information regarding the day and date). Reality Orientation approaches are probably the most widely known intervention techniques for older adults. Studies on the effectiveness of reality orientation indicate that participants become more able to correctly answer questions on orientation (Baines, Saxby and Ehlert, 1987) but it unclear whether these changes greatly impact upon other areas of the individuals’ functioning (Hanley, McGuire and Boyd, 1981).

- **Validation Therapy**

Validation therapy groups were once again specifically developed for those elderly people who are confused and experiencing some degree of cognitive impairment. These groups were developed by Naomi Feil in the USA as a reaction against reality orientation which she believed to be insensitive to the individual’s own psychosocial experience and failed to respond to their confused inner world (Miller and Morris, 1993). It places emphasis on the subjective experience of the individual as opposed to the objective reality. It is hoped that by responding to the individual with empathy, as opposed to confronting them with statements about reality, their experiences can be “validated” in a way that facilitates communication on important themes for the individual. The use of validation therapy in groups has been seen in residential settings (Bleathman and Morton, 1988) where members are individually welcomed to the session and provided with roles within the group. Once again, session sizes are kept small and sessions held regularly. Facilitators tend to take fairly directive roles
in session management as many groups members will be experiencing significant levels of cognitive confusion which result in it being impractical to provide non-directive facilitation. Sessions are spent discussing commonly held feelings and emotions without it being necessary to focus on orientating the individual to the present. One of the significant features of validation groups is the adherence to a rigid routine to provide the group member with an "impressionistic memory" of the group, so allowing them to learn an association between the environment and the group session to follow (Morton, 1997).

Unfortunately, validation therapy has yet to be subjected to independent, controlled studies to evaluate its effectiveness with most data having been published by Naomi Feil (1992, 1993).

- **Reminiscence**

Reminiscence groups are also widely used with the elderly and can be used in conjunction with the reality orientation approach detailed above. Reminiscence is based on Butler's (1963) theory of the need for life review and its development by Ebersole (Capuzzi, Gross and Freil, 1993). It is also influenced by Cumming and Henry's work on ageing and disengagement (Cumming and Henry, 1961 cited in Bornat, 1994). Cumming and Henry note that during the ageing process, individuals naturally become increasingly preoccupied with their own thoughts and memories. Group approaches using reminiscence allow the older person to revisit difficulties and work through unresolved issues. The facilitator helps the older person find positive memories as well as empowering them to confront painful memories which may be inhibited by grief (Bornat, 1994). Group membership in reminiscence groups should remain small to allow for the sharing of memories between group members. It is considered that inclusion in a reminiscence group will enable the participants to value both themselves and their own memories alongside the memories and experiences of others in the group. It also highlights shared experiences and accomplishments so increasing self-esteem and promoting communication and social skills with their peer group (Myers, Poidevant and Dean, 1991). Reminiscence also allows group members
to begin to come to terms with their own life experiences in line with the theories of Erikson (1963) that the move toward integrity and acceptance is a necessary component of older adulthood.

Research into the effectiveness of reminiscence has suggested that participation has an impact on levels of isolation and loneliness while having a positive effect of self-esteem and psychological well being (Osborne, 1989; Sherman, 1987).

- **Remotivation Therapy**
  Remotivation therapy was developed in the 1950's to enable the elderly to regain interest and involvement in their environment whilst encouraging communication and stimulating mental processes (Capuzzi, Gross and Freil, 1990). These groups are designed for people who remain correctly orientated to time, place and person but who have lost interest in both the present and the future. For the group to run effectively, the participants must be able to communicate well, interact with others and have intact memory functioning. The sessions are undertaken 3 times weekly and are based on a five step approach of establishing acceptance and rapport, encouraging a "bridge to reality" (where articles and poems are read by group members), using props to discuss issues related to "the world we live in", discussing positive aspects of members lives and concluding with group members reflecting on the group and planning the next session (Waters, 1984; Kalson, 1982). The focus of the group is on positive experiences of the members and aims to avoid discussion of more personal difficulties and problems (i.e. marital problems, financial difficulties, religion and politics). It is considered that remotivation groups are aimed at encouraging participation in subsequent groups where these issues can be more readily addressed.

- **Psychotherapy groups**
  The final groupwork format highlighted has not been specifically designed for older adults and consequently will only be briefly discussed. Psychotherapy groups with older adults allow for the identification and expression of feelings and emotions e.g. anxiety, loneliness and fear (Capuzzi, Gross and Freil, 1993). This approach allows
the older person to explore and address long-standing conflicts in a safe and contained
environment. The psychotherapeutic approach works in opposition to Freud's belief
regarding the inability of older people to address conflict and is based on the
assumption that these individuals are able to address and process their emotional
difficulties.

**SPECIAL CONSIDERATIONS**

Having discussed the groupwork formats available, it is necessary to spend time
considering what special considerations need to be addressed when undertaking
groupwork with older adults.

Corey and Corey (1997) address some of the unique characteristics of groupwork with
older adults. They highlight a number of issues needing to be considered when
undertaking a group approach with the elderly. They discuss the sensitivity of older
people to the "stigma" of involvement with mental health services making them
reluctant to engage in a trusting, therapeutic alliance. They suggest that the attention
and concentration span of older people is shorter resulting in a need for groups to be
run at a slower pace than would be expected in a younger population. Also, many
individuals may be experiencing cognitive decline or taking medication which may
interfere with their ability to participate in groups and to process the information
being discussed. Individuals may have poor reality orientation resulting in them
forgetting either to attend groups or remain in sessions once present. Attendance may
also be affected by the presence of physical impairments, difficulties accessing
settings due to transportation or the conflicting demands of organisations and other
appointments.

Capuzzi, Gross and Freil (1990) also highlight the need for scheduling groups at times
when participants are alert, giving attention to the physical environment (e.g. access
to bathrooms, comfortable seating) and being sensitive to the physical and sensory
limitations of the client group. They also consider that it is necessary for the
facilitators to take a more directive approach to group leadership in order to actively
encourage group discussion and self-disclosure. They highlight the need to pay attention to transference and counter-transference reactions. Knight (1986) discusses the role of transference and counter-transference but highlights that the richness of the older persons life experiences lends itself to the reflection of many differing relationships onto the therapeutic relationship, so allowing for the exploration of many issues during therapy.

Weiss (1994) discusses the need to provide firm environmental and therapeutic boundaries to sessions. He highlights that older people may be unaccustomed to discussing private and personal details in group settings. Many individuals participating in groupwork are living in residential settings where previous boundaries (privacy, personal space) are no longer present. Individuals may be wary of discussing personal issues due to fear that privacy may not be maintained. The provision of firm boundaries on the group undertaken will help develop a sense of trust which will facilitate the undertaking of open and frank discussion.

Weiss (1994) also discusses the issue of level of cognitive functioning in the allocation of individuals to groups. It has been found that including both confused and cognitively able individuals in the same group has a detrimental effect on the development of group cohesion and trust alongside delays in identifying the goals of the group. By combining both types of older adults, it was found that the needs of the group members varied so widely that it was difficult to provide a therapeutic format which was beneficial to all members.

Finally, as with any form of therapeutic intervention with older adults, consideration should be given to the possibilities of physical and sensory impairments experienced by the participants. Rooms should be well lit to ensure that all individuals can be seen as clearly as possible. Background noise should be kept to a minimum and group members should be seated close to each other to enable the participation of those people with hearing impairment. Finally, seating should be comfortable and suited to the physical needs of the group members.
EVALUATION

The final aspect to be considered in this discussion is the issue of evaluation. The move towards evidence based practice within psychological fields, alongside the publication of the new government white paper "The New NHS", requires that interventions offered to all client groups need to undertake regular evaluation.

While the use of reality orientation techniques have been widely evaluated (Wallis, Baldwin and Higginbotham, 1983; Baines, Saxby and Ehler, 1987), very few of the alternative group approaches for older adults have been subject to rigorous controlled trials. One recent paper undertaking evaluation of group interventions has highlighted some of the difficulties inherent in evaluating group work for older people.

Weiss (1994) undertook an evaluation of group therapy for both cognitive and life review interventions but was unable to find significant improvements on dependant measures. He discusses this difficulty with reference to both the treatment setting and the population under observation. The issues raised in the paper are likely to be important aspects to consider in the evaluation of any older adult group intervention.

Initially, he discusses the fact that for treatment effects to be shown, the statistics undertaken must have significant levels of power. He suggests that the groups conducted should have at least 12 members at outset as in his study, he experienced a drop out rate of 29%. He suggests that by starting with 12 members, this would be sufficient to allow the statistics undertaken to be powerful even if a large drop-out rate is experienced. However, the issues highlighted above indicate that for older adults to gain optimum benefit from groupwork, group sizes should be small enough to allow for the sharing of experiences and the establishment of trust. As discussed, attendance rates at such groups is variable due to individual and organisational difficulties and it cannot be guaranteed that all members attend all sessions or complete the group. Therefore with most groups, sufficient statistical power would not be possible even with the initial numbers, let alone the numbers of people
Weiss also suggests that treatment length should be extended to allow participants to benefit more fully from the groups. He believes that the format undertaken is unfamiliar to many older people and that they may need extra time to acclimatise to the group setting and requirements. However, increasing group length may lead to an increase in the drop out and non-attendance rate further creating difficulties with statistical analysis.

Finally, it needs to be considered that many of the individuals under consideration are experiencing an irreversible cognitive decline which will not be reversed by any form of therapeutic intervention. These individuals may already be significantly confused and disabled and the measurement of any improvement will be impossible. It is necessary therefore to look for realistic therapeutic goals which reduce the rate of cognitive decline and increase quality of life (Woods, 1996).

It appears therefore, that the use of large, controlled studies in this client group may not provide any indication of treatment effects. However, case reports and individual case designs may be more able to isolate the beneficial effects of group interventions. The evaluation of treatments for older adults has yet to be widely undertaken and this needs to be considered in more depth by future researchers.

**SUMMARY**

In summary, a number of specific psychological models have been developed for the use in group settings with older adults. As with any therapeutic intervention with older adults, particular issues have to considered when implementing these interventions. Difficulties arise with the evaluation of such group interventions as a result of the particular presentation of the client group leading to clinicians having to maintain realistic goals aimed at increasing general quality of life.
REFERENCES


Clinical Dossier
Summary of Clinical Experience

Year 1 - Adult Mental Health Core Placement
The placement was based at a community mental health team which comprised psychiatrists, psychologists, social workers, occupational therapists and community psychiatric nurses. Individual, cognitive-behavioural work was undertaken with clients with a wide variety of presenting problems including: depression, anxiety, needle phobia, poor anger control, obsessional-compulsive disorder and chronic fatigue syndrome. Group sessions on cognitive-behavioural approaches to depression were also included. Clients were seen from across the age range from a variety of social backgrounds. Psychometric assessment were undertaken on two clients. The placement provided the opportunity to present a half-day workshop on stress management to nurses undertaking an MSc in cognitive-behavioural therapy.

Year 1 - Learning Disabilities Core Placement.
The placement was based at a community learning disability team which comprised: psychologists, community nurses, occupational therapists and physiotherapists. Clients were seen for individual work focusing on behaviour management and the effects of sexual abuse. The majority of the work undertaken was with carers and staff groups and included the management of difficult behaviours (aggression, theft), facilitating communication in non-verbal clients, cognitive loss in older individuals with Down Syndrome and issues regarding sexuality. Psychometric assessment was undertaken using a range of tools developed specifically for use with people with learning disabilities to enable the appropriate formulation of difficulties and the specific tailoring of intervention strategies. Additionally, an eight session women’s group was undertaken which required the development of the programme, the organisation of venues, assessment and selection of participants and the facilitation of the groups itself. Eight individuals attended group sessions at a local learning disability resource centre. Issues discussed included: women’s health, friendships, fashion, menstruation, sexual health and contraception. Finally, an audit of referrals was undertaken to assess the need for the service to employ a trained counsellor.
Year 2 - Child and Adolescent Core Placement

A community team with a range of health and social services professionals was again the basis for this core placement. Individual work was undertaken with children from between the ages 10 and 16 years regarding bereavement, chronic health problems, early childhood deprivation and phobias. Work with parents was also undertaken for children between the ages of 3 to 7 years to address issues including sleep disturbance, attention and concentration problems, feeding difficulties, soiling and toddler tantrums. Weekly family therapy session were conducted in the team and the opportunity was provided to observe this work and contribute to the case discussions and planning of interventions. Psychometric assessment was conducted on five children. The opportunity was provided to address childhood difficulties within behavioural, cognitive-behavioural and psychodynamic models.

Year 2 - Older Adult Core Placement

This placement was undertaken in a small, uni-disciplinary setting. Difficulties with funding and psychology recruitment resulted in a reduced service to older adults within the region. Consequently, there were few opportunities for direct, individual client work as most work was undertaken using either consultancy, organisational or group approaches to client difficulties. However, individual therapy work was undertaken with two clients, assessments were undertaken on five clients and consultancy was used for a further four clients. It was possible to use group interventions to address both functional and organic difficulties with clients. It was possible to attend monthly psychology meetings in a team undergoing significant change following the merger of local NHS trusts. Additionally, the opportunity was available to facilitate a ½ day psychology workshop on the rationale and process of group work for older adults. Finally, it was possible to participate in ongoing research looking at the provision of residential accommodation for older adults in the region through the attendance of focus groups convened with both staff and relatives.
Year 3 - Neuropsychology Elective Placement
The focus of this placement was neuropsychological assessment and it was based at the Atkinson Morley Hospital. The service was multi-disciplinary and although mainly health based, did contain some social services staff. During the placement, individuals were assessed with a range of neuropsychological difficulties following strokes, tumours and accidents. Additionally, work was undertaken with a number of individuals with deteriorating cognitive impairment due to neuro-sarcoidosis, lupus and multiple sclerosis. Assessments utilised both clinical interview and psychometric assessment tools. Ward meetings were attended fortnightly to discuss new, and current, patients. Weekly meetings regarding the cognitive programme were attended, as were fortnightly care planning meetings that occurred for all clients. Research was undertaken on the progress of patients undergoing the cognitive group. This included setting up a database, entering baseline and outcome data and presenting the findings to the therapists on the team. Additionally, a presentation of the 2nd year research was undertaken for the regional psychology group.

Year 3 - Developmental Disabilities Elective Placement
This final placement was undertaken at a Tier 3, multidisciplinary service for children with developmental disabilities. Work was undertaken both individually and with other professionals (social workers, speech and language therapy and psychiatry). Individual casework was undertaken with the families of children with presenting problems including behavioural management, sleep disturbance, feeding difficulties and school-based problems. Psychometric assessment was undertaken as part of multi-disciplinary assessments on children with a range of developmental disabilities including: autistic spectrum disorders, Down Syndrome and ADHD. Attendance was required at weekly multidisciplinary team meetings to discuss new referrals, feedback on recent assessments and discuss current cases. It was also necessary to attend weekly uni-disciplinary, psychology meetings where new referrals were allocated and time was spent on case presentations. Additionally, ½ day CPD days were held on a monthly basis for psychologists and monthly training seminars were attended at the learning disability service.
Adult Mental Health Case Report Summary

CB - Management of Chronic Fatigue Syndrome

Introduction
The case report related to a 37 year old client (CB) who had been referred for psychology intervention aimed at managing her symptoms of Chronic Fatigue Syndrome (CFS).

Reason for Referral
CB had been experiencing persistent symptoms of fatigue following a bout of food poisoning. She was experiencing numerous physical symptoms of fatigue and her level of daily activity was being dictated by her level of fatigue and symptom presentation.

Personal History
CB had experienced difficult relationships with her parents during childhood, regarding her mother in particular, as being cold, distant and unloving. She had married when she was 16 years old and had one son. She was married for 12 years before getting divorced. She had shared a business with her husband but this was affected by the recession and both she and her husband were declared bankrupt. At the time of referral, CB had resigned from work but was continuing part-time work to supplement her income from Disability Living Allowance. She was in regular contact with her adult son. She was in a relationship but this broke down during the period of intervention.

CB had a sister who was also diagnosed as having CFS with whom she was in daily telephone contact.

Formulation
Initially, the case was formulated through a cognitive-behavioural framework. It was considered that CB’s childhood had resulted in her developing a number of
underlying assumptions regarding achievement and weakness that resulted in a personality characterised by the need for achievement.

Prior to CFS, CB had experienced a number of significant life events which caused her to experience stress. The bout of food poisoning overwhelmed her capacity to cope resulting in her experiencing physical pain and fatigue. Given CB's underlying assumptions, she was unable to allow time for her body to recover and continued to attempt to function at pre-morbid levels of activity. This exacerbated her feelings of fatigue and pain. She began to take extensive periods of rest, resigning from her job to take up employment in more sedentary occupations. This resulted in a general reduction in levels of fitness and any attempt to return to pre-morbid activities resulted in a recurrence of the symptoms of fatigue and pain. CB then entered a cycle of exertion followed by experience of symptoms.

The case study was also formulated from a psychodynamic perspective. The literature however, supports cognitive-behavioural interventions as the most efficacious treatment and this was therefore followed in the treatment plan.

**Intervention**

CB was seen for 12 weekly sessions aimed at looking at ways of increasing activity levels through a graded programme of activity scheduling. Additionally, a cognitive component to the intervention helped isolate negative automatic thoughts and explore alternative ways of perceiving her situation. Through this work, it was possible to engage CB in a positive therapeutic relationship, working with her to address her difficulties.

**Outcome**

Unfortunately, it was not possible for CB to make great progress in addressing her symptoms during the intervention as she experienced physical illness and difficulties in her personal life which left her with few personal resources to address her difficulties.
However, CB was able to recognise the role of psychological processes in the maintenance of her difficulties and indicated that she would be able to put the strategies discussed into practice in the future. Following the intervention detailed, CB was offered further, less frequent, sessions with another psychologist for monitoring of her progress.
Learning Disability Case Report Summary

Chloe: An Overview of Intervention for Aggression and Other Difficulties

Introduction
The case study reported intervention with the family of a 24 year old woman with learning disabilities, Chloe.

Reason for Referral
Chloe had been referred to the Community Learning Disabilities Team (CLDT) for management of her violent and aggressive behaviour within her home. This was particularly directed towards her mother, Jane.

Personal History
Chloe had been diagnosed as having a learning disability when she was two years old. Her mother believed her difficulties resulted from a vaccination for whooping cough although this had never been proven. During childhood, Chloe had also been considered to suffer from Attention Deficit Hyperactivity Disorder and had received medication to control her levels of activity and increase her concentration span.

Chloe had attended a school for children with severe learning difficulties where she progressed well, gaining many self-care skills. Although she had never gained extensive speech, she could communicate using one and two word utterances.

At the time of intervention, Chloe was attending college and day centres during the week. She spent alternate weekends at respite care.

Previous Intervention
Chloe had previously been referred to the CLDT regarding her aggressive behaviour. All previous intervention had been successful in containing the situation in the short-term but difficulties invariably returned.
Just prior to the current intervention, Chloe had been allocated to another team member who had undertaken extensive monitoring of the difficulties which provided a baseline against which to measure any change.

**Formulation**
Meetings were held with Jane to discuss the difficulties being experienced. A number of issues were highlighted as creating problems. The main difficulty at the time was the continued aggression towards Jane. Whilst other issues were considered and addressed, the aggression remained the focus of the formulation.

The difficulties were viewed from both behavioural and systemic models.

- **Behavioural Formulation**
  It was considered that Chloe had learnt through reinforcement that displaying aggressive behaviour was an effective way of manipulating her environment. Her behaviour was being positively reinforced through gaining demands. Jane’s reaction to Chloe’s aggression was being negatively reinforced by Chloe calming down and stopping her aggressive behaviour. This cycle of behaviour was resulting in the aggressive behaviour being maintained within the family environment.

- **Systemic Formulation**
  It was additionally considered that Chloe’s increasing independence was placing strain on the family system causing all members of the family to resist her move towards adulthood. This resistance led to Chloe being responded to as a child which resulted in her frustration and aggression.

**Intervention**
It was considered that it would have been particularly appropriate to provide family therapy to address the transition issues highlighted in the formulation. Unfortunately, Chloe’s father and brother were unwilling to participate in the psychology intervention. Consequently, intervention was undertaken based on the behavioural formulation.
Intervention took the form of weekly support meetings with Jane and the implementation of a behavioural programme aimed at reducing aggressive behaviour whilst increasing more appropriate ways of Chloe influencing her environment. Work with Jane looked at the need for Chloe to increase her level of autonomy. Other issues raised in the assessment (e.g. sleep problems, obsessional behaviour) were also addressed through meetings with Jane.

**Outcome**

Evaluation was undertaken on the number of aggressive outbursts exhibited by Chloe in comparison to the baseline levels. Chloe was seen to have dramatically reduced her aggressive behaviour over the intervention period. Reports from Jane indicated that the home situation was much improved and that she was beginning to respond to Chloe as a developing adult.
The Assessment and Formulation of a Child with Orthopaedic Disabilities

Introduction
This case study presented a psychodynamic assessment of a 10 year old child, Sally, with complex needs in relation to her physical disabilities.

Reason for Referral
Sally was referred to the Child and Family Service by her GP following concerns regarding her behaviour at home. Her parents were having difficulties managing her behaviour and were requesting advice on management techniques.

Personal History
Sally had been born three weeks prematurely following a difficult pregnancy. Temperamentally, Sally was a happy baby achieving most milestones within normal limits. However, she failed her ten month hearing test and regular tests thereafter. Unfortunately, this was not corrected until she was seven years old when she underwent surgery to insert grommets. Consequently, Sally’s speech and language was impaired and she received specialist input from the age of six years.

Additionally, Sally was diagnosed as having a congenital, dislocating hip when she was six months old. She underwent corrective surgery at the age of nine months and spent many months in traction and plaster. This was unsuccessful and Sally subsequently had further operations and periods in plaster to correct difficulties. These were ongoing at the time of assessment. Further, invasive procedures would be required when Sally reached adolescence.

Finally, recent Educational Psychology assessment had diagnosed learning disabilities and dyslexia resulting in a need to move to specialist educational provision.
Formulation
The case was formulated within a model of chronic illness. It was identified that Sally and her family had many risk factors indicating the possibility of experiencing difficulties adjusting to Sally’s disabilities. It was also considered that she had few resistance factors that could mediate against these risks and, those she did possess, were being rendered unusable by the relationships within the family.

Intervention
Initially, it was hoped to undertake work with Sally’s mother to mediate some of the environmental stressors experienced by Sally and it was suggested that she monitor Sally’s behaviour for a period of time. Unfortunately, no records were kept during the monitoring period. Subsequent discussion suggested however, that the family’s main concern was Sally’s ability to cope with her disabilities and it was therefore necessary to spend time with Sally assessing her coping abilities and the themes that were important in her world.

Further Assessment
A number of sessions were undertaken with Sally within a psychodynamic framework. Regular sessions were undertaken using play therapy as a way of accessing important issues in Sally’s life. Sessions focused on the use of drawings, dolls and puppets.

Interpretation
From the assessment sessions, it was possible to identify a number of important themes in relation to attachment, resolution of oedipal issues and adjustment to chronic illness.

Recommendations
Sally was referred for individual work to enable her time to explore her adjustment to her disabilities. It was also hoped that the family would engage in family therapy to help them to explore the impact of these issues in a wider context.
Older Adults Case Report Summary

A Psychological Intervention for Depression and the Impact of Organisational Issues

Reason for Referral
Beryl was referred to the psychology department by her psychiatrist for intervention aimed at addressing her depression.

Personal History
Beryl was one of nine children, six of whom had died in the previous few years. Beryl had married at the age of 21 years and had two daughters. Her marriage had been difficult and she had separated from her husband eight years previously.

Following the birth of her second daughter, she had experienced post-natal depression resulting in admission to a psychiatric hospital where she received ECT. She experienced regular periods of depression throughout the rest of her life and received support from private health providers.

A final issue of importance was a recent hospital admission following pneumonia. Whilst in hospital, Beryl underwent emergency surgery after having her spleen punctured during a pleural tap. This was a very traumatic event and Beryl continued to have nightmares about the event.

Differential Diagnosis
Issues of diagnosis were considered and it was believed that Beryl was experiencing symptoms consistent with both depression and Post-Traumatic Stress Disorder (PTSD). Given the severity of the depression, it was considered that this should be the primary focus of the intervention.

Formulation
Beryl’s history indicated a vulnerability to experiencing depression. Her recent experiences had depleted her coping resources which were overwhelmed by the trauma associated with her admission to hospital. Additionally, Beryl had a number
of negative views regarding psychiatric services and the provision of medication. This resulted in her being unwilling to comply with medication regimes which led to her fluctuating mental state.

**Intervention**

It was hoped to undertake person-centred counselling with Beryl to help her draw links between her previous experiences and current difficulties. Beryl however, was looking for an approach aimed at addressing her daily functioning and was unwilling to discuss her past in any detail. It was considered appropriate therefore to conduct weekly sessions of cognitive-behavioural therapy to address her negative thinking patterns and to increase her level of daily activities.

Additionally, it was necessary to work closely with the staff group supporting Beryl to ensure that the psychology input was viewed as important within her overall care plan. It was necessary to provide staff with advice and guidance on management of Beryl’s anxieties to prevent them feeling overwhelmed by her needs.

**Outcome**

During the psychology intervention, the psychiatrist eventually stabilised Beryl on a medication regime. This increased her mood to the extent that she felt able to re-engage in previously enjoyable activities. During psychology sessions, these activities could be discussed and thought processes that could impede progress were isolated and addressed. Following her enjoyment of these activities, Beryl became increasingly motivated to return to premorbid levels of activity. At the close of the intervention, Beryl was no longer experiencing symptoms of depression and was discharged from the service.

Despite her increased mood, Beryl continued to experience symptoms consistent with a diagnosis of PTSD. Despite being given opportunities to discuss this, Beryl felt it was unnecessary to focus on these issues.
Neuropsychology Case Report Summary

A Neuropsychological Assessment of Cognitive Impairment Following a Road Traffic Accident

Introduction

This case study related to the neuropsychological assessment of a 53 year old woman, Karen, following a stroke experienced after a road traffic accident.

Reason for Referral

Karen had been admitted to the rehabilitation centre following a prolonged period in hospital. She was undergoing physical rehabilitation aimed at increasing her mobility, speech and self-care skills to enable her to return to her own home. Cognitive assessment was required to assess for impairment and suggest strategies for rehabilitation.

Personal History

Karen had left school at 16 years having gained two O'levels. She had worked as a secretary throughout her working life and was employed as a personal assistant to the managing director of a large business just prior to her accident.

She had married when she was 25 years old and had two daughters. Her first husband died in an accident when the children were small. Subsequently, she developed a relationship with a family friend with whom she lived for twenty years. They married just prior to the accident. Whilst on holiday with her husband and youngest daughter, they were involved in a road accident. Karen sustained multiple injuries in the accident and her daughter and husband were killed. Following the accident, she developed left hemiplegia as a result of an infarct in her right, middle cerebral artery. Karen was repatriated to the UK soon after the accident and had remained in hospital since that time.
Karen had a close relationship with her eldest daughter who provided regular support. She was also close to her elderly father but he died just prior to her return home. Additionally, she had a wide circle of friends who visited her regularly.

Hypothesis
A number of hypotheses were considered in the assessment. The nature and site of Karen’s injuries could result in widespread cognitive impairment with particular difficulties in visuo-spatial abilities. Additionally, she appeared to have a left visual neglect. Finally, the influence of depression on her cognitive functioning was considered in the light of her recent bereavements.

Assessment
Karen was assessed using a wide range of neuropsychological assessment measures. These investigated premorbid, and current, intellectual functioning, memory, attention, executive functioning and mood.

Interpretation
Karen had experienced a general decline in cognitive function with particular reference to her non-verbal abilities. She had difficulties with attention and concentration and was suffering from a left visual neglect. It was considered that she was suffering from low mood. This was not viewed as pathological but was considered to reflect an appropriate response to some difficult life events.

Recommendations
Given the death of Karen’s father, it was not possible to undertake work aimed at addressing Karen’s difficulties. However, Karen was scheduled for a further period of rehabilitation at a later date where these issues could be addressed. Karen was also referred to community psychiatric nursing to monitor her mood and intervene if necessary.
Research Dossier
The Need for a Community Learning Disability Team to Employ a Counsellor: A Retrospective Analysis of Client Referrals

February 1998
Year II
Abstract
A retrospective analysis was undertaken on client referral forms to assess whether the Community Learning Disability Team for North Downs would benefit from the employment of a counsellor.

A difficulty in recruiting for psychology posts had resulted in an increased waiting list for individuals needing counselling interventions for life transitions issues. Whilst some of this work was being undertaken by other staff within the team, this was directing them away from clients with difficulties directly within their specialities. It was considered that it may be useful to employ a counsellor to ease pressures on waiting lists.

A framework for allocation of cases to specialities was developed through interviews with representatives from community nursing, counselling and clinical psychology. Referral forms for 93 cases allocated to community nursing, OT and clinical psychology over the previous six months were re-allocated to professional groups using the framework devised. Allocation procedure was subjected to inter-rater reliability checks providing Cohen’s kappa = 0.899 suggesting good reliability in allocation to professions.

Results indicated that 16.1% of the cases reviewed were suitable for allocation to a counsellor. The implications for management following employment of a counsellor were discussed. Recommendations for the re-structuring of the referral forms were made to aid appropriate allocation of cases.
INTRODUCTION
The growth in the field of counselling has recently begun to gain attention within the general psychological literature and the impact this may have on the employment of clinical psychologists has been discussed.

Sibbald et al. (1993) highlighted that primary healthcare settings are increasingly likely to directly employ counsellors within their service, rather than provide access to a clinical psychologist. Miller (1994) explored the reasons for, and consequences of, this development and proposed that the growth of counsellors within these settings stemmed from a number of major issues: the shortage of clinical psychologists, the move towards increased cost-efficiency and the professionalization of counselling.

The shortfall of clinical psychologists was initially highlighted in the MPAG/MAS reports (Parry, 1989). It was recommended that training places should be increased to overcome this difficulty and, while this recommendation has resulted in a significant increase in training places available, the effects of this change have yet to be widely seen within services. Many health trusts are consequently still finding that the demand for qualified clinical psychologists far exceeds the numbers of individuals available to fill posts. Consequently, many posts remain unfilled for considerable lengths of time. This shortage of available clinical psychologists can have a huge impact on the length of waiting lists, resulting in the purchasers feeling frustrated and dissatisfied with the service providers (Claxton and Turner, 1997).

The reduction in funding available within the NHS has also had an impact upon the pattern of employment within services. The move towards more efficient working, and the introduction of the purchaser/provider split, led providers to look for more efficient ways of providing therapeutic intervention for their service users. While the employment of counsellors and nurse therapists is not cheap, they may be perceived as a considerably cheaper option than clinical psychologists (Parker et al., 1997) and this has led to an increase in employment opportunities for these professional groups. It is also considered that counsellors spend a greater percentage of their time in direct client contact, as opposed to clinical psychologists whose professional roles also
include undertaking management tasks, consultancy and other service related work (Shillitoe and Hall, 1997). This difference in roles and responsibilities can further strengthen the perception that counsellors provide a more cost-efficient option than clinical psychologists.

Alongside the shortfall of clinical psychologists, and the drive towards greater cost-efficiency, is the growing status of counselling within the professional arena. Whereas previously, training of counsellors had been lacking a standardised framework, this has been addressed by the British Association of Counselling which has provided guidelines for the accreditation and supervision of its members (Miller, 1994). The status of counselling is still growing and further developments can be expected as a result of the recent introduction of doctoral programmes in counselling psychology.

**Background to the Audit**

The changes in the health service and the publication of the patient's charter have led services to re-evaluate, not only the level of care provided to service users, but the processes by which psychotherapeutic interventions are made available.

Many of the difficulties highlighted within the literature had been experienced by the Community Learning Disability Team (CLDT) in North Downs. A clinical psychologist post had been vacant for some length of time but the service had been unable to recruit suitable applicants and waiting lists for individuals requiring psychological intervention were increasing.

The CLDT was a multi-disciplinary team providing a range of services to individuals with all levels of learning disabilities. This group comprised a number of different professionals including: a consultant psychiatrist, community nurses, clinical psychologists, assistant psychologists, speech and language therapists, occupational therapists, occupational therapy assistants and physiotherapists.
The members of the CLDT had become increasingly aware that a number of non-urgent referrals were being received for service users who required basic counselling to help them come to terms with general life transition issues. These referrals were being allocated to a number of different team members or being allocated to the waiting lists. It was considered that it may be useful to employ a counsellor to undertake work with these individuals. It was believed that this would ease the pressure on waiting lists and leave other team members available to deal with more urgent cases falling within their specialist areas.

Prior to the decision being made regarding the employment of a counsellor, it was considered necessary to undertake an audit of the referrals received by the team to ascertain the extent to which they were suitable for allocation to a counsellor.

Consequently, the following audit was undertaken at the North Downs Community Learning Disability Team.

**THE AUDIT**

**AIMS OF THE AUDIT**

The audit aimed to identify the number of referrals received by the CLDT, during the previous six month period, which may have been suitable for allocation to a counsellor.

**HYPOTHESIS**

It was hypothesised that a significant number of the referrals received during the previous six months would be suitable to receive intervention provided by a counsellor.

**PROCEDURE**

The audit was completed using a retrospective analysis of referrals received by the CLDT over the previous six month period. The referrals examined were those that had been allocated to either clinical psychology, community nursing or occupational
therapy as it was believed that these professions would have received cases appropriate for allocation to a counsellor.

The audit was conducted on the information available from the referral form as this was the basis for initial allocation to professionals within the team. The referral form provided a range of information which was used within the audit:

- Demographic details - name, date of birth and gender of client.
- Referral source.
- Brief description of client difficulties.

Referral forms were collated for all cases identified and relevant information was recorded for analysis.

Interviews were held with two clinical psychologists and one community nurse within the CLDT and one counsellor who worked within a social services setting for people with learning disabilities. These interviews provided their perception of the particular skills of each professional group and the types of referrals that each profession were best able to serve. The information was reviewed to provide a list of the particular client difficulties suitable for referral to each professional group. This framework was then used as a basis for re-allocating cases to professions (community nursing, psychology, occupational therapy, counselling).

The referral forms for each of the identified cases were then examined and decisions were made to enable the re-allocation of cases to professional groups using the framework developed from these interviews. To ensure that the allocation process was not biased, a second rater also reviewed a random sample of the referral forms and re-allocated them to professional groups using the generated list. Inter-rater reliability was then calculated using Cohen’s Kappa co-efficient.
RESULTS

• Client Information

A list of referrals from the previous six months was obtained from the CLDT referral file and 103 clients were identified who had been referred to the three professional groups identified above. Referral forms were found for 93 of these clients. Other forms were not held within files or on waiting lists and could not be located elsewhere. These clients were excluded from the audit undertaken.

The audit was therefore undertaken on 93 clients referred to the service. These individuals ranged from 16 to 68 years old with a mean age of 38.41 years (SD = 13.49 years).

The sample of 93 client referral forms related to 89 individual service users with four clients having been referred to the team on two separate occasions during the six month period. Of these clients, 43 (48.3%) were female and 46 (51.7%) were male. The female clients ranged from 20 to 68 years old with a mean age of 38.93 years (SD = 13.4 years). The male clients ranged from 16 to 65 years old with a mean age of 37.92 years (SD = 13.69 years).

Data on the referring agencies was noted and are summarised in Table 1, a graphical representation of the information can be found in Figure 1

<table>
<thead>
<tr>
<th>Referrer</th>
<th>Community Nurse</th>
<th>General Practitioner</th>
<th>Social Services</th>
<th>Care Home</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Referrals</td>
<td>33 (23.7%)</td>
<td>21 (8.6%)</td>
<td>7 (33.3%)</td>
<td>15 (30.1%)</td>
<td>5 (4.3%)</td>
</tr>
</tbody>
</table>

* = Physiotherapy, Psychology
Of these 93 clients, 48 (51.6%) were initially allocated to a community nurse, 22 (23.7%) were allocated to a psychologist and 23 (24.7%) were referred to an occupational therapist (See Figure 2).

- **Interviews with professionals**
  The interviews conducted provided a wealth of information about the skills considered to be individual to each profession and the areas of skill overlap. From these initial interviews, significant agreement regarding the roles and skills of each
professional group was achieved, enabling the development of a framework for case allocation.

While it was recognised that all disciplines were able to provide basic counselling for many difficulties, interviews with individuals from these disciplines isolated important qualitative differences in the difficulties in which the disciplines would intervene. It was considered that community nursing and occupational therapy could manage some of the relationship and life cycle issues encountered by their clients using basic counselling techniques. However, due to the waiting list pressures encountered by these disciplines, this work could only be short-term in nature and difficulties would be encountered if the client’s problems were discovered to be more complex and intractable than first considered.

It was thought however, that it may be more appropriate for a counsellor to conduct interventions for those clients with relationship, adjustment and life cycle issues, particularly if they were considered to be more long-standing difficulties which would require longer-term intervention. It was considered that the particular skills of a counsellor would tend towards providing more long term contact to those service users who had mild learning difficulties and were experiencing current mild to moderate difficulties in managing their current situations. It was thought that these individuals would have to possess good verbal communication skills to be referred for longer-term counselling.

Finally, it was considered that the pre and post qualification training of clinical psychologists left them with higher order skills which resulted in them being able to work with the particularly complex cases as highlighted in the MAS/MPAG reports. This enabled them to concentrate on those clients with the most complex problems who required intervention on a number of levels, both individually and within systems. It was also considered that the training of clinical psychologists provided them with particular skills for dealing with those individuals who had limited communication skills, severe or profound levels of learning disability and who were experiencing multiple and complex difficulties.
From the interviews it was possible to generate the framework for re-allocation. (See Table 2). All 93 cases identified were examined to ascertain whether they would be suitable to be seen by a counsellor.

**Table 2: Framework for case re-allocation generated from interviews**

<table>
<thead>
<tr>
<th>SKILLS AREAS OF EACH DISCIPLINE</th>
<th>Clinical Psychology</th>
<th>Counselling</th>
<th>Community Nursing</th>
<th>Occupational Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Challenging behaviour</td>
<td>Bereavement / Loss</td>
<td>Health issues</td>
<td>Skills assessment</td>
<td></td>
</tr>
<tr>
<td>Psychometric assessment</td>
<td>Depression</td>
<td>Personal hygiene</td>
<td>Independent living skills</td>
<td></td>
</tr>
<tr>
<td>Systems issues</td>
<td>Anxiety</td>
<td>Accessing primary care</td>
<td>Group work - social skills, assertiveness, anxiety, relaxation</td>
<td></td>
</tr>
<tr>
<td>Risk assessment</td>
<td>Relationship issues</td>
<td>Health education</td>
<td>Sensory stimulation</td>
<td></td>
</tr>
<tr>
<td>OCD</td>
<td>Anger management</td>
<td>Basic counselling</td>
<td>Environmental enrichment</td>
<td></td>
</tr>
<tr>
<td>Phobias</td>
<td>Assertiveness</td>
<td>relation and life cycle issues</td>
<td>Assessment of need for environmental adaptations</td>
<td></td>
</tr>
<tr>
<td>Sexual abuse/abusers</td>
<td>Sexual Abuse</td>
<td>Sex education</td>
<td>Physical health and medication issues</td>
<td></td>
</tr>
<tr>
<td>Eating disorders</td>
<td>Sexuality</td>
<td>Resettlement</td>
<td>Parent craft</td>
<td></td>
</tr>
<tr>
<td>Initial assessments</td>
<td>Adjustment difficulties</td>
<td>Management of behavioural programmes</td>
<td>Management of behavioural programmes</td>
<td></td>
</tr>
</tbody>
</table>

- **Re-allocation**
  
  All the cases identified were re-allocated to professions using the framework identified above. Following re-allocation, 34 (36.6%) were considered appropriate to be allocated to community nursing, 24 (25.8%) to clinical psychology, 20 (21.5%) to occupational therapy and 15 (16.1%) to a counsellor (See Figure 3).
Half of the cases were randomly assigned to a second, independent rater to ensure inter-rater reliability. This rater was also required to re-allocate the cases using the framework generated from the interviews with professionals. The two sets of re-allocation data were analysed for inter-rater reliability using Cohen's kappa coefficient. The resulting index of 0.899 suggested that cases were able to be re-allocated using the framework with a good degree of reliability.

The results from the audit suggested therefore, that a significant proportion of the cases referred to the CLDT during the previous six month period would be suitable for intervention by a counsellor.

**CONCLUSION**

The results of the audit undertaken indicated that a number of the cases allocated to the members of the community team could be allocated to a counsellor. This would ease the pressure on waiting lists and enable other team members to focus more directly on their specialist areas. The cases identified were those where clients were experiencing difficulties adjusting to various life transition issues and would benefit from more long-term contact than the current team were able to provide.

However, despite these results, a number of methodological drawbacks need to be considered before making any firm conclusions from the study.
While inter-rater reliability was calculated, it was only possible to calculate this for half of the cases examined. The degree of consistency suggests that agreement would have been high on the remaining cases but it may have been preferable for both raters to have provided re-allocation data for all of the cases included in the audit.

The major difficulty in the method employed with the study however, was the reliance on referral information for the allocation of cases to professional groups. In many cases, only brief information was available detailing the difficulties being experienced by the client. On some forms, only one or two sentences were provided by the referrer which could have resulted in a simplistic overview of the problems being experienced by the client. It was also noted that few referrers gave any indication of the level of learning disability experienced by the clients and rarely indicated their level of verbal ability. It had been isolated in the interviews that clients deemed suitable for a counsellor were those who had mild levels of disability and possessed good verbal communication skills. The format of the referral form could result in cases being allocated to the counsellor based on referral information which would not fully demonstrate the complexity of the intervention required. Later assessment may result in the client difficulties being deemed unsuitable for this form of intervention and the client may then have to be returned to the waiting list.

If the team considered it appropriate to employ a counsellor, a number of further issues need to be examined. These would include who retains managerial responsibility for the counsellor and the need for the counsellor to have access to professional supervision. Burton (1997) suggests that, while it may be appropriate for other specialities to maintain managerial responsibility for counsellors, it is important for them to receive clinical supervision from senior counsellors who can provide them with supervision appropriate to their theoretical background.

It would also be necessary to redefine the referral format to ensure that full details of the client’s difficulties were available and that an indication of the level of disability was provided. This would help inform the team’s decisions during referral meetings
and so increase the likelihood of appropriate allocation of clients to professional
groups.

It would also be necessary to ensure that whoever is employed in the role of
counsellor to the team has a good understanding of the expression of emotional
difficulties in people with learning disabilities. Many training courses in counselling
rely on general adult mental health populations and, although they may experience
similar difficulties, counselling approaches may have to be adapted to respond to the
needs of people with learning disabilities.

**SUMMARY**

Although the audit suggested that the referrals received by the CLDT during the six
month period under examination would be appropriate for allocation to a counsellor,
it is necessary to consider whether the content of the referral form adequately reflects
the difficulties experienced by the service users. If this is considered to be the case,
care should be taken to ensure that managerial responsibility is clearly defined and
that there is provision made for the individual concerned to receive regular clinical
supervision.

Whatever the decision of the team, it is obvious that there is a need for this client
group to be provided with the opportunity to benefit from long-term counselling
approaches to help them come to terms with any difficult life events they may
experience. Parker et al. (1997) suggest that the inclusion of counsellors within
primary health teams will enable the service user to have access to a “comprehensive
and seamless range of services”. It is time that this option was also made available to
people with learning disabilities.

This information was communicated to the CLDT who subsequently employed a
counsellor (See Appendix I).
REFERENCES


APPENDIX I

Confirmation of receipt of outcome of research.

Dear Liz

Thank you for the final copy of your research on placement on the need for the Community Learning Disability Team to employ a counsellor. It made very interesting reading. I have given copies to the clinical services manager and the team co-ordinator and we have discussed the findings. You may be interested to hear that since you were with us we have been able to make use of a colleague within the learning disability service who has been doing a counselling course to provide some counselling sessions for the Team. Her sessions have proved very valuable. We also used your research in drawing up a bid for some joint finance money to develop the counselling service further, which we would like to do as soon as we have the resources available.

With regards

Tessa Lippold
Chartered Clinical Psychologist
The Assessment of Mental Health
Difficulties in Individuals with Learning Disabilities
General Introduction

The research component of the PsychD (clinical psychology) focused on the area of the diagnosis of mental health problems in people with learning disabilities and spanned the three years of the course.

Initially, a literature review was undertaken on the difficulties in diagnosing psychiatric illness in people with learning disabilities.

The literature review led to a 2nd Year project, Study 1, which assessed the use of a recently developed tool, the Psychopathology Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) checklist (Moss et al., 1998), on a population of individuals with severe and profound disabilities.

In light of the findings of the 2nd Year research, the 3rd Year research (Study 2, Part I) initially replicated and extended the 2nd Year research. Additionally, the 3rd Year research (Study 2, Part II) replicated and extended the Moss et al. (1998) study looking at the reliability, validity and factor structure of the PAS-ADD checklist.
Learning Disability and Mental Illness: Problems Encountered in Dual Diagnosis

Year I
Introduction
The issue of dual diagnosis of mental illness and learning disability is an area that has begun to gain extensive attention within psychological literature. The recognition of mental retardation as separate from insanity or dementia was well established within the literature during the early nineteenth century (Berrios, 1994) but the issue of whether mental illness can exist concurrently with learning disability has been more difficult to reconcile. The majority of research into dual diagnosis has appeared since 1960 and has focused on the frequency and type of psychiatric disorder experienced by people with learning disability alongside the treatment and management approaches used to ameliorate the experience of symptomatology (Ruedrich and Menolascino, 1984).

The literature review undertaken looks initially at reasons for the increase in research interest in this field and at issues of definition. Additionally, it reviews the factors which may predispose people with learning disability to psychiatric illness and the problems encountered with diagnosis in this particular population.

Interest in Dual Diagnosis
The interest in the field of dual diagnosis results from the move towards deinstitutionalisation, the influence of the philosophy of normalisation (Nirje, 1969; Wolfensberger, 1972) and the advent of advocacy involvement for individuals with learning disability.

Definitions of normalisation focus on providing basic rights for individuals with learning disabilities and include the right to appropriate medical care. This works in opposition to previous practices where individuals were prescribed large doses of psychotropic medication aimed at sedation and restraint without proper assessment, diagnosis and aftercare (Szymanski, 1994).

A further factor in the current interest in dual diagnosis in people with learning disability stems from the move towards community care and the adoption of O’Brien’s “five service accomplishments” (1987) by healthcare services. This led to
a re-evaluation of views of "acceptable" behaviour for individuals with learning disability. Previously, disturbed behaviour displayed by people with learning disabilities (e.g. rocking, rumination, head banging, self-injury and aggression) was considered to be an expected concomitant of mental retardation (Ruedrich and Menolascino, 1984). It was soon recognised that individuals raised in home and community environments did not regularly display these behaviours and their "natural relationship" with learning disability was brought into question.

The literature suggests that the presence of mental illness in people with learning disabilities was one of the major factors leading to their admission to institutional settings (Foale, 1956; Penrose, 1962; Menolascino, 1972). It is important therefore, to address the issue of dual diagnosis when planning resettlement of individuals in the community especially as many community placements fail, not as a direct result of the level of learning disability but as a result of the individual's difficulties adapting to a new environment while experiencing neuroses, psychoses or other mental health problems (Kirman, 1973). The added experience of mental illness for individuals with learning disability has a great impact upon their quality of life and plays an important role in their ability to adjust to community living.

Definitions

When examining the literature on dual diagnosis, it is important to explore issues of definition. While it is recognised that many differing definitions of both learning disability and mental illness exist, they do share common themes. The definitions used within this review reflect those adopted most commonly within the dual diagnosis literature. Discussion on the benefits and limitations of these definitions is beyond the scope of this review.

- Learning Disability

The changing approaches towards individuals with learning disabilities has resulted in many changes in terminology and definition over time both in the UK and in America. Although the accepted terminology in the UK is that of "learning disability", the definitions proposed within the American literature refer to the term
"mental retardation". These two terms are used interchangeably within the literature to describe the same basic phenomena.

One of the most widely accepted definitions of mental retardation available is suggested by the American Association on Mental Retardation (1992) and emphasises the combined importance of intellectual functioning, deficits in social adaptation and age of onset:

"Mental retardation is characterised by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before the age of eighteen."

- Mental Illness
Definitions of mental illness are provided by the standard diagnostic criteria. DSM IV (1994) defines mental illness as:

".....a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (a painful symptom) or disability (impairment in one or more important areas of functioning)....." (APA, 1994).

For the purposes of this literature review therefore, dual diagnosis is defined as the coexistence of learning disability and mental illness (Reiss, 1990; Borthwick-Duffy, 1994).
**Vulnerability to Psychiatric Illness**

The literature on dual diagnosis is divided as to whether individuals are more or less likely to experience mental health problems than their non-learning disabled peers and whether this difference is qualitative or quantitative.

The majority of the literature has proposed that people with learning disabilities experience a number of life events and experiences that make them more vulnerable to experiencing mental health problems than the general population.

As early as 1944, Pollock hypothesised that people with learning disabilities are vulnerable to mental health problems due to experiencing a reduced capacity to withstand stress, poor ability to resolve mental and emotional conflict, emotional instability, a lack of social competence and a potential for being led into difficulty by others.

This early work was followed by other authors interested in the role of learning disabilities in the development of psychiatric illness. Cytryn and Lourie (1967) discuss a number of increased hazards in growth and development faced by individuals with learning disability (e.g. the relatively lengthy process of mother recognition and individuation which can lead to over-dependency) which may weaken resilience, making crises more frequent and more difficult to resolve.

Menolascino, Levitas and Greiner (1986) suggest increased vulnerability to mental health problems results from information processing deficits, other associated handicaps and societal rejection.

More recently, Fraser and Nolan (1994) proposed that, in comparison with their non-disabled peers, individuals with learning disabilities are more likely to experience loss and separation, communication difficulties, inadequate discipline, failure to acquire the skills necessary to form reciprocal relationships, adverse environments and adverse life events. These experiences, combined with a lack of opportunity or ability to develop adequate coping mechanisms, leaves them more likely to experience
psychiatric disorder. They also discuss that these individuals may have organic brain damage which may contribute to the experience of concurrent mental illness.

The literature has fewer proponents of the view that people with learning disabilities are less vulnerable to mental health problems than their non-learning disabled peers (Penrose, 1966; Simmons, 1968). These studies tend to lack credibility due to methodological flaws such as sampling biases (Ruedrich and Menolascino, 1984).

The literature reviewed, therefore, suggests that people with learning disabilities experience a number of particular difficulties (e.g. psychosocial stress, organic brain damage, cognitive deficits) which could increase the likelihood of the development of psychiatric illness. In conjunction with these life experiences, the cognitive deficits commonly experienced by these individuals leave them with few, adequate coping mechanisms which compound their difficulties, making it less likely that they can be easily resolved. This combination of adverse life events and inadequate coping mechanisms leaves them vulnerable to experiencing mental health problems which require accurate assessment and intervention.

**Prevalence**

Many studies have been undertaken to estimate prevalence rates of psychiatric disturbance in people with learning disability with results ranging from 10% - 80% (Borthwick-Duffy, 1994).

Reiss (1990) undertook screening of 205 people with learning disability who accessed a community day facility finding an overall rate of dual diagnosis of 39%, Crews et al. (1994) studied 1,273 individuals in residential settings and suggested a dual diagnosis rate of 15.55%, while Borthwick-Duffy and Eyman (1990) found an overall rate of 10% in their study of 78,603 individuals in receipt of state services across residential settings. These studies in themselves show huge variability and demonstrate some of the difficulties inherent in accessing accurate prevalence rates of dual diagnosis. They demonstrate the impact that the methodology employed, and the characteristics of the populations used, have on the results obtained.
The study undertaken by Reiss (1990) focused on individuals within community settings only. The level of disability was recorded and was predominantly those people with mild disabilities. Crews et al. (1994) looked at individuals within residential settings and the population consisted primarily of those individuals with profound disabilities. It is unsurprising therefore, that differing prevalence rates would be obtained as the populations studied are not directly comparable. Borthwick-Duffy and Eyman (1990) studied a more diverse population and the breakdown of their findings upholds the view that rates of diagnosis differ as a result of level of disability with rates of 16% for mild disabilities, 9% for moderate, 5% for severe and 3% for people with profound disabilities.

Also, the selection method of participants varies considerably between studies. Reiss (1990) accessed a random sample of individuals and undertook individual screening for psychiatric diagnosis while both Crews et al. (1994) and Borthwick-Duffy and Eyman (1990) only accessed those individuals whose computerised case information suggested they were already in receipt of a psychiatric diagnosis. Reiss (1990) provided a comparison of psychiatric diagnosis given from current assessment and that provided in case note information. He found that while his study isolated a prevalence rate of 39%, indications of psychiatric diagnosis were found in only 11.7% of client files which suggests that the prevalence rate of dual diagnosis found when using information provided by case note information may well be an underestimate of true figures.

In their review article, Fraser and Nolan (1994) propose dual diagnosis rates of 3% for psychotic illness, 8% - 15% for serious psychiatric disorder and over 50% for minor emotional disorder. Unfortunately, these authors did not provide any indication of the source of these figures but they appear to be based on those suggested by Parsons et al. (1984). However, while Parsons et al. (1984) provide references for a number of studies used in their discussion, they do not indicate which particular studies are used in the calculation of their figures and provide no indication of the methodology employed to arrive at the estimates given. This unfortunately makes it impossible to
access source texts to assess whether they are free from the methodological difficulties highlighted by Borthwick-Duffy (1994).

It is difficult to ascertain, therefore, a true estimate of prevalence of dual diagnosis due to these methodological differences but it is apparent that a number of individuals with learning disabilities can be considered to experience psychiatric illness and it is an important area that needs to be addressed when planning programmes of care.

**Problems in diagnosis**

As noted previously in discussion of the Borthwick-Duffy and Eyman (1990) paper, rates of diagnosis of psychiatric illness in people with learning disabilities vary in accordance with the level of learning disability displayed with the lowest rates of diagnosis being recorded for people with profound and multiple disabilities. However, this outcome appears to be in direct opposition to literature discussed above which suggests that the life experiences of people with learning disabilities result in an increased vulnerability to concurrent mental illness. It would seem that the issues highlighted in the literature regarding vulnerability to psychiatric illness (information processing deficits, experience of loss and separation, communication difficulties, adverse life events etc.) would be most prevalent in those people with the most profound disabilities and therefore leave them with great vulnerability to psychiatric illness. It would seem likely, therefore, that the low rates of dual diagnosis in people with more severe disabilities may not be a reflection of a lack of psychiatric illness in this population per se but instead result from the use of inappropriate procedures for diagnosis. These limitations of standard diagnostic procedures with people with learning disabilities will be discussed below.

Crews et al. (1994) discuss a number of general professional issues which may have an impact upon the low levels of diagnosis of psychiatric illness in learning disabled populations. They highlighted that many professionals believe that people with learning disabilities are unable to suffer from psychiatric disturbance, that there is a lack of interest or training in issues of learning disability and their subsequent
vulnerabilities to psychiatric disturbance, the problem of diagnostic overshadowing¹ (Reiss, Levitan and Szyszko, 1982; Reiss and Szyszko, 1983) and finally, that possible problems with the understanding and communication of client experiences may result in difficulties when using standard diagnostic procedures.

Much of the literature has focused on problems with the use of standard diagnostic criteria with people with learning disabilities. Before looking specifically at the limitations of standard diagnostic criteria for people with learning disabilities, it is worth looking initially at the current debate focusing on the utility of diagnostic criteria in general populations. The use of DSM criteria is well established within the psychiatric community as a basis to enable the receipt of state benefits and healthcare insurance, for consistency in communication and for informing treatment and prognosis (Scotti et al., 1996). However, many feel that the reliance on the medical model of psychiatric illness presented in DSM fails to account for the diversity and complexity of these illnesses. An individual’s behaviour is likely to be influenced by the context in which they find themselves but DSM criteria fail to take account of the functional properties of the behaviours exhibited (Follette, 1996). Research on functional analysis shows that when treatment is aimed at addressing the particular functions of behaviours, effectiveness is increased (McKnight et al., 1984; Iwata et al., 1994). Diagnosis in itself therefore, will do little to inform the clinician of the particular contingencies, both internal and external, which directly influence the exhibition of behaviours and this may result in inappropriate and ineffective interventions being suggested.

Even if these general criticisms of DSM are disregarded, particular difficulties with their use with learning disabled populations are apparent. Prior to DSM III-R (APA, 1987) diagnosis of psychiatric disorder in individuals with learning disabilities was overlooked by some clinicians due to the problems with the diagnostic criteria. In DSM III (APA, 1980), mental retardation was listed on Axis 1 as a major mental disorder resulting in many clinicians diagnosing only mental retardation in learning

¹ Diagnostic overshadowing - abnormal behaviour is seen as a direct consequence of a learning disability rather than being indicative of psychiatric illness
disabled individuals who were referred for psychiatric assessment. The change in classification of mental retardation to Axis 2 (personality and developmental disorders) in DSM III-R resulted in clinicians having to attend to concurrent Axis 2 symptomatology and therefore directly focus on the issues of dual diagnosis (Szymanski, 1994).

Even with this change however, further difficulties arise particularly when using these tools with people with more profound and multiple disabilities. Traditionally, diagnosis relies on the assessment of psychological processes, emotions and affect measured primarily through client self-report. One of the major problems with reliance on these criteria therefore, is the lack of communication skills in some individuals resulting in a lack of self-report information regarding experience of symptoms. Diagnostic interviews also require clients to discuss their experiences on an abstract, conceptual level but many people with learning disabilities do not have a level of cognitive ability which permits this.

Sovner (1986) highlights some of the major limitations of the use of diagnostic criteria with this population and discusses that standard diagnostic criteria fail to account for the presence of concurrent developmental disabilities. He discusses a number of limiting factors of DSM-III criteria when used to diagnose mental illness in individuals with learning disability with particular reference to those individuals with profound and multiple handicaps. He suggests four factors which could result in difficulties with diagnosis:

*Intellectual distortion* relates to difficulties encountered by people with learning disability with abstract thought and communication. As mentioned above, this creates difficulties in the collection of diagnostically relevant material particularly in relation to psychotic symptoms.

*Psychosocial masking* relates to the content of psychiatric symptoms displayed by people with learning disabilities. Sovner (1986) suggests that many individuals with a learning disability lack diverse life experiences which results in symptoms that are
relatively "bland" in presentation. Symptoms identified may be devoid of the richness and inventiveness of non-learning disabled peers with psychiatric illness and may instead resemble non-specific fears.

_Cognitive disintegration_ refers to the tendency of people with learning disabilities to exhibit a deterioration in their level of functioning when under stress, resulting in bizarre, atypical behaviour which may be either misdiagnosed as the presence of psychiatric illness or result in atypical presentation of certain psychiatric illnesses. This is particularly relevant as the literature discussed above highlights the increased likelihood for these individuals to experience stressful life events while having fewer mechanisms available for coping with them.

_Baseline exaggeration_ is the final factor identified by Sovner (1986) and refers to the presence of pre-existing maladaptive behaviour. He states that it may be necessary to not only be sensitive to the presence of new, challenging behaviours indicative of psychiatric illness, but also to attend to quantitative changes in pre-existing behaviours which may also indicate the onset of mental illness.

Sovner (1986) suggests therefore, that diagnosis of psychiatric illness in people with learning disabilities is complicated, not only by difficulties with the communication of symptomatology being experienced, but by the fact that the experience may well be qualitatively different to that experienced by their non-disabled counterparts. The presentation of symptoms may therefore be more subtle and lead to difficulties with identification of psychiatric illness.

Clarke et al. (1994) discuss the use of ICD-10 (WHO, 1992) as a diagnostic tool with individuals with learning disability and conclude that it is adequate for the diagnosis of some mental illnesses but they found problems with the diagnosis of schizophrenia and related disorders. Problems arose due to the poor language and communication skills of those being assessed leading to problems with identification of symptoms, a finding of other researchers in the area (Meadows et al., 1991). It would seem,
however, that the problems identified by Sovner (1986) for the use of DSM diagnostic criteria would also be relevant when examining the use of ICD-10 (WHO, 1992).

Alternatives to Standard Diagnostic Criteria

Given the limitations with the use of standard diagnostic criteria, it is necessary to shift the focus of the assessment procedure away from self-report information gained from individual interviews and instead to look at observable changes in behaviour that may indicate the onset of psychiatric illness.

Clarke et al. (1994) suggest that, where standard assessment procedures are inappropriate, attention should be paid to behaviours indicating the observable features of psychiatric illness particularly with reference to schizophrenic illness (e.g. withdrawal, unexplained changes in behaviour).

Parsons et al. (1984), also advocate assessment based on changes in behaviour. They comment that even individuals with profound learning disabilities develop distinctive personalities and exhibit complex systems of interaction with their environment. They believe that the observation of behaviour can be useful for diagnosis of psychiatric illness in the absence of standard, verbal interviewing techniques.

Ruedrich and Menolascino (1984) agree with the need for clinicians to rely on behavioural signs of mental illness and promote the use of questioning third parties who have regular contact with the individual and may be in a good position to comment on recent changes in behaviour. By undertaking observations and questioning of people who know the individual well, they suggest that the clinician involved will be able to obtain a comprehensive picture of the difficulties being experienced by the individual under assessment which will help direct diagnosis and subsequent implementation of intervention. This approach has its limitations however, as different staff members may have differing opinions on the cause of behavioural change and care would need to be taken to gain objective assessment of behavioural change that is free from subjective attributions of causality.
It seems therefore, that while some authors believe that the standard diagnostic procedures are appropriate for use with the dually diagnosed, at least with individuals falling within the mild to moderate range of learning disabilities, many consider that there are significant limitations to the use of standard classification tools with this population and propose the need for the recognition of behavioural manifestations of psychiatric symptomatology. It is important however, to recognise that reliance on behavioural manifestations of symptomatology can result in problems with differential diagnosis. Clarke et al. (1994) discuss that many behavioural manifestations of symptoms of schizophrenia may be indicative of other diagnoses in individuals with learning disability and emphasise the need to distinguish between schizophrenia and other disorders (e.g. affective disorders, consequences of epilepsy, autism and related disorders). A further difficulty that can be envisaged when relying on behavioural change is the possibility of misdiagnosis due to cognitive disintegration (Sovner, 1986). If changes in behaviour are not subjected to a comprehensive functional analysis, this approach could result in the misattribution of transitory stress reactions resulting in over-diagnosis of psychiatric disorder.

Some authors have attempted to address a number of the diagnostic difficulties using criteria that take account of the presence of developmental disabilities. Hucker et al. (1979) adapt standard diagnostic criteria for depression and mania for individuals with learning disability but problems still exist in the reliance on communication and self-report skills. More recently, Sovner (1986) discusses the development of behaviourally based diagnostic criteria for affective disorders based on those used for diagnosing affective disorders in children (Cantwell, 1983) who present many similar diagnostic difficulties. However these measures would also be sensitive to behavioural changes resulting from transitory increases in psychosocial stress.

The most promising, recent development in the field of diagnostic instruments useful for the diagnosis of the dual problems of learning disability and psychiatric disorder has been the development of a standard, semi-structured, clinical tool specifically designed to isolate mental health problems in learning disabled populations, the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-
ADD) (Moss et al., 1993). This instrument aims to overcome some of the difficulties described above by providing a flexible approach to diagnosis incorporating both client and informant interviewing. Even this approach, however, encounters difficulties in diagnosis of psychiatric illness in severely and profoundly disabled individuals, particularly those individuals who are unable to communicate verbally with symptom detection being positively correlated with client IQ (Moss, Prosser and Goldberg, 1996). Difficulties also arise as the only symptoms detected with any frequency are first rank symptoms, namely auditory hallucinations, and it is recommended that if negative symptoms are to be used in the diagnosis of psychosis then the clinician must attend to information gained from individuals who have a long-term knowledge of the client (Moss, Prosser and Goldberg, 1996).

It seems therefore, that there are no easy answers to the problem of diagnostic procedures suitable for diagnosis of psychiatric illness in people with learning disabilities. Diagnostic criteria alone are inadequate for individuals with the cognitive and communication problems but over-reliance on behavioural changes could also prove unsatisfactory due to difficulties in gaining objective reports of behavioural change from staff and the possibility of misinterpreting responses to stress as indicators of the onset of psychiatric illness.

**Guidelines for Clinicians**

One of the most useful articles available within the literature is that of Sovner and Hurley (1989) which provides clinicians with guidelines to help with the recognition of psychiatric illness in people with learning disabilities. Such guidelines are necessary to enable the clinician to isolate those behaviours that are diagnostically important while being sensitive to already existing difficulties which may confuse the assessment process.

Initially, they state that clinicians should recognise that people with learning disabilities can suffer from the whole range of psychiatric illnesses that are experienced by non-learning disabled individuals and they believe that these are able to be diagnosed and treated. They explained that psychiatric disorders usually present
as maladaptive behaviours (e.g. aggression, self-injury) in people with learning disabilities due to their limited communication skills and therefore it is vital that these behaviours are fully assessed and understood so that appropriate intervention can be provided to address the onset of any psychiatric disturbance. If a full functional analysis is not completed, individuals may be placed on behavioural programmes aimed at eliminating behaviours that are in fact communicating the experience of considerable distress. They propose that maladaptive behaviour indicative of the onset of psychiatric disorder can occur on a number of levels: the expression of primary changes in affect and functioning in line with non-disabled individuals experiencing mental health problems (e.g. sleep disturbance, hallucinations); an increase in previously occurring behaviours (e.g. self-injury, rituals); new and unusual behaviours resulting from environmental reinforcement of behaviours aimed at communicating the experience of distress.

They propose that the origin of psychopathology is multi-determined and hypothesise that there are six forms of psychopathology which, if present individually or in combination, may complicate diagnosis of psychiatric disturbance. These include the display of "primitive behaviours" such as self-stimulation and rocking, behaviours resulting from medical illness or side-effects to medication, autistic behaviours (need for routine, stereotypy) and behaviours resulting from their learning history. They discuss the importance of attending to baseline exaggeration rather than primarily relying on the occurrence of newly emerging behaviours. They relate that maladaptive behaviours rarely occur in isolation. It is important that the assessor attends to all behavioural changes to ensure a complete clinical picture is attained and accurate diagnosis can be made.

Sovner and Hurley (1989) also discuss that the clinical interview alone is rarely all that is needed for an accurate diagnosis. When undertaking psychiatric diagnosis of individuals without learning disabilities, clinicians tend to rely on one interview with the client to gain all the information needed for diagnosis. As discussed earlier, this is problematic in the case of individuals with a learning disability because of difficulties with communication and the ability for abstract thought. Clients with
learning disabilities are recognised to provide professionals with the “right” answers to questions and are prone to acquiescence (Sigelman et al., 1981). To enable an accurate diagnosis of psychiatric disturbance, it is necessary therefore, for the clinician to supplement individual interviews with information from other sources including detailed observation of the client and interviews with caregivers.

In line with other authors in this field, Sovner and Hurley (1989) reiterate that it is virtually impossible to diagnose psychiatric illness, particularly psychosis, in individuals with more profound levels of handicap.

The final point raised by Sovner and Hurley (1989) is that state and trait psychopathology frequently co-exist. Individuals with developmental disabilities may have both organic problems resulting in long-term affective, cognitive and psychomotor difficulties as well as more temporary state psychopathology resulting from psychiatric disorder which will remit following successful treatment of the disorder. It is important to consider whether the behavioural disturbance being exhibited by the individual is long-standing or a recent development. This will enable the clinician to ensure that any recent disturbance that is representative of psychiatric disturbance can be separated from trait behaviours resulting from long term organic impairment.

**Conclusions**

Sovner and Hurley (1989) highlight that during the move towards de-institutionalisation for individuals with learning disability it was presumed that support would be available within the community to help those experiencing emotional or behavioural disturbance. This has not occurred as clinicians were unprepared for the specific difficulties encountered in the assessment, diagnosis and treatment of mental illness in people with learning disability.

The literature reviewed highlights the complexity of the issue of dual diagnosis and the inadequacy of current assessment measures. Not only are there limitations with the use of standardised diagnostic criteria, but reliance on behavioural disturbance as
an indicator of psychiatric illness also presents problems. Sovner and Hurley (1989) emphasise the necessity for clinicians to have a full understanding of adaptive responses to stress in learning disabled individuals and an awareness of the manifestation of psychiatric illness across the range of mental handicaps. This will ensure that assessment isolates those behaviours indicative of psychiatric disturbance as separate from those relating primarily to the level of learning disability. It will also be necessary for clinicians to look at the functional analysis of the behaviours exhibited so that appropriate intervention plans can be implemented.

Most of the literature discussed in the review refers to the use DSM-IIIR. The publication of DSM IV in 1994 (APA) has resulted in some changes to the criteria necessary for diagnosis but the impact of this change has not yet been widely discussed in the literature. The impact of this change needs to be considered in the future. It appears, however, that the changes in the criteria have not even begun to address the role of developmental disabilities in the presentation of psychiatric illness and it is likely that this work will need to be further developed by specialists within the field of learning disabilities.

Despite these problems, studies have shown that individuals with learning disability can, and do, develop the full range of psychiatric conditions. It is the responsibility of the clinician to accept the challenge of diagnosis and develop measures to enable the accurate identification of symptomatology. The continued development of diagnostic instruments to aid clinicians is beginning to take account of the associated problems of psychiatric illness in people with learning disability but none are adequately addressing the full range of difficulties particularly with reference to people with profound disabilities. It is not enough to presume that the absence of recognised symptoms of psychiatric illness in this group indicates the absence of psychiatric illness. Until assessment measures can be developed that reflect the diversity of mental health status in people with varying levels of disability, it is likely that many individuals with treatable psychiatric conditions will be left unserved.
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Small Scale Research Project

Study 1: An Investigation into the Utility of the PAS-ADD Mental Health Checklist as a Screening Tool for People with Severe and Profound Learning Disabilities

Year II
ABSTRACT
The study described assessed the mental health status of 134 people with severe and profound learning disabilities using the PAS-ADD checklist (Moss et al., 1998). Measures were obtained regarding perceptions of ease of use and utility of the checklist from care co-ordinators.

Results indicated the presence of possible psychiatric disorder in eight individuals without previous diagnosis and two of four individuals already in receipt of psychiatric care. All 10 (7.5%) individuals identified had severe learning disabilities. None of those identified as reaching threshold levels for further investigation had profound disabilities.

Data were investigated to assess for the impact of level of disability and other resident characteristics on completion of the checklist. Findings indicate that significantly fewer questions were completed in relation to people with profound disabilities and poor receptive and expressive communication. Qualitative data indicated the checklist was difficult to complete for those individuals with profound disabilities and communication difficulties.

The results suggest that while the PAS-ADD checklist may be an appropriate tool for use with people with severe disabilities, its utility as a screening tool for mental health problems in people with profound disabilities is questionable.
1. LITERATURE REVIEW

1. Introduction

The literature on learning disabilities recognises the co-existence of mental illness with learning disabilities but highlights difficulties inherent in its detection and measurement. These difficulties have led to debate regarding appropriate ways of diagnosing such psychiatric disorders.

The study undertaken assesses the mental health of people with severe and profound disabilities using a recently developed checklist, identifying its strengths and limitations.

A literature review on dual diagnosis has been undertaken previously by the author (see page 106) and a summary is provided to familiarise the reader with the background to the research.

2. Background to Dual Diagnosis

Interest in dual diagnosis stems primarily from the impact of “normalisation” (Nirje, 1969; Wolfensberger, 1972) and the adoption of O’Brien’s “five service accomplishments” (O’Brien, 1987) by service providers. This led towards community care for people with learning disabilities and highlighted the role of mental health difficulties in the failure of such community care (Ruedrich and Menolascino, 1984).

3. Prevalence

Studies report prevalence rates of dual diagnosis ranging from 10% - 80%, findings being influenced by the use of differing definitions and sampling techniques (Borthwick-Duffy, 1994).

Definitions of learning disability rely on either formal measures of intellectual functioning or measures of adaptive behaviour. For example Rutter and Graham (1970), Rutter et al. (1976) and Meadows et al. (1991) rely on psychometric definitions of intellectual disability while Borthwick-Duffy and Eyman (1990) and
Cherry et al. (1997) report levels of adaptive functioning. Other studies pay little obvious attention to issues of definition, providing no statement of classification systems used (James and Mukherjee, 1996). Similar difficulties are experienced with definitions of mental illness due to the evolving nature of psychiatric classification systems and difficulties in applying them to people with learning disabilities.

Examples of variation in methodology are seen in studies by Reiss (1990), Crews et al. (1994) and Borthwick-Duffy and Eyman (1990). Reiss (1990) studied individuals accessing a community day facility, Crews et al. (1994) studied individuals in residential settings, while Borthwick-Duffy and Eyman (1990) reported on individuals in receipt of state services across residential settings. These studies found prevalence rates of 39%, 15.55% and 10% respectively.

Many studies therefore, vary on sampling techniques and definitions employed, resulting in it being difficult to disentangle the relative impact of either on results obtained.

The most extensive population study undertaken estimated rates of psychiatric illness for people with mild, moderate, severe and profound disabilities at 16%, 9%, 5% and 3% respectively (Borthwick-Duffy and Eyman, 1990). Unfortunately, this study only identified clients with psychiatric diagnoses recorded on file. Reiss (1990) identified that rates of dual diagnosis on client files increased from 11.7% to 39% following individual screening, suggesting an underestimate of dual diagnosis rates from client files. Consequently, it is likely that Borthwick-Duffy and Eyman (1990) underestimate the true rates of dual diagnosis.

4. Vulnerability
The literature reviewed highlights the increased vulnerability of people with learning disability to mental health problems due to factors including: poor coping styles, lack of social support, communication problems and organic brain damage (Pollock, 1944; Menolascino, Levitas and Greiner, 1986; Fraser and Nolan, 1994), factors most prevalent in individuals with severe and profound disabilities. It seems strange
therefore, that lower prevalence rates are reported for these groups as opposed to people with milder disabilities who have greater social support and more practised coping strategies so enabling them to process emotional conflict more effectively.

5. Measurement of Dual Diagnosis
The discrepancy between expected and recorded prevalence rates may be partially explained by difficulties using standard diagnostic criteria in this population. Generally, diagnosis of psychiatric illness relies on gathering self-report information. This process relies on the client’s level of communication and their capacity to provide information on their internal experiences. These abilities are limited, or lacking, in people with severe and profound disabilities.

Sovner’s (1986) paper on dual diagnosis highlights how communication difficulties and the idiosyncratic nature of symptom presentation, particularly in individuals with severe and profound disabilities, can distort standard psychiatric assessment. He suggests four factors causing difficulties: intellectual distortion\(^2\), psychosocial masking\(^3\), cognitive disintegration\(^4\) and baseline exaggeration\(^5\).

6. Measurement Tools
The limitations of standard diagnostic criteria led researchers to develop tools sensitive to the presentation of psychiatric illness in people with learning disabilities. Focus shifted from reliance on individual interviews towards diagnosis based on behavioural change indicative of psychiatric disorder (Parsons et al. 1984; Ruedrich and Menolascino, 1984; Clarke et al. 1994).

\(^2\) Difficulties with abstract thought & communication affecting ability to gain diagnostically relevant material.

\(^3\) Individual’s lack of diverse life experience leading to presentation of relatively “bland” symptoms.

\(^4\) Tendency for individuals to show a temporary, reversible reduction in cognitive function as a reaction to stress which may lead to misdiagnosis.

\(^5\) Previously existing maladaptive behaviour may increase following onset of psychiatric disorder. Clinicians needs to be alert to quantitative, as well as qualitative, changes.
6.1. Checklist Measures
The main checklists developed to date are the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson et al., 1984) and the Reiss screen (Reiss, 1987).

6.1.1 The PIMRA
The PIMRA, a 56 item scale, is closely associated with DSM III-R diagnostic criteria. It provides diagnoses on 7 subscales and has informant and self-report versions (Sturmey et al., 1991). Test re-test reliability ranges from 0.42 - 1.00 (Senatore et al., 1985) with inter-rater reliability ranging from 70% - 95% (Iverson and Fox, 1989). However, independent studies have found less promising reliabilities (Aman et al., 1986; Watson et al., 1988).

6.1.2. The Reiss Screen
The Reiss Screen is a 36 item, alphabetical listing of key symptoms (including definitions and examples) indicative of one or more DSM III-R disorder (Reiss, 1997).

The scale has factor content validity and an alpha coefficient of internal reliability of 0.84 (Reiss, 1987, 1988). However, Sturmey et al., (1996) dispute the factor structure suggested by Reiss. Reiss (1997) disputes Sturmey’s findings and debate continues regarding the reliability and factor content of the tool. Reiss (1997) accepts however the limitations of the tool with people with severe disabilities.

6.2. Interview Based Tools
The most promising, recent development in interview based approaches is a semi-structured clinical tool designed specifically for people with learning difficulties, the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) (Moss et al., 1993).
6.2.1. The PAS-ADD

The PAS-ADD, originally developed from the Present State Examination (PSE), is currently based on the Schedules for Clinical Assessment in Neuropsychology (SCAN) (WHO, 1994) (Moss et al., 1996; Costello et al., 1997). It utilises respondent and key informant interviews allowing flexible assessment, appropriate for people with a wide range of disabilities.

Preliminary studies established reliability and validity (Moss et al., 1993; Costello, et al., 1997; Moss et al., 1997a). Moss et al. (1993) established a mean kappa of 0.72 for inter-rater reliability while Costello et al. (1997) found a mean kappa of 0.65 using the revised version of the PAS-ADD. Good validity against clinical psychiatric diagnosis was found particularly in relation to depressive and psychotic symptoms (Moss et al., 1997a).

6.3. Strengths and Limitations of Measurement Tools

Mental health checklists are useful initial screening tools as they are quick to administer and tend not to require specialist staff input. However, reliance on untrained care staff means they cannot replace full psychiatric screening.

Difficulties arise with the application of the Reiss screen and PIMRA to individuals with severe and profound disabilities due to the reliance on DSM III in the PIMRA and the poor reliability with people with severe disabilities using the Reiss screen.

Alternatively, interview based procedures such as the PAS-ADD are time consuming and costly. Care workers may not recognise indicators of psychopathology in people with severe and profound disabilities thus further complicating the route to full psychiatric assessment (Moss and Patel, 1993).

It is important therefore, to identify a checklist able to detect possible mental health problems in people with severe and profound disabilities to guide care staff in referral for full psychiatric assessment.
6.4. The PAS-ADD Checklist

The authors of the PAS-ADD have developed the PAS-ADD checklist for use by non-specialist carers (Moss et al., 1997b). This screens for mental health difficulties and can lead to comprehensive psychiatric assessment to enable accurate diagnosis (Moss et al., 1998).

Moss et al. (1998) investigated reliability and validity of the PAS-ADD checklist. Inter-rater reliability was established at an overall kappa of 0.42 in relation to individual items. More encouragingly, 83% agreement was found on need for further assessment. Validity against previous psychiatric diagnosis was also investigated with 22/24 residents with severe psychiatric disorders being identified by the checklist. Validity was less adequate for participants with previously identified mild psychiatric disorder with only 9/16 reaching threshold levels.

Inter-rater reliability was investigated using participants with a mean IQ of 30.5 (range 14 - 47) suggesting that the checklist is suitable for individuals with severe and profound disabilities.

7. Rationale for the Present Study

The diagnosis of psychiatric disorder is most difficult in people with severe and profound disabilities whose poor verbal communication skills result in difficulties assessing their inner emotional state. Most literature discusses dual diagnosis in people with mild and moderate disabilities and fails to address the needs of people with more severe disabilities (Sturmey et al., 1991).

Given the paucity of good mental health assessments for people with severe and profound disabilities, and the assertion that the PAS-ADD checklist is suitable for use with this population, it was considered useful to undertake a wide survey of individuals with severe and profound disabilities using this checklist. Due to the scarcity of literature regarding its utility, a further questionnaire was developed to assess aspects of utility, gain demographic information and collate information on the informants perception of the checklist.
II. AIMS
To assess whether, as suggested by Moss et al. (1998), the PAS-ADD checklist could identify possible mental illness in an inpatient population of people with severe and profound disabilities.

III. OBJECTIVES
1) To undertake a survey of the mental health of people with severe and profound disabilities using the PAS-ADD checklist.
2) To establish whether the checklist could be used effectively by care co-ordinators.
3) To ascertain the views of care co-ordinators on the utility of the PAS-ADD checklist.

IV. HYPOTHESES
1) The PAS-ADD checklist would identify possible mental health difficulties in people with severe and profound disabilities.
2) The PAS-ADD checklist would be less effective in detecting possible mental illness in those with profound learning disabilities.
3) Care co-ordinators would have greater difficulty completing the checklist when their nominated clients had profound learning disabilities.
4) Care co-ordinator views on the ease of use and utility of the checklist would be influenced by client characteristics such as level of disability.
V. METHOD

1. Measures Used

1.1. PAS-ADD Checklist

The PAS-ADD checklist was completed by informants who had known the resident for at least six months.

The checklist contains two sections (See Appendix I). Section 1 (Questions 20 - 37) collates information regarding life events experienced over the previous year (e.g. death of relatives or friends, injury and illness, change in work status, substance misuse, any event or change in routine which caused distress).

Section 2 contains 29 questions (Questions 41 - 69) focusing on the previous four weeks. Questions relate to manifestations of affective / neurotic disorders, organic disorders and psychotic disorders (See Table 1).

Table 1: Areas covered by the PAS-ADD checklist.

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<tr>
<th>Question Number</th>
<th>Sub-Scale</th>
<th>Areas Covered</th>
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<td>41 - 61</td>
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<td>• concentration</td>
</tr>
<tr>
<td>59 - 64</td>
<td>Organic conditions</td>
<td>• sleep patterns</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• concentration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• irritability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• self-care skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• memory functioning</td>
</tr>
<tr>
<td>65 - 69</td>
<td>Psychotic disorder</td>
<td>• hallucinations &amp; delusions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• display of odd gestures &amp; mannerisms</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• odd use of language</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• any other behavioural change</td>
</tr>
</tbody>
</table>
The informant registers indicators exhibited and the extent to which they have been problematic. The checklist uses a four point rating scale: has not happened, has occurred but has not been a problem, has been a problem and finally, has been a serious problem. Weighted scores relating to the clinical significance of indicators are provided by the checklist authors (Moss et al., 1998).

Scores are summed to detect the presence of possible psychiatric disorder. Threshold values are provided for each of the three main areas under assessment. If scores obtained fall at, or above, threshold levels, further psychiatric assessment is recommended.

1.2. Utility Measures

1.2.1. Omitted Questions

Where informants cannot answer checklist questions, they are instructed to place a line through them. As omitted information would make the checklist less effective at detecting possible mental illness, the number of omitted questions on each questionnaire were summed to provide a measure of utility.

1.2.2. Utility Questionnaire

This questionnaire was developed to test hypotheses 3 and 4 (See Appendix II).

Fifteen questions gained residents’ demographic information i.e. age, disability (level and diagnosis), presence of sensory / motor impairment, presence of behavioural problems, level of communication and details of medical or psychiatric illnesses.

Seven questions related to care co-ordinators including name, age, gender, qualifications and experience.

One question asked for ratings on ease of checklist completion on a five point scale from “very easy” to “very difficult”.

Further questions asked for ratings, on a five point scale, on the likelihood of the checklist identifying psychiatric disturbance in their resident. Co-ordinators also rated their perception of the mental health status of the resident.

A final question asked for ratings of usefulness of the checklist on a five point scale from “not at all useful” to “very useful”.

2. Sample
2.1. Residents
Participants were residents of an institution providing care for approximately 450 people with learning disabilities. Assessments were undertaken on 162 individuals within multiple disability homes. Of these, 13 had only mild and moderate disabilities and incomplete questionnaires (client or care co-ordinator demographic data missing) were received on 15 individuals. These subjects were excluded from the analysis. The final sample contained 134 participants with severe and profound disabilities.

2.2. Care Co-ordinators
While Moss et al. (1998) suggest checklists are completed by non-specialist staff, many keyworkers were not proficient in English. Therefore, resident’s care co-ordinators completed the checklists. Care co-ordinators had overall responsibility for residents and were responsible for care planning. All had basic nursing qualifications. Thirty one care co-ordinators completed questionnaires.

3. Procedure
Ethics approval was gained from East Surrey Local Research Ethics Committee (see Appendix III).

The study was initially piloted on six people with learning disabilities in a community setting to ensure that the utility questionnaire accessed appropriate information. The questionnaire was subsequently altered to include information regarding carer’s perceptions of the mental health of their residents.
In the main study, home managers were visited to discuss the rationale for the project and the procedure for implementation. They were provided with checklists and utility questionnaires for each resident and requested to ask care co-ordinators to complete checklists for each resident followed by the utility questionnaire. Further appointments were made to collect data.

Where care co-ordinators failed to complete the utility questionnaires, individual appointments were made to collect missing data.

VI. STATISTICAL ANALYSIS
Data were analysed using non-parametric statistical tests as the data were not normally distributed.

VII. RESULTS
1. Description of the Resident Sample
1.1. Age / Sex distribution
Seventy six residents were male (age range 35 - 73 years, mean = 49.32, SD = 6.26), 58 were female (age range 32 - 82 years, mean = 52.12, SD = 9.92).

1.2. Level of Disability
One hundred residents (74.6%) had severe learning disabilities and 34 (25.4%) had profound disabilities.

1.3. Sensory Impairment
Ten participants (7.5%) were partially sighted, 11 (8.2%) were functionally blind. Four participants (3.0%) were hearing impaired, three (2.2%) were deaf.

1.4. Communication
Many participants had communication difficulties (See Tables 2 & 3).
Table 2: Level of expressive communication

<table>
<thead>
<tr>
<th>Level of Expressive Communication</th>
<th>Number of participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No expressive communication</td>
<td>45</td>
<td>33.6%</td>
</tr>
<tr>
<td>Uses non-verbal communication</td>
<td>53</td>
<td>39.6%</td>
</tr>
<tr>
<td>Uses signs / symbols / makaton</td>
<td>2</td>
<td>1.5%</td>
</tr>
<tr>
<td>Has a limited verbal repertoire</td>
<td>32</td>
<td>23.9%</td>
</tr>
<tr>
<td>Has good verbal skills</td>
<td>2</td>
<td>1.5%</td>
</tr>
</tbody>
</table>

Table 3: Level of receptive communication

<table>
<thead>
<tr>
<th>Level of Receptive Communication</th>
<th>Number of participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>32</td>
<td>23.9%</td>
</tr>
<tr>
<td>Understands non-verbal communication</td>
<td>18</td>
<td>13.4%</td>
</tr>
<tr>
<td>Understands signs / symbols / makaton</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Understands simple, verbal commands</td>
<td>77</td>
<td>57.5%</td>
</tr>
<tr>
<td>Understands verbal communication</td>
<td>7</td>
<td>5.2%</td>
</tr>
</tbody>
</table>

1.5. Developmental Disorders

Ninety-four participants (70.1%) had non-specific learning disabilities, others had a variety of diagnosed developmental disabilities (see Figure 1).
Figure 1: Presence of Developmental Disorder

- microcephaly (2.2%)
- cerebral palsy (7.5%)
- PKU (1.5%)
- autism (6.7%)
- cerebellar ataxia (0.7%)
- down syndrome (10.4%)
- cerebral atrophy (0.7%)
- Non specific (70.1%)

1.6. Previously Diagnosed Psychiatric Disorder

Few residents had previously diagnosed psychiatric disorders. One (0.7%) had dementia, two (1.5%) had psychosis and one (0.7%) was suffering from mania. All these residents had severe learning disabilities.

1.7. Other Factors

Despite low prevalence rates of diagnosed psychiatric disorder, a significant number of clients (25.4%) received anti-psychotic medication. It was unclear whether this was to manage psychotic illness or behavioural disturbance and anxiety. Figure 2 provides details of medication.
Figure 2: Medication prescribed to residents.

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antipsychotic &amp; other (3.7%)</td>
<td></td>
</tr>
<tr>
<td>Combination* (1.5%)</td>
<td></td>
</tr>
<tr>
<td>Anticonvulsant &amp; other (17.9%)</td>
<td></td>
</tr>
<tr>
<td>Antipsychotic &amp; anticonvulsant (6.0%)</td>
<td></td>
</tr>
<tr>
<td>Antipsychotic (14.2%)</td>
<td></td>
</tr>
<tr>
<td>No medication (21.6%)</td>
<td></td>
</tr>
<tr>
<td>Anticonvulsant (15.7%)</td>
<td></td>
</tr>
<tr>
<td>Missing data (0.7%)</td>
<td></td>
</tr>
<tr>
<td>Other* (18.7%)</td>
<td></td>
</tr>
</tbody>
</table>

* includes sedatives, medication for intestinal problems, antibiotics, asthma medication

Many clients had mobility problems although 54 (40.3%) were able to walk unaided (See Table 4).

Table 4: Participants’ level of mobility

<table>
<thead>
<tr>
<th>Level of Mobility</th>
<th>Number of participants</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walks unaided</td>
<td>54</td>
<td>40.3%</td>
</tr>
<tr>
<td>Requires occasional help</td>
<td>16</td>
<td>11.9%</td>
</tr>
<tr>
<td>Requires regular help</td>
<td>12</td>
<td>9.0%</td>
</tr>
<tr>
<td>Non-mobile / uses wheelchair</td>
<td>52</td>
<td>38.8%</td>
</tr>
</tbody>
</table>

Fifty (37.3%) participants had no physical health problems, 60 (44.8%) had epilepsy and 24 (17.9%) experienced other difficulties e.g. spastic quadriplegia, obesity, ataxia, dysphagia.

Fifty five (41%) participants had no behavioural problems, 63 (47%) had mild problems and 16 (12%) had severe problems.
1.8. Summary
In addition to learning disabilities, many residents had multiple impairments: 21 (15.7%) had visual impairment, seven (5.2%) had hearing impairment, 80 (59.7%) had mobility problems, 84 (62.7%) experienced physical health problems and almost all had communication difficulties.

2. Characteristics of the Care Co-ordinator Sample
2.1. Age / Sex Distribution
Of the 31 care co-ordinators, nine were male and 22 female. Five fell within the age range 25 - 34 years, 13 were between 35 - 44 years, 12 were between 45 - 54 years and one was over 55 years.

2.2. Experience and qualifications
Care co-ordinators had a mean of 19.36 years (SD = 7.16 years) experience of working with people with learning disabilities (range 15 months - 33 years). All had professional nursing qualifications. Nine care co-ordinators were home managers, six were deputy home managers and 16 were SEN or staff nurses.

2.3. Questionnaires completed
Each care co-ordinator completed between one and 10 questionnaires dependent on the number of residents under their care (mode = 4).

3. TESTING HYPOTHESES 1 & 2 (Scores attained on the PAS-ADD Checklist)
3.1. Frequency Distributions of Scores within Sub-Scales
3.1.1. Affective / Neurotic Disorders Scale
One hundred and twenty residents (89.5%) obtained a score of zero. Ten residents (7.5%) obtained scores of 1 - 5, four residents (3%) exceeded the threshold of six or above.

3.1.2. Organic Conditions Scale
One hundred and twenty five residents (93.3%) scored zero. Seven residents (5.2%) obtained scores of 1 - 4, two (1.5%) reached threshold levels of five or above.
3.1.3. Psychotic Disorders Scale
One hundred and twelve residents (83.6%) obtained a score of zero. Thirteen (9.7%) scored one and nine (6.7%) scored above the threshold of two or above.

3.2. Possible Psychiatric Disorder
The PAS-ADD checklist identified ten residents (7.5%) as experiencing possible psychiatric disorder. Six appeared to have a single psychiatric disorder, four were classified as having more than one psychiatric disorder. *This data upholds hypothesis 1.*

One, female resident (0.75%) exhibited behaviour suggestive of affective / neurotic disorder, five residents (3.7%) (one female, four male) displayed behaviour suggestive of psychotic disorder.

Of those with a dual psychiatric classification, two clients (1.5%) (one male, one female) exceeded thresholds in both affective / neurotic disorder and psychotic disorder, one male client (0.75%) exceeded thresholds on organic and psychotic scales and one male, client (0.75%) exceeded thresholds in all three sub-sections of the checklist. Details of these clients are presented in Table 5.
Table 5: Details of clients exceeding threshold values on the PAS-ADD checklist and related care co-ordinator information.

| Subject Number | Age | Sex | Level of Disability | Diagnosed Disability | Psychiatric Diagnosis | Expressive Communication | Receptive Communication | Medication | ID* | Age | Sex | Experience (Yrs) | Qualifications |
|----------------|-----|-----|---------------------|----------------------|-----------------------|-------------------------|------------------------|------------|-----|-----|---------------|----------------|
| 104            | 40  | F   | Severe              | Autism               | None                  | Body Language          | Good Understanding     | Anti psychotic | For | 55  | 64  | F              | 20             | RNMH           |
| 64             | 50  | M   | Severe              | Autism               | None                  | No Expressive          | Simple Commands        | Anti psychotic | G   | 45  | 54  | F              | 25             | RNMH           |
| 107            | 43  | F   | Severe              | None                 | None                  | Limited Verbal         | Simple Commands        | Anti psychotic | J   | 35  | 44  | F              | 23             | RMN            |
| 145            | 60  | M   | Severe              | None                 | None                  | Limited Verbal         | Simple Commands        | Anti convulsant | Fa  | 25  | 34  | M              | 5              | RNMH           |
| 161            | 47  | M   | Severe              | Autism               | None                  | Limited Verbal         | Simple Commands        | Anti psychotic | N   | 45  | 54  | M              | 19             | RNMH           |
| 168            | 50  | M   | Severe              | None                 | None                  | Limited Verbal         | Simple Commands        | Anti psychotic | N   | 45  | 54  | M              | 19             | RNMH           |
| 3              | 41  | F   | Severe              | None                 | None                  | Body Language          | Simple Commands        | Anti psychotic | T   | 35  | 44  | F              | 14             | RNMH, SEN      |
| 116            | 65  | M   | Severe              | Down Syndrome        | None                  | Limited Verbal         | Simple Commands        | Other          | Fa  | 25  | 34  | M              | 5              | RNMH           |
| 142            | 62  | M   | Severe              | None                 | Psychosis             | Limited Verbal         | Good Understanding     | Anti convulsant | Foo | 35  | 44  | M              | 24             | SEN            |
| 120            | 62  | M   | Severe              | Down Syndrome        | Alzheimer             | Good Verbal Skills     | Good Understanding     | Anti psychotic | Fa  | 25  | 34  | M              | 5              | RNMH           |

Key for threshold values exceeded:
- Green: Affective disorders scale
- Blue: Psychotic disorders scale
- Red: Both Affective & Psychotic disorders scales
- Blue-green: Both Organic & Psychotic disorders scales
- Red-green: All three PAS-ADD scales

* Carer identification code
3.3. Details of Care Co-ordinators who Identified Possible Presence of Psychiatric Disorder
The ten clients were identified by seven care co-ordinators. One care co-ordinator identified three clients (out of a total of four) and one identified two clients (out of a total four).

3.4. Relationship of PAS-ADD “Diagnosis” to Previous Psychiatric Diagnosis
Of the 10 clients, two had previous psychiatric diagnoses. One was identified as having dementia and was the client exceeding the threshold on all three PAS-ADD checklist subsections. The other client, exceeding the threshold on organic and psychotic scales, had a previous diagnosis of psychosis.

3.5. PAS-ADD “Diagnosis” and Level of Disability
All clients above threshold values had severe learning disabilities. None had profound disabilities and none had sensory impairment. This upholds hypothesis 2.

4. TESTING HYPOTHESIS 3 (Omitted Questions).
4.1. Frequency
Sixty three residents (47%) had one or more questions omitted. There was a mean number of 2.14 (SD = 3.27, range 0 - 14) unanswered questions.

4.2. Relationship between level of disability and number of questions omitted.
To test hypothesis 3, residents were divided into disability categories provided by care co-ordinators and data were screened to assess the impact of disability level on number of questions omitted. Means and standard deviations are presented in Table 6. Significantly more questions were omitted when clients had profound disabilities (Mann Whitney U, z = -3.52, p = 0.0004)
Table 6: Means and Standard Deviations - Level of Disability

<table>
<thead>
<tr>
<th>Level of Disability</th>
<th>Number of cases</th>
<th>Mean Number of Questions Omitted</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe Learning Disability</td>
<td>100</td>
<td>1.60</td>
<td>2.79</td>
</tr>
<tr>
<td>Profound Learning Disability</td>
<td>34</td>
<td>3.74</td>
<td>4.03</td>
</tr>
</tbody>
</table>

_Hypothesis 3 was upheld._

4.3. Relationship Between Expressive Communication and Number of Questions Omitted

The mean number of questions omitted increased as individuals’ level of communication decreased (See Table 7).

Table 7: Omitted questions as a function of clients’ expressive communication

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of cases</th>
<th>Mean Number of Questions Omitted</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No expressive communication</td>
<td>45</td>
<td>2.93</td>
<td>3.56</td>
</tr>
<tr>
<td>2 - Non-verbal communication</td>
<td>53</td>
<td>2.40</td>
<td>3.58</td>
</tr>
<tr>
<td>3 - Signs / symbols</td>
<td>2</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>4 - Limited verbal skills</td>
<td>32</td>
<td>0.86</td>
<td>1.77</td>
</tr>
<tr>
<td>5 - Good verbal skills</td>
<td>2</td>
<td>0.00</td>
<td>0.00</td>
</tr>
</tbody>
</table>

Differences between the groups were significant (Kruskal-Wallis, $\chi^2 = 9.68$ (4df), $p = 0.046$). Post hoc Mann-Whitney U rank sum tests were conducted using significance levels of 0.005 (0.05 ÷ number of tests conducted) to protect against Type I errors. These isolated a near significant group difference between Group 1 (No expressive communication) & Group 4 (Limited verbal skills) at $z = -2.69$ ($p = 0.007$).

As group differences could be obscured by small sample sizes in each cell, conditions were collapsed into two groups: individuals with expressive communication (previously groups 3, 4 & 5) and individuals with no verbal or symbolic expressive communication (previously groups 1 & 2) (See Table 8).
Table 8: Omitted questions as a function of level of expressive communication.

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of Cases</th>
<th>Mean Number of Questions Omitted</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No verbal / symbolic expressive communication</td>
<td>98</td>
<td>2.64</td>
<td>3.56</td>
</tr>
<tr>
<td>Verbal or symbolic communication</td>
<td>36</td>
<td>0.78</td>
<td>1.69</td>
</tr>
</tbody>
</table>

Significantly more questions were omitted for people with no communication (Mann-Whitney U, $z = 6.44$ (1df), $p = 0.011$).

4.3.2. Relationship Between Receptive Communication and Number of Questions Omitted.

The number of questions omitted increased as individuals’ level of understanding decreased (See Table 9).

Table 9: Omitted questions as a function of clients’ receptive communication.

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of Cases</th>
<th>Mean Number of Questions Omitted</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No understanding</td>
<td>32</td>
<td>3.44</td>
<td>4.10</td>
</tr>
<tr>
<td>2 - Non-verbal communication</td>
<td>18</td>
<td>1.94</td>
<td>3.06</td>
</tr>
<tr>
<td>3 - Signs / symbols</td>
<td>0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4 - Simple verbal commands</td>
<td>77</td>
<td>1.83</td>
<td>2.93</td>
</tr>
<tr>
<td>5 - Good understanding</td>
<td>7</td>
<td>0.14</td>
<td>0.38</td>
</tr>
</tbody>
</table>

Differences between groups were significant (Kruskal-Wallis, $\chi^2 = 8.71$ (3df), $p = 0.033$). Post hoc Mann Whitney U tests were conducted, again protecting against Type 1 errors using significance levels of 0.0083 (0.05/6). No significant differences were found.

Again, due to small sample sizes data was collapsed into two groups: individuals with no understanding of verbal or symbolic communication (previously groups 1 & 2) and individuals who could understand either signs, symbols or verbal communication (previously groups 3, 4 & 5). Means and standard deviations were calculated (See Table 10).
Table 10: Omitted questions in relation to level of receptive communication

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of cases</th>
<th>Mean Number of Questions Omitted</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding of verbal / symbolic communication</td>
<td>50</td>
<td>2.90</td>
<td>3.79</td>
</tr>
<tr>
<td>Understands verbal or symbolic communication</td>
<td>84</td>
<td>1.69</td>
<td>2.85</td>
</tr>
</tbody>
</table>

Results were significant (Mann-Whitney U, z = -2.03, p = 0.043) suggesting care co-ordinators omitted more questions for clients with poor understanding of communication.

4.3.3. Other Client Characteristics
Non-significant findings were observed for all other client characteristics explored (See Appendix IV).

4.4. Particular Questions Causing Difficulties
The frequency of non-response to specific questions was examined to ascertain which questions caused particular difficulties.

Particular difficulties were experienced with questions 63 - 69 referring to indicators of organic conditions and psychotic illness (e.g. questions 63, 66 and 68 remained unanswered for 29.9%, 31.3% and 29.1% of the clients respectively). Difficulties were also found with: question 48 relating to attempted suicide and suicidal ideation (unanswered for 17.2% of residents); question 46 relating to repetitious behaviour (omitted for 9% of residents); question 53 - confidence with others (omitted for 11.2%); question 54 - suspicious behaviour (omitted for 10.5%); question 56 - self esteem (omitted for 11.2%); question 60 - concentration (omitted for 8.2%); question 61 - restlessness (omitted for 7.5%).

4.5. Reasons provided for omitting questions
Written explanations accompanied unanswered questions. The content of questions creating particular difficulty, along with co-ordinators comments can be found in Table 11.
### Table 11: Co-ordinators reasons for unanswered PAS-ADD questions

<table>
<thead>
<tr>
<th>Question number</th>
<th>Content</th>
<th>Care Co-ordinator comments</th>
</tr>
</thead>
</table>
| 46              | Repeated actions, such as checking over and over that door is locked | • Unable to do anything for herself  
• Unable to perform these tasks | • Unable to do these things |
| 48              | Attempts suicide or talks about suicide | • Unable to understand the concept  
• Unable to perform this task | • Limited understanding / communication  
• Not able to contemplate |
| 53              | Shows loss of confidence with other people, such as repeatedly asking for reassurance | • Unable to speak  
• Communication is limited  
• Does not speak well  
• Unable to convey inner feelings | • He does not convey his inner thoughts  
• Unable to detect these behaviours in “R” |
| 54              | Suspicious, un-trusting behaviour as if someone is trying to harm them or is talking about them | • Unable to speak  
• Not able to understand and express himself  
• Unable to detect this  
• Limited communication because of disability | • I don’t know whether she feels emotions  
• He does not convey his inner thoughts  
• Unable to detect these behaviours in “R” |
| 56              | Loss of self-esteem, feeling worthless | • Unable to understand concept  
• Has no speech  
• Difficult to say due to disability | • Not able to communicate her feelings  
• Unable to express feelings |
| 60              | Less able to concentrate on chosen activities such as watching T.V............... | • All activities induced by staff  
• His concentration span is short  
• Prefers to sit alone  
• Has profound difficulties | • Profoundly handicapped  
• Always had a short attention span |
| 61              | Restless or pacing, unable to sit still | • Unable to walk  
• Physically disabled | • Wheelchair bound  
• Resident unable to sit up |
| 63              | Less able to use self-care skills, such as dressing bathing, using the toilet, and cooking | • Does not perform these skills  
• Totally dependent on nursing staff for personal hygiene  
• Care staff do this for him  
• Has not acquired these skills | • Physically disabled  
• Needs total nursing care  
• No self help skills  
• Unable to carry out these tasks due to disability |
| 64              | More forgetful or confused than usual, such as forgetting what has been said ........ | • Unable to communicate  
• Has not acquired these skills  
• Drowsy most of the time  
• Wheelchair bound, needs escort | • Unable to carry out these tasks due to disability  
• N/A – physically disabled |
| 65              | Strange experiences for which other people can see no cause, such as hearing voices or seeing things ........ | • Unable to speak  
• Unable to assess due to disability  
• Communication is limited  
• Not able to express thoughts | • Unable to assess due to profound LD  
• Not able to indicate these thoughts |
| 66              | Strange beliefs for which other people can see no reason ........ | • Does not speak well enough  
• Not able to indicate these thoughts to carers  
• Cannot express inner thoughts | • Not able to vocalise strange beliefs  
• Communication is limited  
• No speech |
| 68              | Odd or repetitive use of language | • Unable to speak  
• Makes not meaningful sounds  
• Makes unmeaningful sounds | • No use of language  
• “R” uses non-verbal communication |

**Key to question numbers**

- Affective / neurotic disorders scale
- Organic disorders scale
- Questions used in both affective/ neurotic & organic disorders scale
- Psychotic disorders scale

| H | Affective / neurotic disorders scale |
| H | Organic disorders scale |
| Q | Questions used in both affective/ neurotic & organic disorders scale |
5. TESTING HYPOTHESIS 4 (Ease of Use)

5.1. Initial data.
On the 5 point scale ascertaining ease of completion, 60 (44.8%) of care co-ordinators considered the PAS-ADD checklist to be very easy to complete, 35 (26.1%) rated it easy to complete; 27 (20.1%) rated it neither easy or difficult, 9 (6.7%) rated it difficult to complete and 3 (2.2%) considered it very difficult to complete.

5.2. Relationship of Resident Characteristics to Ease of Use
Non-significant results were found on all analyses undertaken (See Appendices V and VI).

5.3. Qualitative Information
Comments regarding ease of use were provided in 72 (53.7%) of the utility questionnaires. Fifty two (72.2%) of these comments were positive, 11 (15.3%) were negative and 9 (12.5%) were neutral.

5.3.1. Positive responses
Positive comments generally related to the accessible language used and the straightforward nature of the questions (See Table 12).
Table 12: Positive comments regarding ease of use

- "Questions were straight forward and not fuzzy"
- "It is written in plain English."
- "(Easy)... as have known the lady for a long time."
- "Very straight forward."
- "Questions are easy to understand."
- "With general knowledge of (Client), we found the questions relatively easy."
- "Very easy to follow."
- "Self explanatory."

5.3.2. Negative comments

Difficulties arose for some care co-ordinators due to the complex needs and level of disability of their clients (See Table 13).

Table 13: Difficulties with use of the PAS-ADD checklist

- "The PAS-ADD does not completely cover the client’s needs or assessment."
- ".... Particularly difficult to complete because the resident has a profound learning difficulty. I feel the questions are for people with more ability to express their feelings and communicate."

6. TESTING HYPOTHESIS 4 (Utility of Checklist)

6.1. Initial data

Opinion was divided on perceptions of usefulness. Responses on 25 (18.7%) questionnaires stated the checklist was very useful and 29 (21.6%) stated it was slightly useful. However, 37 (27.6%) considered it not particularly useful, 11 (8.2%) believed it to be not at all useful. The remaining 32 ratings (23.9%) remained undecided.
6.2. Relationship of Resident Characteristics to Perceptions of Utility
The client’s level of disability was related to perceptions of ease of use (Mann-Whitney U, \( z = -2.074, \ p = 0.038 \)). All other client characteristics were non-significant (See Appendices VII and VIII).

6.3. Qualitative information
Comments on utility were made on 66 (49.3%) utility questionnaires. Of these, 22 (33.3%) were positive, 28 (42.4%) were negative and 16 (24.3%) were neutral.

6.3.1 Positive comments
Most positive comments concentrated on its usefulness as a screening tool (See Table 14).

Table 14: Positive comments regarding usefulness.

- “All questions are relevant.”
- “It covers the main areas.”
- “Clearly, it highlights some of the mental health problems.”
- “Is very useful and helpful in obtaining information.”
- “Good to enable further investigation where appropriate.”
- “A good screening tool for mental health problems with severe learning disabilities”

6.3.2. Negative comments
Reservations had two main components. The first related to general difficulties detecting mental health problems in people with severe and profound disabilities. The second issue raised was concern over the time frame used (see Table 15).
Table 15: Negative comments on utility of PAS-ADD checklist.

<table>
<thead>
<tr>
<th>Difficulties Relating to Level of Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “This type of tool for severe learning difficulties needs review due to inability to express views and wishes. Limited speech of this client.”</td>
</tr>
<tr>
<td>• “Not detailed enough and does not show a true picture of the client’s profile and behaviour.”</td>
</tr>
<tr>
<td>• “I think information from using this tool is not sufficient for screening purposes.”</td>
</tr>
<tr>
<td>• “(Client) is too profoundly handicapped, mentally and physically.”</td>
</tr>
<tr>
<td>• “Most people with learning disabilities have problems indicating their inner thoughts.”</td>
</tr>
<tr>
<td>• “Questions relating to people with more severe difficulties would be useful.”</td>
</tr>
<tr>
<td>• “… It will not be very effective for those residents who have no verbal communication … it is a challenge to staff to measure mental health status”</td>
</tr>
<tr>
<td>• “… (resident) is unable to communicate if she is having any hallucinations”</td>
</tr>
<tr>
<td>• “… (resident) does not have the mental capabilities of comprehending or expressing psychotic experiences …… He has little verbal communication”</td>
</tr>
<tr>
<td>• “Not useful for this resident due to disabilities.”</td>
</tr>
<tr>
<td>• “Due to resident’s learning disability and lack of communication, she is difficult to assess.”</td>
</tr>
<tr>
<td>• “Not useful for this particular resident because of profound disabilities.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concern Over Time Frame</th>
</tr>
</thead>
<tbody>
<tr>
<td>• “All information is asked for over last four weeks – seems a short time.”</td>
</tr>
<tr>
<td>• “Poor and not in depth. Not able to assess a person’s change in behaviour in four weeks observation.”</td>
</tr>
</tbody>
</table>
VIII. DISCUSSION

The purpose of the study was to survey the mental health status of individuals with severe and profound disabilities and to assess the utility of the PAS-ADD checklist as a screening tool for this population.

1. Hypothesis 1

Hypothesis 1 was partially upheld. The PAS-ADD checklist identified ten individuals with severe learning disabilities (10% of all participants with severe learning disabilities) as having possible psychiatric disorder, eight of these had no previous diagnosis. Six of these participants were identified as having a single psychiatric disorder, with four being identified as experiencing dual psychiatric disorder.

These findings contrast with the prevalence rate of 5% quoted for people with severe disabilities in the Borthwick-Duffy and Eyman (1990) study. As mentioned previously, it is likely that the Borthwick-Duffy and Eyman study underestimate the true prevalence rates of dual diagnosis due to the reliance on client file information. Assuming the validity of the PAS-ADD checklist, the 10% figure found in this study is more likely to be a true reflection of actual rates exhibited.

2. Hypothesis 2

Hypothesis 2 was also upheld. The PAS-ADD checklist failed to identify the presence of behaviour indicative of psychiatric disorder in any of the 34 residents judged to have profound disabilities. This is at odds with the literature suggesting dual diagnosis rates of at least 3%. This result may either indicate that the small sample size assessed did not contain any individuals experiencing mental health problems or that the PAS-ADD checklist is not a sensitive enough tool to identify mental health difficulties in people with profound disabilities.

The results obtained on omitted questions support the view that the checklist is not sensitive enough to isolate mental health problems in people with profound disabilities. Numbers of omitted questions increased as a function of level of
disability and communication, whilst co-ordinator comments isolated difficulties when using the tool with people who could not communicate their feelings of distress.

It should be noted that there was a lack of independence in the data with regard to identification of clients with psychiatric diagnosis. One care co-ordinator identified three clients and one identified two. This could suggest that these informants are more sensitive to indicators of psychiatric disorder in their clients. Alternatively, it may be that they are more able to deal with the most difficult residents and therefore likely to be care co-ordinator to those individuals with mental health problems.

3. Hypothesis 3
Hypothesis 3 was also upheld as indicated by the increased number of questions omitted for residents with profound disabilities with as many as 14 questions remaining unanswered for some clients. Such a large number of unanswered questions will have a great impact upon the possible scores attained, and subsequently influence the sensitivity of the measure to the detection of mental health problems.

The authors of the checklist do not provide guidance on the number of questions to be completed to retain the validity and reliability of the PAS-ADD checklist.

4. Hypothesis 4
Results attained on hypothesis four were more ambiguous. Care co-ordinator ratings of both ease of use and utility were generally unrelated to client characteristics with the exception that the checklist was perceived as less useful for people with profound disabilities. This is at odds with the data collected on omitted questions which found relationships with both level of disability and level of communication.

It is recognised that data collected from care co-ordinators regarding this hypothesis was lacking independence due to the numbers of checklists and questionnaires completed by some co-ordinators. It is possible therefore, that ratings provided on utility and ease of use may have been global ratings as opposed to being related to specific client characteristics. It is likely therefore, that the number of omitted
questions for each resident provides a more accurate individualised reflection of the relationship between client characteristics and both utility and ease of use.

If number of omitted questions is used as the variable under consideration, hypothesis four was upheld. Both level of disability and level of communication influenced the ease of use and utility of the questionnaire.

It was considered that care co-ordinator characteristics, e.g. length of experience, may influence their ratings of both ease of use and utility but investigation of these variables was beyond the scope of the present study.

5. Summary of Findings
In summary therefore, all initial hypotheses were upheld. The PAS-ADD checklist was able to identify possible mental health difficulties in severely disabled individuals without previous psychiatric diagnosis. No individuals with profound disabilities were identified.

The study provided an assessment of a large population of people with severe and profound disabilities using sophisticated informants. Despite the reliance on such informants however, the difficulties in assessment of people with profound disabilities was not overcome using the PAS-ADD checklist.

6. Methodological Critique
A number of methodological difficulties were experienced in the completion of the study which may have influenced the results obtained.

6.1. Sampling Technique and Definitions Used
Given earlier discussion on the limitations of the use of client files in the survey of mental health difficulties, a large sample of individuals were individually assessed using the PAS-ADD checklist. Assuming the validity of the results obtained, the survey upholds the findings of Reiss (1990) that client file information is not sufficient to use in prevalence studies given the detection of eight clients without
previous diagnosis. It would have been useful to gain full psychiatric assessment of these individuals to validate the checklist diagnosis. Unfortunately this was not possible due to work pressures experienced by the psychiatric service.

It was also noted that the use of idiosyncratic measures of learning disability could also influence the results obtained. Unfortunately, individual assessment of client level of disability was not possible due to the large sample size assessed. IQ data were only available on very few of the residents identified and consequently it was necessary to rely on care co-ordinator perceptions of level of disability. It was considered unlikely that consistent judgements on level of disability had been reached between care co-ordinators and that judgements did not necessarily relate to any standard criteria.

6.2. Validity and Reliability of the PAS-ADD Checklist

It was recognised that the only data available on the validity and reliability of the PAS-ADD checklist was available from Moss et al. (1998) and that no independent studies have yet been undertaken to substantiate their claims. Data from the present study can only be considered meaningful if the measure can be considered reliable and valid.

Notably the checklist failed to identify two of the four clients with previous psychiatric diagnosis. It would be useful to have gained psychiatric opinion on these individuals to assess whether they continue to have psychiatric disorder and the seriousness of symptomology.

6.3. Use of Care Co-ordinators

A further difficulty arose with the lack of independence introduced into the data by care co-ordinators completing more than one questionnaire. This was considered at the early stages of the study but statistical analysis aimed at addressing the lack of independence was beyond the scope of the project.
6.4. Masking of Symptoms

One final point needing to be considered when viewing the results from the research is the use of anti-psychotic medication with a large proportion of the residents. Many of those receiving such medication did not have a psychiatric diagnosis. It is likely that the use of such medical regimes for the management of behavioural difficulties will mask the presentation of psychiatric illness leaving many conditions undetected.

7. Future Directions for Research

The study undertaken identified that the PAS-ADD checklist is an appropriate tool for the screening of people with severe disabilities. Its utility with people with profound disabilities is doubtful as many questions create difficulties for informants. Consideration needs to be given to the issues of omitted questions and a cut-off point may be necessary beyond which results obtained should not be considered valid.

Further work needs to be undertaken to isolate particular presentation of mental health problems in people with profound disabilities to enable the development of tools specific to their needs.

It is also apparent that independent studies are required to test the validity and reliability of the checklist with all levels of disability.
REFERENCES


APPENDIX I

PAS-ADD Checklist.

The PAS-ADD Checklist asks about problems which sometimes happen if a person has poor mental health. The checklist aims to help staff and carers to decide whether assessment of an individual’s mental health may be helpful.

The person completing the checklist should have known the individual for at least six months, if possible.

If you do not have all the information you need, try to get it; for example, if you know the person only during the day, you may not know how well they sleep, and you may wish to ask someone whose information is reliable.

Before rating, it is important to ensure that the person does not have any uncorrected hearing or vision problems. Such problems can result in symptoms which may be confused with mental health problems.

<table>
<thead>
<tr>
<th>Date</th>
<th>.................................................................</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your name (person completing the checklist)</td>
<td>.................................................................</td>
</tr>
<tr>
<td>Name of the person the checklist is about</td>
<td>.................................................................</td>
</tr>
<tr>
<td>Your relationship to the person (eg. keyworker, mother, community nurse, etc.)</td>
<td>.................................................................</td>
</tr>
<tr>
<td>Length of time you have known the person</td>
<td>.................................................................</td>
</tr>
</tbody>
</table>

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The University of Manchester,
Oxford Road,
Manchester M13 9PL,
UK
SECTION 1 - LIFE EVENTS

Here is a list of life events. If the person has gone through any of these IN THE PAST YEAR, please tick the box next to the event. If none of these events have happened, please tick the box at the end of this page.

- □ Death of a first degree relative (a parent, child, spouse, brother or sister)
- □ Death of a close family friend carer or other relative
- □ Serious illness or injury
- □ Serious illness of close relative carer or friend
- □ Move of house or residence
- □ Break up of steady relationship (a girlfriend or boyfriend)
- □ Separation or divorce
- □ Alcohol problem
- □ Drug problem
- □ Serious problem with a close friend, carer, neighbour or relative
- □ Unemployed/seeking work for more than one month
- □ Retirement from work
- □ Laid off or sacked from work
- □ Something valuable lost or stolen
- □ Problems with police or other authority
- □ Major financial crisis
- □ Sexual problem

□ Any other event or change of routine which may have caused distress to the individual (Please describe briefly)

..........................................................
..........................................................
..........................................................

OR

□ NONE OF THE ABOVE EVENTS
**SECTION 2 - PROBLEMS**

Each question asks about problems the person may have had in the PAST FOUR WEEKS. Some questions may seem similar to others, but please answer all the questions. Read each question carefully and put a cross in the column which gives the best answer to the question. To calculate A, B, C, D & E, add up the numbers in each of the boxes that you have ticked.

<table>
<thead>
<tr>
<th>Question</th>
<th>Has not happened in the past four weeks</th>
<th>Has happened but has not been a problem for the person</th>
<th>Has been a problem for the person in the past four weeks</th>
<th>Has been a serious problem for the person in the past four weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>41 Loss of energy, has become tired much of the time (if known to be due to exertion or bodily illness, put a tick in column 2)</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>42 Loss of interest and enjoyment, such as spending less time doing things that the person likes to do</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>43 Sad or &quot;down&quot; (noticed for at least three days in the past four weeks)</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>44 Sudden intense fear or panic triggered by situations or things, such as being alone, crowds, thunder, etc.</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>45 Fearful or panicky (not triggered by situations or things)</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>46 Repeated actions, such as checking over and over that a door has been locked, or having to do things in a particular order</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>47 Too happy or &quot;high&quot; (noticed for at least three days in the past four weeks)</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>48 Attempts suicide or talks about suicide</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>49 Loss of appetite and enjoyment of food (if this is known to be due to dieting or bodily illness, put a tick in column 2)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>50 Increased appetite, over-eating</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>51 Change of weight, enough to make clothing fit less well (if known to be due to dieting or bodily illness, put a tick in column 2)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>52 Startled by sudden sounds or movements</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>53 Shows loss of confidence with other people, such as repeatedly asking for reassurance</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>54 Suspicious, un-trusting, behaving as if someone is trying to harm them or is talking about them</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**SCORE A: ........................................**
If you cannot answer a question, then PUT A LINE THROUGH THE QUESTION and write the reason. For example, if the person does not speak well enough for you to know if they have strange beliefs, cross out that question and write that reason.

<table>
<thead>
<tr>
<th></th>
<th>Has not happened in the past four weeks</th>
<th>Has happened but has not been a problem for the person</th>
<th>Has been a problem for the person in the past four weeks</th>
<th>Has been a serious problem for the person in the past four weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>55</td>
<td>Avoids social contact more than usual for the person</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>56</td>
<td>Loss of self-esteem, feeling worthless</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>57</td>
<td>Delay in falling asleep - at least one hour later than the person's usual time</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>58</td>
<td>Waking too early (at least one hour before the person's usual time) and unable to sleep again</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

**SCORE B:** ........................................

<table>
<thead>
<tr>
<th></th>
<th>Has not happened in the past four weeks</th>
<th>Has happened but has not been a problem for the person</th>
<th>Has been a problem for the person in the past four weeks</th>
<th>Has been a serious problem for the person in the past four weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>59</td>
<td>Broken sleep, waking up for an hour or more, before falling back to sleep.</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>60</td>
<td>Less able to concentrate on chosen activities such as watching television, reading, or other hobbies</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>61</td>
<td>Restless or pacing, unable to sit still</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>62</td>
<td>Irritable or bad tempered</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

**SCORE C:** ........................................

<table>
<thead>
<tr>
<th></th>
<th>Has not happened in the past four weeks</th>
<th>Has happened but has not been a problem for the person</th>
<th>Has been a problem for the person in the past four weeks</th>
<th>Has been a serious problem for the person in the past four weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>63</td>
<td>Less able to use self-care skills, such as dressing, bathing, using the toilet, and cooking</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>64</td>
<td>More forgetful or confused than usual, such as forgetting what has been said or getting lost in familiar places</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

**SCORE D:** ........................................

<table>
<thead>
<tr>
<th></th>
<th>Has not happened in the past four weeks</th>
<th>Has happened but has not been a problem for the person</th>
<th>Has been a problem for the person in the past four weeks</th>
<th>Has been a serious problem for the person in the past four weeks</th>
</tr>
</thead>
<tbody>
<tr>
<td>65</td>
<td>Strange experiences for which other people can see no cause, such as hearing voices or seeing things that other people do not</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>66</td>
<td>Strange beliefs for which other people can see no reason, such as the person believing someone or something is controlling his/her mind or that s/he has special powers</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>67</td>
<td>Odd gestures or mannerisms</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>68</td>
<td>Odd or repetitive use of language</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>69</td>
<td>Any other behavioural problem which is a change from the person's usual</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

**SCORE E:** ........................................
APPENDIX II

Utility Questionnaire.

CARE CO-ORDINATOR INFORMATION

1. Name: .................................................................

2. Sex (please circle):
   M / F

3. Age (please circle):
   24 & under  25 - 34  35 - 44  45 - 54  55 - 64  65 +

4. Job title: ....................................................................................................................................

5. Details of professional qualifications:
   ....................................................................................................................................................
   ....................................................................................................................................................

6. Previous experience working with people with learning disabilities (e.g. length of time, levels of disability, employment roles):
   ....................................................................................................................................................
   ....................................................................................................................................................

7. Have you used the PAS-ADD checklist previously? Yes / No
   If yes, please indicate how many times ..........................................................

RESIDENT INFORMATION

1. What is the resident’s date of birth? ..................................................................................

2. What sex is the resident? M / F

3. How long have you been the resident’s care co-ordinator? ..........................................

4. Does the resident have a diagnosed psychiatric illness? Yes / No / Don’t Know
   If Yes, please provide details: .................................................................................................

5. Does the resident have a diagnosed developmental disability or syndrome?
   (e.g. Down Syndrome, Fragile X, Autism) Yes / No / Don’t Know
   If Yes, please provide details: .................................................................................................

6. Is the resident on any medication? Yes / No / Don’t Know
   If Yes, please provide details: .................................................................................................
   ....................................................................................................................................................
7. **Does the resident have any medical or physical health problems?**
   (e.g. Epilepsy, Diabetes)  
   Yes / No / Don’t Know
   If Yes, please provide details: ..............................................................
   ............................................................................................................
   ............................................................................................................

8. **Does the resident have behavioural problems?**
   No Problems  □  Mild / Moderate Problems  □  Severe Problems  □

9. **Please indicate the resident’s level of mobility.**
   Walks unaided  □  Requires occasional help  □
   Consistently requires help or walking frame  □  Non-mobile / requires wheelchair  □

10. **Please indicate the level of the resident’s vision.**
    No impairment / vision corrected with glasses  □  Partially sighted  □  Blind  □

11. **Please indicate the level of the resident’s hearing.**
    No impairment / hearing corrected with aids  □  Hearing impaired  □  Deaf  □

12. **Level of disability.**
    Mild  □  Moderate  □  Severe  □  Profound  □

13. **IQ (if known).** ..........................  Not known  □

14. **How would you describe the resident’s level of expressive communication?**
    No expressive communication  □
    Uses primarily non-verbal communication (body language, facial expression)  □
    Uses primarily signs / symbols / Makaton  □
    Has a limited verbal skills  □
    Has good verbal skills  □

15. **How would you describe the resident’s level of receptive communication?**
    Has no understanding  □
    Understands primarily non-verbal communication (body language, facial expression)  □
    Understands primarily signs / symbols / Makaton  □
    Understands simple, verbal commands  □
    Has a good understanding of verbal communication  □
COMPLETION OF THE PAS-ADD

1. Overall, how easy / difficult was it to complete the PAS-ADD for this particular resident?

   1 2 3 4 5
   Very Easy Very Difficult

   Please explain your reasons for your answer:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................

2. a) Do you think that this resident has an affective or neurotic disorder? (e.g. depression, anxiety, phobias)  Yes / No / Don’t Know

   Please explain your reasons for your answer:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................

   If "yes" to 2 (a), approximately how long do you think this has been present?
   Less than 1 month / 1-3 months / 3-6 months / 6 months-1 year / over 1 year

   b) How good do you think the PAS-ADD is at gathering information that helps us to know if this resident has an affective or neurotic disorders? (e.g. depression, anxiety, phobias)

   1 2 3 4 5
   Very good Not at all good

   Please explain your reasons for your answer:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................

3. a) Do you think that this resident has an organic disorder? (e.g. dementia)  Yes / No / Don’t Know

   Please explain your reasons for your answer:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................

   If “yes” to 3 (a), approximately how long do you think this has been present?
   Less than 1 month / 1-3 months / 3-6 months / 6 months-1 year / over 1 year

   b) How good do you think the PAS-ADD is at gathering information that helps us to know if this resident has an organic disorder? (e.g. dementia)

   1 2 3 4 5
   Very good Not at all good

   Please explain your reasons for your answer:
   ..........................................................................................................................
   ..........................................................................................................................
   ..........................................................................................................................

4. a) Do you think that this resident has a psychotic disorder? (e.g. schizophrenia, hallucinations, delusions) Yes / No / Don’t Know

Please explain your reasons for your answer:

If “yes” to 4 (a), approximately how long do you think this has been present?
Less than 1 month / 1-3 months / 3-6 months / 6 months-1 year / over 1 year

b) How good do you think the PAS-ADD is at gathering information that helps us to know if this resident has a psychotic disorder? (e.g. schizophrenia, hallucinations, delusions)

1  2  3  4  5
Very good Not at all good

Please explain your reasons for your answer:

5. In general, how useful do you think the PAS-ADD checklist is for use as a screening tool for mental health problems in people with severe learning difficulties?

1  2  3  4  5
Very Useful Not at all Useful

Please explain your reasons for your answer:

Any other comments.

THANK YOU FOR COMPLETING THIS INFORMATION SHEET
APPENDIX III

Ethics Approval Letter.

EAST SURREY LOCAL RESEARCH ETHICS COMMITTEE

Santhams,
West Park Hospital,
Horton Lane,
Epsom, Surrey,
KT19 8PB.

SH/AJR
20th March 1998.

E. Crabtree,
3, Springfield Road,
Guildford, Surrey,
GU1 4DW.

Dear Ms Crabtree,

RE: AN INVESTIGATION INTO THE UTILITY OF THE PAS-ADD MENTAL
HEALTH CHECKLIST AS A SCREENING TOOL FOR PEOPLE WITH
PROFOUND LEARNING AND MULTIPLE DISABILITIES
REF: 82ECPA(103)

The Committee have read your proposal and consider that it does not require ethical
approval for it to proceed.

Yours sincerely,

Selina Harris,
Manager - ESLREC

(NoEthApp)
**APPENDIX IV**

**Statistical Analysis of Client Characteristics in Relation to Omitted Questions.**

**Hearing Impairment**

<table>
<thead>
<tr>
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\[ \chi^2 = 3.90 \ (df = 2) \ (p = 0.142) \]

**Vision**

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\[ \chi^2 = 0.16 \ (df = 2) \ (p = 0.9225) \]

**Behavioural Problems**

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\[ \chi^2 = 5.31 \ (df = 2) \ (p = 0.07) \]
APPENDIX V

Mann-Whitney U Tests on Influence of Level of Disability & Communication on Perceptions of Ease of Use.

### Level of Disability

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\[
Z = -0.32 \ (p = 0.746)
\]

### Expressive Communication

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\[
Z = -0.27 \ (p = 0.785)
\]

### Receptive Communication

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<tr>
<td>No Receptive Communication</td>
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\[
Z = -0.49 \ (p = 0.6229)
\]
APPENDIX VI

Kruskal-Wallis Tests on Influence of Sensory Impairment and Behavioural Difficulties on Perceptions of Ease of Use.

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$\chi^2 = 2.09 \ (df = 2) \ (p = 0.352)$

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$\chi^2 = 0.62 \ (df = 2) \ (p = 0.735)$

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<td>70.75</td>
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$\chi^2 = 2.40 \ (df = 2) \ (p = 0.301)$
APPENDIX VII
Mann-Whitney U Tests on Influence of Level of Communication on Perceptions of Utility.

Expressive Communication

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\[ Z = -1.005 \ (p = 0.315) \]

Receptive Communication

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<tr>
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<td>66.95</td>
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\[ Z = -0.22 \ (p = 0.826) \]
APPENDIX VIII


Hearing Impairment

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\[ \chi^2 = 3.34 \text{ (df = 2) (p = 0.189)} \]

Vision

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\[ \chi^2 = 5.82 \text{ (df = 2) (p = 0.055)} \]

Behavioural Problems

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\[ \chi^2 = 3.94 \text{ (df = 2) (p = 0.140)} \]
Major Research Project

Study 2: An Investigation into the PAS-ADD Mental Health Checklist as a Screening Tool for People with Learning Disabilities

Year III
ABSTRACT

The research described had two components.

Initially, it replicated and extended previous research by the present author investigating the utility of the PAS-ADD checklist across all ranges of individuals with learning disabilities. Results upheld previous research findings that the checklist was less useful with individuals with severe and profound disabilities and with individuals who had communication difficulties. Thirty-two residents (14.2%) were assessed as experiencing symptoms consistent with psychiatric disorder relating to 20%, 18.6%, 8.6% and 0% of those with mild, moderate, severe and profound disabilities respectively. The relationship of these figures to previously reported prevalence rates were discussed. The use of residents from an institutional setting resulted in some difficulties in generalising findings to other settings.

Secondly, the study replicated and extended a study by Moss et al. (1998) investigating the validity, reliability and factor structure of the checklist. Inter-rater reliability was poor, ranging from 0.15 - 0.59 for the main threshold scores and total scores, considerably lower than seen in Moss et al. (1998). Test re-test reliability was established in the study and ranged between 0.583 and 0.71, all in excess of 0.001 levels of probability. Validity was investigated and appeared poor. Methodological flaws in this component of the study were significant and findings on validity of the checklist were viewed with caution. Finally, the factor structure of the structure was investigated. Results were not in agreement with the 8 factor structure proposed by Moss et al. (1998). Instead a 5 factor structure was established, of which only 3 factors appeared clinically relevant. Implications for further research were discussed.
1. LITERATURE REVIEW

1. Introduction
In recent years, the issue of the existence of mental health difficulties in people with learning disabilities has become more widely discussed within both psychiatric and psychological literature. Discussion has focused on issues of prevalence (Rutter and Graham, 1970; Rutter et al., 1976; Borthwick-Duffy and Eyman, 1990; Reiss, 1990; Meadows et al., 1991; Cherry et al., 1997), vulnerability factors (Pollock, 1944; Menolascino, Levitas and Greiner, 1986; Fraser and Nolan, 1994; Rojahn and Tasse, 1996) and difficulties in diagnosis (Parsons et al., 1984; Ruedrich and Menolascino, 1984; Sovner, 1986; Clarke et al., 1994). A more detailed discussion of these issues has been presented previously (see Literature Review) and they will therefore be discussed only briefly.

2. Background
Researchers have almost consistently argued that individuals with learning disabilities are vulnerable to mental health difficulties as a result of experiencing biological, environmental and psychosocial risk factors. These include poor social skills, lack of social support, impoverished living conditions, lack of communication skills and neurological deficits.

The interest in dual diagnosis has heightened as a consequence of the move towards community care for people with learning disabilities and is particularly pertinent due to mental health being a key priority in the “Health of the Nation” policy. It was noted in the move towards community living that services were not prepared for the difficulties experienced by those with a dual diagnosis thus heightening the risk of placement breakdown (Prosser, 1999).

Reported rates of dual diagnosis in individuals with learning disabilities vary from 10% to 80% depending on criteria for inclusion, methodology employed, definitions of both level of disability and psychiatric disorder, and the populations sampled (Borthwick-Duffy, 1994). The most extensive study undertaken suggests rates of 16%, 9%, 5% and 3% for individuals with mild, moderate, severe and profound levels
of disability respectively (Borthwick-Duffy and Eyman, 1990) but the reliance on client file information may result in this being an underestimate of true rates of illness.

3. Measurement

Given the recognition of dual diagnosis as a relevant phenomenon in the lives of people with learning disabilities and the consequent impact such experiences have on their quality of life, it is necessary for individuals to have access to mental health services skilled in the detection of the sometimes idiosyncratic nature of symptom presentation in this population. Research has highlighted many of the difficulties in symptom detection and psychiatric diagnosis with these individuals (Reiss, Levitan and Szyszko, 1982; Reiss and Szyszko, 1983; Sovner, 1986; Meadows et al., 1991; Szymanski, 1994). The interest in dual diagnosis has led to the development of a number of tools specifically for identifying the presence of psychiatric disorder in people with learning disability. These aim to address some of the difficulties identified and include the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Sturmey et al., 1991), the Reiss screen (Reiss, 1987) and the three levels of the Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) (Moss et al., 1993). The benefits and drawbacks of these tools have been identified previously by the author and will not be discussed in detail (see Study 1).

4. The PAS-ADD Checklist

One of the most recently developed tools for the assessment of psychiatric disorder in people with learning disabilities is the three tiered PAS-ADD assessment, the full PAS-ADD, the mini PAS-ADD and the PAS-ADD checklist. In this author’s previous study, a general survey of individuals with severe and profound disabilities was undertaken using the PAS-ADD checklist. It concluded that the checklist was less effective in assessing individuals with profound disabilities and poor levels of communication. At the time of the previous study, there was little published information regarding either the reliability or validity of the checklist, or guidelines on the levels of disability for which the checklist was particularly relevant. The study undertaken suggested difficulties with some individuals and it was considered
necessary to undertake a wider study of the checklist with individuals from all ranges of disability. During the first study, a paper was published by the checklist authors detailing the factor analysis, reliability and validity of the checklist (Moss et al., 1998). It was considered useful therefore to replicate their study, enhancing the techniques used and adding to the data available.

The study presented by Moss et al. (1998) will be discussed in detail below. A brief overview of their methodology will be provided alongside a detailed critique of the design used and the conclusions drawn.

4.1. Reliability
4.1.1. General Issues
Classical theory suggests that for any trait, an individual can be assumed to have a true score. However, observed scores are subject to random error. An assessment measure is reliable when the true score is close to the observed score (Hammond, 1995).

The assessment of mental health status in people with learning disabilities relies on the estimation of their experiences by observers. This reliance on outside observers is likely to introduce measurement error into the assessment as opinions may be subjective and vary over time. Additionally, the structure of the assessment measure itself may influence the scores attained and introduce measurement error. These influences on measurement result in it being necessary to provide an estimate of the reliability of the measurement tool i.e. the likelihood that you will achieve the same results over repeated trials (Carmines and Zeller, 1979; Lehman, 1991).

Reliability can be assessed on the internal consistency of tests - *split-half reliability*, the reliability over different raters - *inter-rater reliability* and the reliability over time - *test re-test reliability*. Moss et al. (1998) provide a measure of the inter-rater reliability of the PAS-ADD checklist but failed to investigate its test re-test reliability. Given the differing scales within the checklist, it would not be appropriate to provide measures of internal consistency.
4.1.2. Reliability of the PAS-ADD Checklist

Moss et al. (1998) conducted an inter-rater reliability study on a mixed hospital and community sample of 66 learning disabled individuals. This was selected to include individuals already known to be experiencing mental health problems alongside those not receiving psychiatric input. The ages of individuals ranged from 16 years to 69 years (mean = 37 years) and IQ estimates ranged from 14 - 47 (mean = 30.5). Standard deviations were not provided for either measure. Ratings of symptoms were provided by both carers and family members in all but seven cases where two carer ratings were used. Spearman rank correlations on the three internal scales, total scores and five alternative scales were used to provide measures of reliability. Rater agreement for all scales was above 0.55 with a correlation for the total scores of 0.79. Individual item scores were dichotomised, and questions where greater than 10% of scores were positive for symptom identification were entered into the reliability calculations. Rates of inter-rater agreement were seen of kappa = 0.3 - 0.8 for individual items. An overall mean kappa of 0.42 was found. Percentage agreement on case identification, i.e. whether individuals had scores placing them above one of the three thresholds, reached 79%.

Critique

A number of methodological issues were raised by the reliability procedure used by Moss et al. (1998).

The use of care staff and family members for inter-rater reliability measures was inappropriate. The population under consideration was that of hospital and community residents. Given this, it is unlikely that the carers and family would spend equivalent time with the person under assessment, indeed some family members may have only visited their relative weekly or fortnightly. Additionally, it is doubtful that both raters would have seen the same behaviours exhibited by the individual, as the environment is known to influence the expression of behaviours. Further, knowledge of mental health could vary between the two sets of raters. Whilst care staff may not have undergone specific mental health training, their experience of working in an environment caring for people with disabilities would undoubtedly make them more
aware of the idiosyncratic nature of the presentation of mental health problems in this population. They would have an understanding of the wide range of behaviours considered “normal” with people with disabilities and therefore have a wider knowledge base from which to undertake mental health assessments. Using individuals with similar knowledge and experience could enhance the inter-rater reliabilities found by Moss et al. (1998).

Additionally, the test re-test reliability of the checklist was not assessed. Whilst it is recognised that mental health status may change reasonably rapidly, it is necessary to have an indication of test re-test reliability.

4.2. Validity

4.2.1. General Issues

The validity of an assessment tool is of equivalent importance to the reliability but may be harder to establish (Schweigert, 1994). The validity of a measurement tool is given by whether it measures what it purports to measure (Hammond, 1995). Validity can be assessed using a number of techniques: content validation (e.g. face validity), criterion validation (both predictive and concurrent) and construct validation.

While many researchers use face validation to assess the validity of a measure, this lacks objectivity (Hammond, 1995). It is generally necessary to subject the data to a more rigorous, statistical analysis to assess validity. Moss et al. (1998) examine the criterion-related, concurrent validity of diagnoses given by their checklist. They compare scores in excess of threshold levels to known psychiatric diagnosis by a psychiatrist specialised in the assessment of mental health problems in individuals with learning disabilities. Internal consistency of threshold scale scores, and alternative a priori scales, using Cronbach’s alpha (Cronbach’s alpha on internal scales can also be considered to be a measure of internal reliability) is also provided.

4.2.2. Validity of the PAS-ADD Checklist

Moss et al. (1998) highlight the difficulties inherent in providing a “gold standard” against which to measure the validity of the checklist particularly given the
difficulties in diagnosis of psychiatric disturbance in this population. They investigated 59 individuals already known to psychiatric services, some well and some ill, and compared the ratings of carers with estimates of illness provided by a psychiatrist specialising in the mental health of people with learning disabilities. Results led to the conclusion that the checklist displays “broadly satisfactory” validity with detection of cases being 26% for individuals with no current illness, 56% for mild disorders and 92% for those considered to have major psychiatric disturbance by the psychiatrist.

_Critique_

These results indicate a false positive rate of 26% for people with no current illness and 46% rate of non identification in people with mild difficulties. These rates should not be considered “broadly satisfactory”.

4.3. Factor Analysis of the PAS-ADD Checklist

Moss et al. (1998) provide details of a factor analysis and measure of internal consistency on 209 individuals assessed using the PAS-ADD checklists. The factor analysis, using Quartimax rotation isolated 8 factors accounting for 65.3% of the variance.

_Critique_

There are a number of significant methodological flaws in the factor analysis as described by Moss et al. (1998). First, the process used to analyse the results attained is insufficiently clear. Details are not provided regarding the allocation of items to categories to allow for the factor analysis. However, a personal communication with Moss (1999) indicated that scores were dichotomised into the presence and absence of symptoms.

Secondly, the authors state that they subjected the data to factor analysis using a Quartimix method of rotation. This rotation assumes data will provide “orthogonal”, uncorrelated factors. However, the assumption that data resulting from the assessment of mental health status are uncorrelated seems unwarranted. Indeed,
Moss et al.'s results suggest two "depression" factors which would seem highly likely to be correlated. A more appropriate analysis would rotate data obliquely using Oblimin to allow for correlation of factors to be taken into account.

Thirdly, Moss et al. make no statement regarding the method of factor extraction used in the study. Personal communication with Moss (1999) confirmed that, as with many studies using Factor Analytic techniques, they extracted factors using the Kaiser-Guttman criterion (i.e. those factors with Eigen values greater than 1). Despite being a commonly used method of factor extraction, it is widely recognised as a "clumsy" way of interpreting data that results in more factors being isolated than is appropriate. Instead it is suggested that "parallel analysis" is undertaken with randomly generated data (Thompson and Daniel, 1996) and factors extracted with eigen values greater than those in the random data set.

Fourthly, factors are provided using variables loading 0.5 or greater on the factors under consideration. This is a highly conservative way of reporting data as most texts recommend looking at data with loadings of 0.32 or greater (Tabachnick and Fidell, 1996).

Fifthly, a number of questions arise concerning the content of particular factors. For example, two questions can each be found in two factors. Question 60 (difficulties concentrating) is present in both the restlessness and phobic anxiety factors and question 46 (repeated actions) is present in both the psychotic and autistic spectrum factors. This highlights that the factor analysis has failed to achieve simple structure i.e. that each item should only load highly on one factor. Given that factors were only reported for variables of 0.5 and greater, the chance of achieving simple structure should be increased. It could be hypothesised therefore that the inclusion of variables with loadings of 0.32 or greater would increase the overlap between factors thus reducing the likelihood of achieving simple structure.
Sixthly, Moss et al. report a number of factors with very few items, a common error in factor analysis: the depression and non-specific factors contain only two items. The interpretation of such factors is suspect.

In addition to flaws in the statistical methodology, there are concerns regarding the interpretation of factor categories and their relation to the checklist threshold scales. Moss et al. report eight factor categories: depression (1), restlessness, phobic anxiety, psychosis, hypomania, autistic spectrum, depression (2) and non-specific. While the allocation of the items to these factors appears valid, a number of questions arise when examining the data more closely. First, no mention is made of those items that do not load on any of the factors, question 53 (loss of confidence) and question 61 (restlessness and pacing) despite their continued inclusion in the checklist (questions 51 (weight change) and 69 (any other change in behaviour) were excluded from the analysis due to not contributing to the final score (Moss, 1999)). It is also intriguing to note that the question relating to “restlessness and pacing” does not feature in the “restlessness” factor calling into question the labelling of this factor.

It is also interesting to note that although the factor analysis did not isolate any factors considered to represent the “organic” set of disorders, this is considered to be covered within the checklist. It is possible that the sample assessed did not contain any individuals experiencing organic disorders so resulting in this not being picked up in the factor analysis. However there is no discussion of this issue in the paper.

Finally, it would seem appropriate to provide a measure of the internal consistency of the factors identified in the analysis. The authors chose instead to provide internal consistencies on the threshold scales and a set of a priori scales developed to reflect symptom constellations for specific disorders. They discuss that it would be inappropriate to provide Alpha coefficients on the eight factors isolated by the factor analysis. This is not the case however, as it is necessary to undertake internal consistency analysis on factors to provide a measure of the inter-correlation between items. The use of idiosyncratic measures, unrelated to these factors is open to question.
II. RATIONALE FOR THE PRESENT STUDY

The interest in the dual diagnosis of learning disability and mental health difficulties has resulted in the development of a number of tools specifically tailored for measuring psychiatric illness in individuals whose symptoms and experiences do not easily fit into the standard diagnostic criteria used to assess psychiatric disturbance. The PAS-ADD checklist is one such measure but a number of questions arise as to the ways in which the factor structure, reliability and validity of the tool has been assessed. Independent research is required to replicate their findings.

In addition, a previous study by the current author has isolated limitations with the use of the checklist with people at the low end of the ability range who have limited expressive and receptive communication. It was considered useful to undertake a wider survey of individuals with a range of disabilities to ascertain the utility of the checklist with individuals without communication difficulties.

III. AIMS AND OBJECTIVES

Given that the study undertaken replicated previous studies, it was not appropriate to generate hypotheses for testing. Instead the study is constructed on the basis of a number of aims and objectives.

1. Replication and extension of previous research by the present author. To replicate previous research regarding the utility of the PAS-ADD checklist with individuals with learning disabilities. The study aimed to extend assessment to include individuals across the range of levels of disability looking at issues of utility and ease of use.


2.1. Test re-test reliability. The study aimed to assess test re-test reliability.

2.2. Inter-rater reliability. The study provided measures of inter-rater reliability, extending the Moss et al. procedure to include carers of similar experience and qualifications. Inter-rater reliability should be enhanced by using raters with
similar understanding of the presentation of mental health problems in people with learning disabilities.

2.3. **Validity.** The study replicated the validity procedure used by Moss et al. (1998).

2.4. **Factor Structure.** The factor analysis undertaken by Moss et al. (1998) was replicated on a larger sample of individuals. The procedure for analysis was enhanced by using an alternative method of factor analysis that accounted for relatedness in the data.

2.5. **Internal Consistency.** Measures of the internal consistency of both the factors extracted and the threshold scales were calculated.
IV. STUDY 2 (PART I) - AN INVESTIGATION INTO THE UTILITY OF THE PAS-ADD CHECKLIST WITH PEOPLE WITH LEARNING DISABILITIES

1. Method

1.1. Measures Used

As with the previous study undertaken by the author, two measures were used for the study, the PAS-ADD checklist and the utility questionnaire designed specifically for the study.

1.1.1. The PAS-ADD checklist

The PAS-ADD checklist contains two sections. The first looks at life events experienced by those with learning disabilities within the past year. The second contains indicators of any mental health problems (i.e. affective / neurotic disorders, organic disorders and psychotic disorders) they might display. The latter requires ratings on a four point scale of severity from “has not happened” to “has been a serious problem” for the individual. Each score is weighted for the significance of the behavioural indicator. Threshold values are provided for each of the three main psychiatric disorders under examination and individuals obtaining scores equal to, or above, these levels are recommended to undergo more extensive psychiatric examination.

1.1.2. Utility Measures

The utility of the checklist was measured in two ways:

- Omitted Questions

Checklist instructions advise the informant to omit questions when characteristics of the client result in it being impossible to answer with any degree of certainty. The number of questions omitted for each client was therefore used to provide an indication of the utility of the measure.
• Utility Questionnaire

This questionnaire was developed during the study reported previously. It provided demographic information for both clients and informants. For clients, it detailed: age, level of disability, level of communication, presence of sensory or motor impairment and details of medical and psychiatric history. For informants, information included: name, age, gender, professional qualifications and length of experience with the client group.

1.2. Sample

1.2.1. Residents

Residents of a learning disability institution providing care for approximately 450 people were assessed. This sample of residents was drawn from the same institution as reported in the previous study. Those residents who participated in the first study were excluded. The potential sample comprised 309 residents. Two homes with 50 residents were unable to participate due to low staffing levels and large workloads. Data on a further 20 residents was mislaid in the postal service and was therefore not available for analysis. Three residents died prior to completion of the checklists and three residents had been relocated to community homes. A further seven checklists were not completed by the time of submission of the report. The final data set therefore contained 226 residents.

1.2.2. Informants

As in the previous study, questionnaires were completed by qualified care co-ordinators. Key-workers were excluded as many had few qualifications and were not proficient in English. Care Co-ordinators had overall responsibility for the care planning of the residents and had basic nursing qualifications. Despite this, staffing problems led to some homes using their key-workers to complete questionnaires. In total, sixty four informants completed questionnaires.

1.3. Procedure

Ethics approval was gained from East Surrey Local Research Ethics Committee (See Appendix I).
Initially, home managers were telephoned to introduce and explain the rationale for the project. Appointments were arranged to discuss procedures in greater detail and to provide managers with checklists to be completed by their staff. It was agreed that completed questionnaires would be returned by post to the author. When questionnaires were incomplete, these were returned to the informant with a memo detailing the further information required. Telephone contact was made with home managers to chase up questionnaires that had not been received within an eight week time frame.

2. Statistical Analysis

Preliminary observation of the data indicated that it was not normally distributed and the data were therefore analysed using non-parametric statistical tests.

3. Results

3.1. The Resident Sample

This information was derived from the utility questionnaire.

3.1.1. Age / sex distribution

One hundred and twenty four residents were male (age range 22 - 88 years, mean = 50.79, SD = 14.10). One hundred and two residents were female (age range 26 - 95 years, mean = 50.86, SD = 17.75).

3.1.2. Level of Disability

Forty residents (17.7%) had mild learning disabilities, 86 (38.1%) had moderate disabilities, 93 (41.2%) had severe disabilities and six (2.7%) were considered to have profound disabilities. Data were missing on one resident.

3.1.3. Sensory Impairment

Fifteen residents (6.6%) were partially sighted and five (2.2%) were blind but had intact hearing. Five (2.2%) had hearing impairment and two (0.9%) were deaf but had intact vision. A further eight residents (3.5%) had both visual and hearing
impairment. Data were missing on four residents (1.8%). One hundred and eighty seven residents (82.7%) had no sensory impairment.

3.1.4. Communication

Ninety nine residents (43.8%) had good understanding of verbal communication and 83 (36.7%) had good expressive verbal communication. The remaining residents had either receptive (56.2%) or expressive (63.3%) communication difficulties. These data are detailed in Tables 1 and 2.

Table 1: Level of expressive communication

<table>
<thead>
<tr>
<th>Level of Expressive Communication</th>
<th>Number of residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>No expressive communication</td>
<td>22 (9.7%)</td>
</tr>
<tr>
<td>Uses non-verbal communication</td>
<td>35 (15.5%)</td>
</tr>
<tr>
<td>Uses signs / symbols / makaton</td>
<td>20 (8.8%)</td>
</tr>
<tr>
<td>Has limited verbal repertoire</td>
<td>66 (29.2%)</td>
</tr>
<tr>
<td>Has good verbal skills</td>
<td>83 (36.7%)</td>
</tr>
</tbody>
</table>

Table 2: Level of receptive communication

<table>
<thead>
<tr>
<th>Level of Receptive Communication</th>
<th>Number of residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>No understanding</td>
<td>2 (0.9%)</td>
</tr>
<tr>
<td>Understands non-verbal communication</td>
<td>11 (4.9%)</td>
</tr>
<tr>
<td>Understands signs / symbols / makaton</td>
<td>5 (2.2%)</td>
</tr>
<tr>
<td>Understands simple, verbal commands</td>
<td>109 (48.2%)</td>
</tr>
<tr>
<td>Good verbal understanding</td>
<td>99 (43.8%)</td>
</tr>
</tbody>
</table>

3.1.5. Developmental Disorders

Fifteen residents (6.6%) were diagnosed as having Down Syndrome; 30 (13.3%) had Autism and eight (3.5%) experienced other, less common, developmental disorders (e.g. Turner’s Syndrome, Kleinfelter’s Syndrome and PKU). The remaining residents (76.1%) had no diagnosed developmental disorder. Data were not available on one resident.

3.1.6. Diagnosed Psychiatric Disorder

One resident (0.4%) had a dementing condition, 14 (6.2%) had psychotic disorders, 15 (6.6%) had depressive disorders and one (0.4%) was diagnosed as having a
schizoid personality disorder. Data were missing on two residents (0.8%). The remaining residents (85.4%) had no psychiatric diagnosis.

### 3.1.7. Medical Conditions

Sixty six residents (29.2%) had epilepsy and 30 (12.8%) suffered from a variety of physical complaints including asthma, diabetes, cancer, heart disease and bowel problems. Data were missing on three residents. The remaining residents (58%) were in good physical health.

### 3.1.8. Medication

Despite the low rates of both physical and psychiatric disorder, only 34 residents (15.0%) were not receiving medication. Many residents were receiving combinations of medication. One hundred and twelve residents (49.6%) were receiving anti-psychotic medication, 84 (37.2%) were prescribed anti-convulsant medication, 27 (12.0%) were on anti-depressant medication, five (2.2%) received anxiolytic medication, 35 (15%) received medication to control side effects of anti-psychotic medication and 55 (15.5%) received other medication including sedatives, contraception, laxatives and vitamins. Data were missing on five residents (2.2%).

### 3.1.9. Other Factors

The final information gained on residents related to mobility and behavioural problems.

Thirty five residents (15.5%) required occasional help with mobility, 23 (10.2%) required regular help and 16 (7.15%) were confined to wheelchairs. The remainder (67.3%) had no mobility problems.

One hundred and forty four residents (63.7%) had mild / moderate behavioural difficulties and 28 (12.4%) were described as exhibiting severe difficulties. Data were missing on one individual. Fifty three (23.5%) were not exhibiting behavioural disturbance.
3.2. The Informant Sample

3.2.1. Age/Sex Distribution.
Twenty six (40.6%) of the informants were male and 38 (59.4%) were female. Two (3.1%) were aged 24 years and under, 10 (15.6%) were in the age band 25 - 34, 23 (35.9%) were between 35 - 44 years, 25 (39.1%) were between 45 - 54 years and two were between 55 - 64 years. Two informants did not provide their age.

3.2.2. Experience and qualifications.
Only nine of the informants (14.1%) were non-qualified members of staff, 31 (48.5%) were qualified nursing staff, eight (12.5%) were deputy home managers and the remaining 16 informants (25%) were home managers. Staff had on average 29.26 years of experience (SD = 8.43) with a range of 3 years - 40 years.

3.2.3. Questionnaires completed
Each informant was responsible for a number of residents in their care and the number of questionnaires completed by each informant ranged from one to 16 (mode = 1).

3.3. Identification of mental health difficulties

3.3.1. Frequency Distribution of Score within Subscales

Affective / Neurotic Disorders Scale
Seventeen residents (7.5%) achieved threshold levels of six or above, 45 (19.9%) scored between 1 - 5 and 164 (72.6%) scored zero.

Organic Conditions Scale
Eight residents (3.5%) achieved threshold levels of five or above, 38 (16.8%) scored between 1 - 4 and 180 (79.6%) scored zero.

Psychotic Disorders Scale
Twenty three residents (10.2%) achieved threshold levels of two or above, 30 (13.3%) obtained a score of one and 173 (76.5%) obtained scores of zero.
3.3.2. Psychiatric Disorder identified by the PAS-ADD
The PAS-ADD checklist identified 32 (14.2%) individuals as possibly experiencing psychiatric disorder. Twenty one residents (9.3%) were identified as experiencing a single psychiatric disorder: seven (3.1%) with indicators of affective / neurotic disorder and 14 (6.2%) with indicators of psychotic disorder.

Of those residents with indicators of multiple psychiatric disturbance, two (0.9%) reached threshold on the affective / neurotic and the organic disorders scales, one (0.4%) reached thresholds on organic and psychotic disorders scales and three (1.3%) reached threshold levels on affective / neurotic and psychotic disorders scales. Five residents (2.2%) reached threshold values on all three psychiatric subscales.

Details of these clients are presented in Appendix II.

The 32 residents were identified by 22 informants who identified between one and three cases each.

3.3.3. PAS-ADD Cases and Previous Diagnosis
Of those clients identified by the PAS-ADD, eight had previous psychiatric diagnoses: three had affective / neurotic diagnoses, three had psychotic diagnoses and one had been identified as suffering from an organic disorder. Data were missing on the previous psychiatric diagnosis of one of these individuals. Twenty four individuals with recognised psychiatric disorder were not identified by the checklist.

3.3.4. PAS-ADD Cases and Level of Disability
Eight cases identified were individuals with mild learning disabilities, 16 had moderate learning disabilities and eight experienced severe disabilities as assessed by the informants. This related to 20%, 18.6%, 8.6% and 0% of all the individuals assessed with mild, moderate, severe and profound disabilities respectively.
3.4. Number of omitted questions
Informants omitted answers to questions for 62 (27.4%) of the residents assessed. A mean of 1.08 (SD = 2.3, range 0 - 11) questions were omitted.

3.4.1. Relationship between level of disability and number of omitted questions
The impact of assigned level of disability on the number of omitted questions was analysed. Means and standard deviations are provided in Table 3.

<table>
<thead>
<tr>
<th>Level of Disability</th>
<th>Number of Cases</th>
<th>Mean Number of Omitted Questions</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>40</td>
<td>0.78</td>
<td>1.17</td>
</tr>
<tr>
<td>Moderate</td>
<td>86</td>
<td>0.50</td>
<td>1.86</td>
</tr>
<tr>
<td>Severe</td>
<td>93</td>
<td>1.69</td>
<td>2.58</td>
</tr>
<tr>
<td>Profound</td>
<td>6</td>
<td>4.50</td>
<td>3.89</td>
</tr>
</tbody>
</table>

The small number of residents present in the profound disability group resulted in it not being possible to include this group in the analysis.

Significant group differences were found on the number of omitted questions (Kruskal-Wallis, $\chi^2 = 15.51$ (2df), $p = 0.0004$). Post hoc Mann Whitney U tests were conducted using significance levels of 0.0167 (0.05 ÷ number of tests conducted i.e. 3) to protect against Type I errors. These isolated significant group differences between omitted questions for individuals with mild and severe disabilities ($z = -3.41$, $p = 0.0007$) and for omitted questions for those with moderate and severe disabilities ($z = -4.50$, $p = 0.0000$).

3.4.2. Relationship between Level of Expressive Communication and Number of Omitted Questions
The mean number of omitted questions by level of expressive communication is detailed below in Table 4.
Table 4: Means and Standard Deviations of Omitted Questions by Level of Expressive Communication

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No expressive communication</td>
<td>22</td>
<td>1.41</td>
<td>1.68</td>
</tr>
<tr>
<td>2 - Non-verbal communication</td>
<td>35</td>
<td>3.23</td>
<td>3.49</td>
</tr>
<tr>
<td>3 - Signs / symbols</td>
<td>20</td>
<td>1.30</td>
<td>2.30</td>
</tr>
<tr>
<td>4 - Limited verbal skills</td>
<td>66</td>
<td>1.09</td>
<td>2.33</td>
</tr>
<tr>
<td>5 - Good verbal skills</td>
<td>83</td>
<td>0.02</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Differences between groups were significant (Kruskal-Wallis, $\chi^2 = 37.72$ (4df), $p = 0.0000$). Post-hoc Mann Whitney U tests were again conducted to isolate specific significant group differences using significance levels of 0.005 (0.05 / 10) to protect for Type I errors. Significant group differences were found for those individuals with good verbal skills and all other groups (Group 1 - no expressive communication, $z = -6.83$, $p = 0.0000$; Group 2 - non-verbal communication, $z = -7.5246$, $p = 0.0000$; Group 3 - use of signs / symbols, $z = -4.71$, $p = 0.0000$; Group 4 - those with limited verbal skills, $z = -4.49$, $p = 0.0000$). Significant group differences were also found between individuals using non-verbal forms of communication (Group 2) and those with limited verbal skills ($z = -3.71$, $p = 0.0002$).

3.4.3. Relationship between omitted questions and level of receptive communication

The mean number of questions omitted by level of receptive communication is detailed below in Table 5.

Table 5: Means and Standard Deviations of Omitted Questions by Level of Receptive Communication

<table>
<thead>
<tr>
<th>Level of Understanding</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No understanding</td>
<td>2</td>
<td>5.00</td>
<td>7.07</td>
</tr>
<tr>
<td>2 - Non-verbal communication</td>
<td>11</td>
<td>1.64</td>
<td>3.36</td>
</tr>
<tr>
<td>3 - Signs / symbols</td>
<td>5</td>
<td>0.00</td>
<td>0.00</td>
</tr>
<tr>
<td>4 - Simple verbal commands</td>
<td>109</td>
<td>1.83</td>
<td>2.68</td>
</tr>
<tr>
<td>5 - Good understanding</td>
<td>99</td>
<td>0.17</td>
<td>0.83</td>
</tr>
</tbody>
</table>

Given the wide difference in group sizes, for the purposes of statistical analyses, the data were collapsed into two main groups: individuals with and without understanding of verbal communication. The resulting means and SD’s are presented in Table 6.
Table 6: Means and Standard Deviations of Omitted Questions by Level of Receptive Communication

<table>
<thead>
<tr>
<th>Level of Understanding</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No understanding of verbal communication</td>
<td>18</td>
<td>1.56</td>
<td>3.42</td>
</tr>
<tr>
<td>2 - Some understanding of verbal communication</td>
<td>208</td>
<td>1.04</td>
<td>2.18</td>
</tr>
</tbody>
</table>

Mann Whitney U tests failed to find a significant group difference \((z = -0.17, p = 0.86)\). However, these results should be viewed with caution as even with collapsing the data, group sizes are still significantly different from one another.

3.3.5. Other Client Characteristics

Other client characteristics were explored to assess whether they had an impact upon the number of questions omitted by the informants (i.e. sensory impairment, mobility and behavioural difficulties). Again, some group sizes resulted in data being collapsed into two main groups. Neither hearing ability nor the presence of behavioural disturbance significantly influenced the number of omitted questions (See Appendix III) however the role of visual impairment was significant \((z = -2.4721, p = 0.0134)\). Means and SD’s are noted below (Table 7).


<table>
<thead>
<tr>
<th>Visual Impairment</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Impairment</td>
<td>198</td>
<td>0.99</td>
<td>2.29</td>
</tr>
<tr>
<td>Some Impairment</td>
<td>28</td>
<td>1.71</td>
<td>2.28</td>
</tr>
</tbody>
</table>

3.3.6. Particular Questions Omitted

As in the previous study, the frequency of omitted answers was examined to ascertain which particular questions created difficulties for informants.

Difficulties were experienced with the same questions previously identified. Percentages omitted were less than seen previously however, possibly reflecting the differing population demographics with reference to level of disability and communication abilities. Details of the questions omitted and the respective percentages of clients for whom they were unanswered can be seen in Table 8.
Table 8: Co-ordinators reasons for unanswered PAS-ADD questions

<table>
<thead>
<tr>
<th>Question number</th>
<th>Content</th>
<th>Percentage of clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>46</td>
<td>Repeated actions, such as checking over and over that door is locked</td>
<td>2.7%</td>
</tr>
<tr>
<td>48</td>
<td>Attempt suicide of talks about suicide</td>
<td>16.4%</td>
</tr>
<tr>
<td>53</td>
<td>Shows loss of confidence with people, i.e. repeatedly asking for reassurance</td>
<td>10.2%</td>
</tr>
<tr>
<td>54</td>
<td>Suspicious, un-trusting behaviour e.g. as if someone is trying to harm them</td>
<td>5.3%</td>
</tr>
<tr>
<td>56</td>
<td>Loss of self-esteem, feeling worthless</td>
<td>9.7%</td>
</tr>
<tr>
<td>60</td>
<td>Less able to concentrate on chosen activities such as watching T.V.</td>
<td>0.9%</td>
</tr>
<tr>
<td>61</td>
<td>Restless or pacing, unable to sit still</td>
<td>3.1%</td>
</tr>
<tr>
<td>63</td>
<td>Less able to use self-care skills, e.g. dressing bathing, using the toilet</td>
<td>5.3%</td>
</tr>
<tr>
<td>64</td>
<td>More forgetful or confused than usual, e.g. forgetting what has been said</td>
<td>5.3%</td>
</tr>
<tr>
<td>65</td>
<td>Strange experiences, e.g. hearing voices or seeing things</td>
<td>13.7%</td>
</tr>
<tr>
<td>66</td>
<td>Strange beliefs for which other people can see no reason</td>
<td>17.7%</td>
</tr>
<tr>
<td>68</td>
<td>Odd or repetitive use of language</td>
<td>12.4%</td>
</tr>
</tbody>
</table>

Key to question numbers
- Affective / neurotic disorders scale
- Organic disorders scale
- Questions used in both affective/neurotic & organic disorders scale
- Psychotic disorders scale

3.5. Perceptions of usefulness

3.5.1. Ratings of utility

On the 5 point scale relating to utility of the checklist, informants on 37 of the questionnaires (16.4%) considered the PAS-ADD “extremely useful”, 50 (22.1%) reported it was “very useful”, 77 (34.1%) considered it was “useful”, 41 (18.1%) believed it was “not very useful” and 19 (8.4%) considered it “not at all useful”. Data were missing from two informants.

3.5.2. Relationship between client characteristic and perceptions of utility of questions

Kruskal-Wallis analyses on the relationship between resident characteristics and ratings of usefulness of the checklist were undertaken. Non-significant results were obtained for all characteristics with the exception of degree of behavioural problems (See Appendix IV).

The mean and standard deviations of perceptions of utility by categories of behavioural difficulties can be seen in Table 9. Group differences were significant (Kruskal-Wallis, $\chi^2 = 6.14$ (2df), $p = 0.0463$).
Table 9: Means and Standard Deviations of Perceptions of Utility by Level of Behavioural Problems.

<table>
<thead>
<tr>
<th>Behavioural Problems</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Problems</td>
<td>53</td>
<td>2.83</td>
<td>1.25</td>
</tr>
<tr>
<td>Mild / Moderate Problems</td>
<td>142</td>
<td>2.69</td>
<td>1.16</td>
</tr>
<tr>
<td>Severe Problems</td>
<td>28</td>
<td>3.25</td>
<td>1.01</td>
</tr>
</tbody>
</table>

Post-hoc Mann Whitney U tests were conducted to isolate specific significant group differences using significance levels of 0.0167 (0.05 ÷ 3) to protect for Type I errors. A significant group difference was established between those individuals with mild / moderate problems and those exhibiting severe behavioural difficulties (z = -2.57, p = 0.0103).

3.6. Perceptions of ease of use

3.6.1. Ratings of ease of use

On the 5 point scale relating to ease of use, informants on 67 of the questionnaires (29.6%) considered the PAS-ADD “very easy” to complete, 52 (23.1%) reported it was “easy”, 76 (33.6%) considered it was “neither easy or difficult” and 30 (13.3%) considered it “difficult” to complete. No raters considered the PAS-ADD “very difficult” to complete and data were missing from one informant.

3.6.2. Relationship between resident characteristics and perceptions of ease of use

Kruskal-Wallis analyses on the relationship between resident characteristics and ratings of ease of use were undertaken. Non-significant results were obtained for all characteristics with the exception of level of expressive communication (See Appendix V).

The mean and standard deviations of ease of use according to level of expressive communication can be seen in Table 10. Group differences were significant (Kruskal-Wallis, $\chi^2 = 13.98$ (4df), p = 0.0073).
Table 10: Means and Standard Deviations of Perceptions of Ease of Use by Level of Expressive Communication

<table>
<thead>
<tr>
<th>Level of Communication</th>
<th>Number of Cases</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - No expressive communication</td>
<td>22</td>
<td>2.90</td>
<td>0.92</td>
</tr>
<tr>
<td>2 - Non-verbal communication</td>
<td>35</td>
<td>2.57</td>
<td>0.82</td>
</tr>
<tr>
<td>3 - Signs / symbols</td>
<td>20</td>
<td>2.35</td>
<td>1.04</td>
</tr>
<tr>
<td>4 - Limited verbal skills</td>
<td>66</td>
<td>2.02</td>
<td>1.02</td>
</tr>
<tr>
<td>5 - Good verbal skills</td>
<td>82</td>
<td>2.26</td>
<td>1.10</td>
</tr>
</tbody>
</table>

Post-hoc Mann Whitney U tests were again conducted to isolate specific significant group differences using significance levels of 0.005 (0.05 \( \div \) 10) to protect for Type I errors. A significant group difference was found between ease of use for individuals with limited verbal skills (Group 4) and those with no expressive communication (Group 1) \( (z = -3.431, p = 0.0006) \).

A) INTER-RATER RELIABILITY
This study investigated the inter-rater reliability of the PAS-ADD checklist using a subsection of participants and informants used in the survey detailed in Study 1.

1. Method
1.1. Measures Used
The PAS-ADD checklist and both the client and informant information sections of the Utility questionnaire were used.

1.2. Sample
1.2.1. Residents
Fifty residents were chosen at random prior to data collection for the purpose of assessing the inter-rater reliability of checklists completed by informants. Residents were taken from the larger sample who participated in the general survey. Sample attrition (as described previously) resulted in a final sample of 37 residents.

1.2.2. Informants
Rater 1 was the identified care co-ordinator as used in the main study. Rater 2 was another member of staff nominated by the home manager. Twenty four staff members completed rating one and 19 raters completed rating two.

1.3. Procedure
The inter-rater reliability study was completed simultaneously to the main survey. Home managers were provided with additional questionnaires on the random sample of residents. They were required to nominate a further member of staff, who knew the resident well, to complete these questionnaires with instructions that the two raters were not to liaise in questionnaire completion. All questionnaires were returned to the author via the postal service.
2. Statistical Analysis

Data were analysed using the same procedures as those employed by Moss et al. (1998).

Inter-rater agreement was examined in two ways. Firstly, on total scores, threshold scores and five alternative, *a priori*, scales identified by Moss et al. (1998) relating to depression, anxiety, psychosis, dementia and autism. Secondly on agreement of those individuals scoring over threshold levels.

It was not possible to investigate individual item agreement due to the low numbers of individuals gaining scores which could contribute to the analysis.

3. Results

3.1. Resident Sample

Fifteen residents were male (age range 27 - 77 years, mean = 47.67 years, SD = 15.75) and 22 were female (age range 32 - 87 years, mean = 57.36 years, SD = 16.42). Four (10.8%) had mild disabilities, 14 (37.8%) had moderate disabilities, 17 (45.9%) had severe disabilities and 2 (5.4%) were profoundly disabled.

3.2. Informant Sample

3.2.1. Age/Sex Distribution.

*Rater 1*

Eight (33.3%) of the informants were male and 16 (66.7%) were female. Three (12.5%) were in the age band 25 - 34, nine (37.5%) were between 35 - 44 years, 10 (41.7%) between 45 - 54 years and two (8.3%) were between 55 - 64 years.

*Rater 2*

Five (26.3%) of the informants were male and 14 (73.7%) were female. Four (21.1%) were in the age band 25 - 34, 7 (36.8%) were between 35 - 44 years and eight (42.1%) between 45 - 54 years.
3.2.2. Experience and qualifications.

*Rater 1*

Two of the informants (8.4%) were non-qualified members of staff, 12 (50%) were qualified nursing staff, four (16.7%) were deputy home managers and the remaining six informants (25%) were home managers. Staff had on average 20.91 years of experience (SD = 7.72) with a range of 9 years - 40 years. They had known the residents under examination for an average of 3.57 years (SD = 3.39, range 2 months - 10 years).

*Rater 2*

One of the informants (10.8%) was a non-qualified member of staff, six (31.6%) were qualified nursing staff, three (15.8%) were deputy home managers and the remaining 9 informants (47.4%) were home managers. Staff had on average 21.85 years of experience (SD = 6.54) with a range of 10.5 years - 33 years. They had known the residents under examination for an average of 3.47 years (SD = 3.39, range 2 months - 10 years).

3.2.3. Questionnaires completed

Each informant was responsible for a number of residents in their care and the number of questionnaires completed by these individuals ranged from one to four (mode = 1) for both raters 1 and 2.

3.3. Inter rater reliability

3.3.1. Correlations between raters on scale scores

Spearman rank correlations were calculated (See Tables 11 & 12). Correlations quoted by Moss et al. (1998) are provided in brackets for comparison.

<table>
<thead>
<tr>
<th>Threshold Scales</th>
<th>Spearman r</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective / Neurotic</td>
<td>0.59 (0.76)</td>
<td>0.000</td>
</tr>
<tr>
<td>Organic</td>
<td>0.15 (0.55)</td>
<td>0.368</td>
</tr>
<tr>
<td>Psychotic</td>
<td>0.31 (0.60)</td>
<td>0.064</td>
</tr>
<tr>
<td>Total Scores</td>
<td>0.53 (0.79)</td>
<td>0.001</td>
</tr>
</tbody>
</table>
Table 12: Correlations of scores on ‘a priori’ scales.

<table>
<thead>
<tr>
<th>‘A Priori’ Scales</th>
<th>Spearman r</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>0.24 (0.70)</td>
<td>0.145</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.31 (0.57)</td>
<td>0.061</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0.32 (0.60)</td>
<td>0.053</td>
</tr>
<tr>
<td>Dementia</td>
<td>0.27 (0.55)</td>
<td>0.106</td>
</tr>
<tr>
<td>Autism</td>
<td>0.16 (not reported)</td>
<td>0.346</td>
</tr>
</tbody>
</table>

As can be seen from the tables above, inter-rater agreement was only significant on the affective / neurotic disorders scale and the total scores and even then, the correlation coefficients were not high. Agreement between raters on all other scales, including the a priori scales (Table 12), was poor.

3.3.2. Further analysis

Given findings reported previously regarding the significant influence that the clients’ level of disability and ability to communicate had upon the raters ability to complete PAS-ADD checklists, it was considered possible that these factors may have exerted an influence on the inter-rater reliabilities observed. It was believed that by looking at sub-populations within the inter-rater reliability study, improved reliabilities might be found.

Data were divided on the basis on both level of disability (mild & moderate (n = 18) vs. severe & profound (n = 19)) and level of expressive communication (verbal communication (n = 23) vs. non-verbal communication (n = 14)). It was not possible to view data on the basis of level of receptive communication due to only two residents not understanding verbal communication.

3.2.2.1. Level of Disability

Spearman rank correlations were calculated (Tables 13 & 14).
Table 13: Correlations of scores of threshold scales and total scores

<table>
<thead>
<tr>
<th>Threshold Scales</th>
<th>Mild / Moderate Disabilities</th>
<th>Severe / Profound Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman r</td>
<td>p value</td>
</tr>
<tr>
<td>Affective / Neurotic</td>
<td>0.56</td>
<td>0.016</td>
</tr>
<tr>
<td>Organic</td>
<td>0.15</td>
<td>0.565</td>
</tr>
<tr>
<td>Psychotic</td>
<td>0.23</td>
<td>0.367</td>
</tr>
<tr>
<td>Total Scores</td>
<td>0.41</td>
<td>0.093</td>
</tr>
</tbody>
</table>

Table 14: Correlations of scores of threshold scales and total scores

<table>
<thead>
<tr>
<th>‘A Priori’ Scales</th>
<th>Mild / Moderate Disabilities</th>
<th>Severe / Profound Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman r</td>
<td>p value</td>
</tr>
<tr>
<td>Depression</td>
<td>0.19</td>
<td>0.462</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.25</td>
<td>0.325</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0.24</td>
<td>0.332</td>
</tr>
<tr>
<td>Dementia</td>
<td>0.29</td>
<td>0.246</td>
</tr>
<tr>
<td>Autism</td>
<td>0.27</td>
<td>0.287</td>
</tr>
</tbody>
</table>

Even when allowing for the influence of level of disability, inter-rater agreement on symptom presentation was poor.

3.2.2.2. Level of Expressive Communication

Again, Spearman rank correlations were calculated (Table 15 & 16).

Table 15: Correlations of scores of threshold scales and total scores

<table>
<thead>
<tr>
<th>Threshold Scales</th>
<th>Verbal Communication</th>
<th>Non-Verbal Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman r</td>
<td>p value</td>
</tr>
<tr>
<td>Affective / Neurotic</td>
<td>0.61</td>
<td>0.002</td>
</tr>
<tr>
<td>Organic</td>
<td>0.14</td>
<td>0.537</td>
</tr>
<tr>
<td>Psychotic</td>
<td>0.24</td>
<td>0.268</td>
</tr>
<tr>
<td>Total Scores</td>
<td>0.57</td>
<td>0.005</td>
</tr>
</tbody>
</table>
Table 16: Correlations of scores of threshold scales and total scores

<table>
<thead>
<tr>
<th>'A Priori' Scales</th>
<th>Verbal Communication</th>
<th>Non-Verbal Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Spearman r</td>
<td>p value</td>
</tr>
<tr>
<td>Depression</td>
<td>0.14</td>
<td>0.512</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.24</td>
<td>0.266</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0.28</td>
<td>0.199</td>
</tr>
<tr>
<td>Dementia</td>
<td>0.26</td>
<td>0.223</td>
</tr>
<tr>
<td>Autism</td>
<td>0.23</td>
<td>0.295</td>
</tr>
</tbody>
</table>

Again, with the exception of the affective / neurotic threshold scale and the total scores, inter-rater reliability remained poor even when the influence of level of communication was considered.

3.3.3. Percentage agreement on case identification

Agreement on individuals identified as above or below the threshold scores was reached on 28 cases (75.7%) roughly in agreement with the 79% figure quoted by Moss et al. (1998) (See Table 17).

Table 17: Percentage inter-rater agreement on case identification

<table>
<thead>
<tr>
<th>Rater 2</th>
<th>No threshold crossed</th>
<th>Threshold crossed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rater 1</td>
<td>23 (62.2%)</td>
<td>1 (2.7%)</td>
</tr>
<tr>
<td></td>
<td>8 (21.6%)</td>
<td>5 (13.5%)</td>
</tr>
</tbody>
</table>

This agreement tended to reflect agreement on non-cases. As can be seen disagreement occurred on nine of the possible 14 cases identified by at least one rater.

When correcting for expected levels of agreement using Cohen's kappa however, a value of $k = 0.392$ was found. Bakeman and Gottman (1989) suggest that values of above 0.7 would suggest reasonable inter-rater agreement. The value of 0.392 did not reach this criterion, further questioning the inter-rater reliability of the checklist.
B) TEST RE-TEST RELIABILITY

The test re-test reliability of the PAS-ADD checklist was assessed using a subsection of participants and informants used in the large scale survey.

1. Method
1.1. Measures Used
The PAS-ADD checklist was used, and details of the informants were gathered from the care co-ordinator information section of the utility questionnaire (also described previously).

1.2. Sample
1.2.1. Residents
The sample used in the test re-test reliability study were a randomly selected subsection of 50 residents used in the general survey, some of whom had already been selected for the inter-rater reliability study. Residents were from 16 homes within the institution.

1.2.2. Informants
Again informants were qualified members of staff responsible for the care of the resident. Twenty staff members completed checklists.

1.3. Procedure
The test re-test reliability study was completed at the same time as the main survey. Initial forms were distributed with the main survey at which time no mention was made regarding the need to fill in the second checklist. On receipt of the initial forms, further appointments were made with the informant for three weeks following initial completion of the checklist. This time frame was necessary to ensure that there was an overlap in time of assessment as the form only relates to behaviours exhibited within a four week period. The author then attended appointments with the informants for completion of the second form to ensure all sections were completed. Despite being present during completion, the author did not advise or comment on completion of the checklists.
2. Statistical Analysis

Data were analysed using the same procedures as those employed by Moss et al. (1998).

Agreement was examined in two ways. Firstly, on total scores, threshold scores and the five alternative, *a priori*, scales. Secondly, on agreement of those individuals scoring over threshold levels.

It was not possible to investigate individual item agreement due to the low numbers of individuals gaining scores which could contribute to the analysis.

3. Results

3.1. The Resident Sample

Twenty three residents were male (age range 22 - 88 years, mean = 51.57 years, SD = 14.26) and 27 were female (age range 27 - 93 years, mean = 57.33 years, SD = 17.35). Fifteen (30%) had mild disabilities, 19 (38%) had moderate disabilities, 14 (28%) had severe disabilities and 2 (4%) were profoundly disabled.

3.2. The Informant Sample

3.2.1. Age/Sex Distribution.

Eight (40%) of the informants were male and 12 (60%) were female. Four (20%) were in the age band 25 - 34, eight (40%) were between 35 - 44 years and eight (40%) between 45 - 54 years.

3.2.2. Experience and qualifications.

One informant (5%) was a non-qualified member of staff, 12 (60%) were qualified nursing staff, one (5%) was a deputy home manager and six (30%) were home managers. Staff had on average 17.2 years of experience (SD = 7.61) with a range of 4 years - 30 years. They had known the residents under examination for an average of 3.38 years (SD = 2.90, range 6 months - 10 years).
3.2.3. Questionnaires completed
The number of clients reported on by informants ranged from one to six (mode = 2).

3.3. Test re-test reliability
3.3.1. Correlations between ratings over time on scale scores
Spearman rank correlations were calculated (See Table 18 & 19).

Table 18: Correlations of scores of threshold scales and total scores

<table>
<thead>
<tr>
<th>Threshold Scales</th>
<th>Spearman r</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective / Neurotic</td>
<td>0.59</td>
<td>0.000</td>
</tr>
<tr>
<td>Organic</td>
<td>0.60</td>
<td>0.000</td>
</tr>
<tr>
<td>Psychotic</td>
<td>0.71</td>
<td>0.000</td>
</tr>
<tr>
<td>Total Scores</td>
<td>0.53</td>
<td>0.000</td>
</tr>
</tbody>
</table>

Table 19: Correlations of scores on ‘a priori’ scales.

<table>
<thead>
<tr>
<th>‘A Priori’ Scales</th>
<th>Spearman r</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>0.61</td>
<td>0.000</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.50</td>
<td>0.000</td>
</tr>
<tr>
<td>Psychosis</td>
<td>0.55</td>
<td>0.000</td>
</tr>
<tr>
<td>Dementia</td>
<td>0.58</td>
<td>0.000</td>
</tr>
<tr>
<td>Autism</td>
<td>0.15</td>
<td>0.29</td>
</tr>
</tbody>
</table>

Test re-test reliability was good with significant correlations being observed for all scores with the exception of the autism ‘a priori’ scale.

3.3.2. Percentage agreement on case identification over time
General agreement on whether individuals were isolated on one or more threshold scales was reached on 43 cases (86%) (See Table 20).

Table 20: Percentage agreement on case identification over time

<table>
<thead>
<tr>
<th>Time</th>
<th>No threshold crossed</th>
<th>Threshold crossed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1</td>
<td>No threshold crossed</td>
<td>35 (70%)</td>
</tr>
<tr>
<td></td>
<td>Threshold crossed</td>
<td>3 (6%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 (8%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>8 (16%)</td>
</tr>
</tbody>
</table>
Again, much of this reflected consistency on the identification of non cases over time, with disagreement on seven of the possible 15 identified cases.

When correcting for expected levels of agreement using Cohen’s kappa, a value of $k = 0.605$ was found. This again, did not quite reach the 0.7 level suggested by Bakeman and Gottman (1989) as being necessary to indicate reasonable agreement between ratings.
C) VALIDITY

1. Method

1.1. Measures used.
As previously, all residents included in the validity study were assessed using the PAS-ADD checklist.

1.2. Sample

1.2.1. Residents
Those included in the validity study were 32 residents from 14 homes who were already known to be in receipt of a psychiatric diagnosis.

1.2.2. Informants
Again informants were qualified members of staff responsible for the care of the resident. Twenty two staff members completed checklists.

1.3. Procedure
Raters were asked for information on known psychiatric diagnosis of their residents. Those isolated as having such diagnoses were included in the validity tests. Known diagnoses were then checked against threshold scores attained on the PAS-ADD checklist.

2. Statistical analysis
Data were not subjected to rigorous analysis due to the small number of cases identified as experiencing mental health difficulties in the sample. The percentage of cases identified was viewed.

3. Results

3.1. Resident Sample
Nineteen residents were male (age range 29 - 87 years, mean = 52.89 years, SD = 17.74) and 13 were female (age range 36 - 95 years, mean = 54.46 years, SD = 17.48). Eight (25%) had mild disabilities, nine (28.1%) had moderate disabilities, 15 (46.9%) had severe disabilities, none were profoundly disabled.
3.1.1. Diagnosed Psychiatric Disorders

All residents had psychiatric diagnoses with most residents suffering from either depressive disorders (14 residents, 43.8%) or psychotic disorders (14 residents, 43.8%). Further details can be seen in Table 21. Diagnostic data were missing on one resident.

<table>
<thead>
<tr>
<th>Psychiatric Diagnosis</th>
<th>Number of residents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>1 (3.1%)</td>
</tr>
<tr>
<td>Psychosis</td>
<td>2 (6.3%)</td>
</tr>
<tr>
<td>Mania</td>
<td>1 (3.1%)</td>
</tr>
<tr>
<td>Manic depression</td>
<td>4 (12.5%)</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>12 (37.5%)</td>
</tr>
<tr>
<td>Depression</td>
<td>10 (31.3%)</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>1 (3.1%)</td>
</tr>
</tbody>
</table>

3.1.2. Medication

Only one resident was not receiving medication. Twenty four (75%) received anti-psychotic medication, five (15.6%) were on anti-depressants, 12 (37.5%) were on anti-convulsants and four (12.5%) were receiving other medication including sedatives, contraception, laxatives and vitamins. Data were missing on the medication received by three of the residents.

3.2. Informant Sample

3.2.1. Age/Sex Distribution

Eight (36.4%) of the informants were male and 14 (63.6%) were female. Four (18.8%) were in the age band 25 - 34, 10 (45.5%) were between 35 - 44 years, seven (31.8%) were between 45 - 54 years and one (4.5%) was between 55 - 64 years.

3.2.2. Experience and qualifications

Twelve raters (54.6%) were qualified nursing staff, two (9%) were deputy home managers and eight (36.36%) were home managers. Staff had on average 18.08 years of experience (SD = 7.65) with a range of 4 years - 30 years. They had known
the residents under examination for an average of 4.7 years (SD = 3.7, range 5 months - 13 years).

### 3.2.3. Questionnaires completed

Each informant completed between one and three questionnaires (mode = 1).

### 3.3. Validity

#### 3.3.1. Cases identified

Four individuals (12.5%) crossed threshold scores on the affective neurotic scale, two on the organic disorders scale (6.25%) and seven (21.88%) on the psychotic disorders scale. Some individuals however exceeded threshold scores on more than one threshold scale and cases identification therefore accounted for only eight (25%) of those individuals known to be experiencing psychiatric disorder. There was however a reasonable relationship between the particular threshold scale exceeded and known diagnosis. Information regarding this can be seen in Table 22.

<table>
<thead>
<tr>
<th>Subject Number</th>
<th>Threshold scale exceeded</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>154</td>
<td>Psychotic</td>
<td>Psychosis</td>
</tr>
<tr>
<td>155</td>
<td>Psychotic</td>
<td>Psychosis</td>
</tr>
<tr>
<td>157</td>
<td>Psychotic</td>
<td>Depression</td>
</tr>
<tr>
<td>195</td>
<td>Psychotic</td>
<td>Not specified</td>
</tr>
<tr>
<td>217</td>
<td>Affective / neurotic</td>
<td>Organic</td>
</tr>
<tr>
<td></td>
<td>Organic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychotic</td>
<td></td>
</tr>
<tr>
<td>219</td>
<td>Affective / neurotic</td>
<td>Psychosis</td>
</tr>
<tr>
<td></td>
<td>Psychotic</td>
<td></td>
</tr>
<tr>
<td>225</td>
<td>Affective / neurotic</td>
<td>Affective / neurotic</td>
</tr>
<tr>
<td></td>
<td>Organic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Psychotic</td>
<td></td>
</tr>
<tr>
<td>226</td>
<td>Affective / neurotic</td>
<td>Affective / neurotic</td>
</tr>
</tbody>
</table>

75% of those clients with known psychiatric diagnosis were not identified by the checklist.
D) FACTOR STRUCTURE

The factor analysis replicated that of Moss et al. (1998) on the PAS-ADD checklist.

1. Method

1.1. Measures Used

The PAS-ADD checklist. Details of the informants and raters were gathered from the utility questionnaire.

1.2. Sample

1.2.1. Residents

The sample used in this analysis consisted of the complete sample of 226 individuals from the current research alongside data collected on 134 residents reported in previous research.

1.2.2. Informants

Informants were members of staff responsible for the care of the resident. Eighty five informants completed questionnaires.

1.3. Procedure

Data were collected as detailed in previously. Items were scored dichotomously on the basis of presence or absence of symptoms.

2. Statistical Analysis

The procedure of factor analysis used by Moss et al. (1998) i.e. extraction of factors using Eigen values greater than one and Quartimax rotation was replicated. The limitations of this analysis have been discussed previously and therefore data were also subjected to a more rigorous approach. Principle components analysis was conducted with factor extraction using parallel analysis. Data were rotated obliquely using oblimin.

Factors extracted and the threshold scales used to highlight mental health difficulties were analysed for internal consistency using Cronbach’s alpha.
Questions 51 (change in weight) and 69 (any other behavioural change) were omitted from this part of the analysis as they did not contribute to the final scores attained and were used for information purposes only.

3. Results

3.1. Resident Sample
Two hundred residents were male (age range 22 - 88, mean = 50.23, SD = 11.76) and 160 were female (age range 26 - 95, mean = 54.52, SD = 15.45). Forty residents (11.1%) had mild disabilities, 86 (23.9%) had moderate disabilities, 193 (53.6%) had severe disabilities and 40 (11.1%) had profound disabilities. Data were missing on one resident's level of ability.

3.2. Characteristics of Informant Sample
3.2.1. Age/Sex Distribution.
Thirty one (36.5%) of the informants were male and 54 (63.5%) were female. Two (2.4%) were under 25 years, 13 (15.3%) were in the age band 25 - 34, 32 (37.7%) were between 35 - 44 years, 33 (38.8%) between 45 - 54 years and three (3.5%) were over 55 years. Two informants did not provide their age.

3.2.2. Experience and qualifications.
All but nine (10.6%) of the informants were qualified nursing staff and had known the residents for between two months and 31 years (mean = 3.6 years, SD = 3.6 years).

3.2.3. Questionnaires completed
Informants completed questionnaires for between one and 16 residents (mode = 1).

3.3. Factor structure
3.3.1. Replication using Quartimax rotation
Principle components analysis using Eigen values greater than one isolated 8 factors with eigen values between 1.01 - 6.23. These accounted for 64.1% of the variance.
The pattern matrix can be seen in Table 23. If items were selected on the basis of loadings greater than 0.5 (as used by Moss et al., 1998), simple structure was almost achieved with the exception of questions 65 (strange experiences) which loaded on factors I and VII. However, if items were extracted with loadings greater than 0.32, the items within factors became less clear with seven questions loading on more than one factor.
Table 23: Pattern matrix - quartimax rotation - 8 factors

<table>
<thead>
<tr>
<th>Question Number and Content</th>
<th>Factor I Organic / Psychotic / Autistic</th>
<th>Factor II Withdrawal</th>
<th>Factor III Sleep Disorder</th>
<th>Factor IV Anxiety</th>
<th>Factor V Depression</th>
<th>Factor VI Unspecified</th>
<th>Factor VII Psychosis</th>
<th>Factor VIII Invalid Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>64 - more forgetful, confused</td>
<td>*0.809</td>
<td>0.201</td>
<td>0.100</td>
<td>-0.065</td>
<td>-0.136</td>
<td>0.016</td>
<td>-0.026</td>
<td>0.093</td>
</tr>
<tr>
<td>54 - suspicious, untrusting</td>
<td>*0.798</td>
<td>-0.003</td>
<td>-0.009</td>
<td>0.048</td>
<td>-0.016</td>
<td>0.026</td>
<td>0.162</td>
<td>0.092</td>
</tr>
<tr>
<td>46 - repeated actions, checking</td>
<td>*0.771</td>
<td>-0.074</td>
<td>0.048</td>
<td>0.029</td>
<td>-0.020</td>
<td>0.200</td>
<td>0.288</td>
<td>-0.113</td>
</tr>
<tr>
<td>53 - loss of confidence with people</td>
<td>*0.762</td>
<td>-0.002</td>
<td>-0.094</td>
<td>0.144</td>
<td>0.096</td>
<td>-0.103</td>
<td>0.096</td>
<td>-0.153</td>
</tr>
<tr>
<td>48 - attempts, talks about suicide</td>
<td>*0.755</td>
<td>-0.009</td>
<td>-0.216</td>
<td>0.031</td>
<td>0.130</td>
<td>-0.120</td>
<td>-0.140</td>
<td>-0.033</td>
</tr>
<tr>
<td>63 - decreased self care skills</td>
<td>*0.721</td>
<td>-0.057</td>
<td>0.106</td>
<td>-0.068</td>
<td>-0.073</td>
<td>-0.037</td>
<td>0.175</td>
<td>0.121</td>
</tr>
<tr>
<td>68 - odd use of language</td>
<td>*0.716</td>
<td>-0.032</td>
<td>0.054</td>
<td>0.058</td>
<td>0.010</td>
<td>0.014</td>
<td>-0.145</td>
<td>-0.214</td>
</tr>
<tr>
<td>66 - strange beliefs</td>
<td>*0.714</td>
<td>-0.094</td>
<td>0.151</td>
<td>-0.117</td>
<td>0.042</td>
<td>0.034</td>
<td>-0.439</td>
<td>0.102</td>
</tr>
<tr>
<td>56 - loss of self-esteem</td>
<td>*0.629</td>
<td>0.155</td>
<td>0.059</td>
<td>-0.074</td>
<td>0.140</td>
<td>0.128</td>
<td>-0.098</td>
<td>0.212</td>
</tr>
<tr>
<td>65 - strange experiences</td>
<td>*0.602</td>
<td>-0.071</td>
<td>0.185</td>
<td>-0.111</td>
<td>0.031</td>
<td>0.085</td>
<td>*0.561</td>
<td>0.083</td>
</tr>
<tr>
<td>60 - reduced concentration</td>
<td>*0.517</td>
<td>0.096</td>
<td>0.286</td>
<td>0.054</td>
<td>-0.270</td>
<td>0.341</td>
<td>0.001</td>
<td>-0.178</td>
</tr>
<tr>
<td>41 - loss of energy, tiredness</td>
<td>0.040</td>
<td>*0.856</td>
<td>0.168</td>
<td>-0.068</td>
<td>0.121</td>
<td>-0.077</td>
<td>0.142</td>
<td>-0.035</td>
</tr>
<tr>
<td>42 - loss of interest and enjoyment</td>
<td>0.011</td>
<td>*0.847</td>
<td>0.178</td>
<td>0.223</td>
<td>0.095</td>
<td>-0.039</td>
<td>0.088</td>
<td>-0.015</td>
</tr>
<tr>
<td>55 - avoids social contact</td>
<td>0.041</td>
<td>*0.700</td>
<td>-0.054</td>
<td>0.107</td>
<td>0.005</td>
<td>0.192</td>
<td>-0.198</td>
<td>0.077</td>
</tr>
<tr>
<td>57 - delay falling asleep</td>
<td>0.077</td>
<td>0.171</td>
<td>*0.761</td>
<td>0.080</td>
<td>0.091</td>
<td>-0.015</td>
<td>0.055</td>
<td>0.092</td>
</tr>
<tr>
<td>58 - waking too early</td>
<td>0.066</td>
<td>0.017</td>
<td>*0.692</td>
<td>-0.038</td>
<td>0.466</td>
<td>0.031</td>
<td>-0.066</td>
<td>0.006</td>
</tr>
<tr>
<td>59 - broken sleep</td>
<td>0.187</td>
<td>0.007</td>
<td>*0.673</td>
<td>0.066</td>
<td>-0.074</td>
<td>-0.039</td>
<td>-0.014</td>
<td>-0.078</td>
</tr>
<tr>
<td>62 - irritable, bad tempered</td>
<td>-0.007</td>
<td>0.195</td>
<td>0.434</td>
<td>0.399</td>
<td>0.247</td>
<td>0.131</td>
<td>-0.034</td>
<td>-0.037</td>
</tr>
<tr>
<td>45 - non-specific fears</td>
<td>0.035</td>
<td>0.070</td>
<td>0.138</td>
<td>*0.849</td>
<td>0.089</td>
<td>-0.069</td>
<td>0.075</td>
<td>0.111</td>
</tr>
<tr>
<td>44 - phobias</td>
<td>0.019</td>
<td>0.089</td>
<td>0.014</td>
<td>*0.820</td>
<td>0.068</td>
<td>0.087</td>
<td>0.020</td>
<td>0.128</td>
</tr>
<tr>
<td>43 - sad or down</td>
<td>0.011</td>
<td>0.062</td>
<td>0.108</td>
<td>0.106</td>
<td>*0.731</td>
<td>0.131</td>
<td>-0.065</td>
<td>0.042</td>
</tr>
<tr>
<td>49 - loss of appetite</td>
<td>0.088</td>
<td>0.122</td>
<td>0.107</td>
<td>0.281</td>
<td>*0.526</td>
<td>-0.121</td>
<td>0.280</td>
<td>0.081</td>
</tr>
<tr>
<td>47 - too happy, high</td>
<td>0.020</td>
<td>0.056</td>
<td>0.052</td>
<td>*0.403</td>
<td>*0.503</td>
<td>0.028</td>
<td>-0.080</td>
<td>-0.222</td>
</tr>
<tr>
<td>50 - increased appetite</td>
<td>0.033</td>
<td>0.000</td>
<td>-0.129</td>
<td>-0.051</td>
<td>0.083</td>
<td>0.724</td>
<td>0.054</td>
<td>0.038</td>
</tr>
<tr>
<td>67 - odd gestures, mannerisms</td>
<td>0.232</td>
<td>0.063</td>
<td>0.156</td>
<td>0.116</td>
<td>-0.015</td>
<td>0.692</td>
<td>-0.039</td>
<td>-0.033</td>
</tr>
<tr>
<td>61 - restless, pacing</td>
<td>0.490</td>
<td>-0.033</td>
<td>0.101</td>
<td>0.035</td>
<td>0.136</td>
<td>0.160</td>
<td>*0.556</td>
<td>0.093</td>
</tr>
<tr>
<td>52 - easily startled</td>
<td>0.069</td>
<td>0.028</td>
<td>0.011</td>
<td>0.202</td>
<td>0.023</td>
<td>-0.001</td>
<td>0.004</td>
<td>0.858</td>
</tr>
</tbody>
</table>

* Those items extracted using loadings of 0.5 or greater as used by Moss et al (1998)
Whilst eight factors were calculated from the data using the Moss et al. procedure, they bear little resemblance to those found in the original paper. In addition, the largest factor, Factor 1, contained a wide variety of symptoms which could be attributable to a number of differing psychiatric diagnoses. Factor VI made little clinical sense and the inclusion of only one item within Factor VII resulted in it being invalid.

3.3.2. Analysis using Oblique rotation

Following replication of the procedure utilised by Moss et al. (1998), data were subjected to a further principle components analysis. Factors were extracted using the parallel analysis technique (see Appendix VI for eigen values from random matrix) which indicated that it was necessary to view the data on the basis of five underlying factors. Data were rotated using oblimin and items with variables loading greater than 0.32 were isolated.

The 5 factors isolated accounted for 52.0% of the variance.

The pattern matrix can be seen in Table 24. As can be seen, again simple structure was almost achieved with only two items loading on more than one factor.
Table 24: Pattern matrix - oblimin rotation - 5 factors

<table>
<thead>
<tr>
<th>Question Number and Content</th>
<th>Factor I Organic / Psychotic / Autistic</th>
<th>Factor II Anxiety</th>
<th>Factor III Withdrawal</th>
<th>Factor IV Depression / Sleep Disorder</th>
<th>Factor V Non-Specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>54 - suspicious, untrusting</td>
<td>0.813</td>
<td>0.089</td>
<td>-0.012</td>
<td>0.090</td>
<td>-0.001</td>
</tr>
<tr>
<td>64 - more forgetful, confused</td>
<td>0.803</td>
<td>-0.144</td>
<td>-0.221</td>
<td>0.003</td>
<td>0.038</td>
</tr>
<tr>
<td>48 - attempts, talks about suicide</td>
<td>0.791</td>
<td>0.041</td>
<td>0.028</td>
<td>0.148</td>
<td>-0.141</td>
</tr>
<tr>
<td>53 - loss of confidence with people</td>
<td>0.779</td>
<td>0.158</td>
<td>0.007</td>
<td>0.109</td>
<td>-0.112</td>
</tr>
<tr>
<td>46 - repeated actions, checking</td>
<td>0.753</td>
<td>0.082</td>
<td>0.052</td>
<td>0.041</td>
<td>0.161</td>
</tr>
<tr>
<td>63 - decreased self care skills</td>
<td>0.739</td>
<td>-0.040</td>
<td>0.030</td>
<td>-0.009</td>
<td>-0.565</td>
</tr>
<tr>
<td>68 - odd use of language</td>
<td>0.689</td>
<td>-0.029</td>
<td>0.050</td>
<td>-0.070</td>
<td>0.064</td>
</tr>
<tr>
<td>66 - strange beliefs</td>
<td>0.680</td>
<td>-0.206</td>
<td>0.131</td>
<td>-0.250</td>
<td>0.067</td>
</tr>
<tr>
<td>56 - loss of self-esteem</td>
<td>0.612</td>
<td>-0.039</td>
<td>-0.144</td>
<td>-0.093</td>
<td>0.049</td>
</tr>
<tr>
<td>65 - strange experiences</td>
<td>0.547</td>
<td>-0.240</td>
<td>0.120</td>
<td>-0.308</td>
<td>0.143</td>
</tr>
<tr>
<td>61 - restless, pacing</td>
<td>0.494</td>
<td>0.229</td>
<td>-0.001</td>
<td>-0.000</td>
<td>0.016</td>
</tr>
<tr>
<td>45 - non-specific fears</td>
<td>-0.006</td>
<td>0.808</td>
<td>-0.016</td>
<td>-0.035</td>
<td>0.057</td>
</tr>
<tr>
<td>44 - phobias</td>
<td>-0.028</td>
<td>0.790</td>
<td>-0.033</td>
<td>0.070</td>
<td>0.200</td>
</tr>
<tr>
<td>47 - too happy, high</td>
<td>-0.032</td>
<td>0.460</td>
<td>0.020</td>
<td>-0.225</td>
<td>-0.029</td>
</tr>
<tr>
<td>52 - easily startled</td>
<td>0.101</td>
<td>0.330</td>
<td>-0.018</td>
<td>0.056</td>
<td>-0.045</td>
</tr>
<tr>
<td>41 - loss of energy, tiredness</td>
<td>0.024</td>
<td>-0.131</td>
<td>-0.886</td>
<td>-0.083</td>
<td>-0.164</td>
</tr>
<tr>
<td>42 - loss of interest and enjoyment</td>
<td>-0.027</td>
<td>0.118</td>
<td>-0.854</td>
<td>-0.063</td>
<td>-0.055</td>
</tr>
<tr>
<td>55 - avoids social contact</td>
<td>-0.004</td>
<td>-0.008</td>
<td>-0.692</td>
<td>0.090</td>
<td>0.191</td>
</tr>
<tr>
<td>58 - waking too early</td>
<td>-0.032</td>
<td>0.007</td>
<td>0.034</td>
<td>-0.837</td>
<td>-0.077</td>
</tr>
<tr>
<td>57 - delay falling asleep</td>
<td>-0.017</td>
<td>0.001</td>
<td>-0.159</td>
<td>-0.691</td>
<td>0.003</td>
</tr>
<tr>
<td>59 - broken sleep</td>
<td>0.010</td>
<td>-0.081</td>
<td>-0.001</td>
<td>-0.585</td>
<td>0.058</td>
</tr>
<tr>
<td>62 - irritable, bad tempered</td>
<td>-0.109</td>
<td>0.352</td>
<td>-0.143</td>
<td>-0.448</td>
<td>0.149</td>
</tr>
<tr>
<td>43 - sad or down</td>
<td>-0.035</td>
<td>0.310</td>
<td>0.135</td>
<td>-0.284</td>
<td>-0.089</td>
</tr>
<tr>
<td>67 - odd gestures, mannerisms</td>
<td>0.107</td>
<td>0.102</td>
<td>-0.042</td>
<td>-0.141</td>
<td>0.680</td>
</tr>
<tr>
<td>50 - increased appetite</td>
<td>-0.043</td>
<td>0.070</td>
<td>0.008</td>
<td>0.078</td>
<td>0.060</td>
</tr>
<tr>
<td>60 - reduced concentration</td>
<td>0.421</td>
<td>-0.011</td>
<td>-0.103</td>
<td>-0.131</td>
<td>0.462</td>
</tr>
<tr>
<td>49 - loss of appetite</td>
<td>0.104</td>
<td>0.024</td>
<td>-0.106</td>
<td>-0.214</td>
<td>-0.330</td>
</tr>
</tbody>
</table>
Again, Factor I contained the same items as seen in the previous analysis which relate to a number of psychiatric diagnoses. The inclusion of data within five factors however, resulted in more discrete factor clusters. Factors II, III and IV appeared to relate to distinct clinical entities i.e. anxiety, psychological withdrawal and emotional/physical expressions of depression respectively. Again however, one factor (V) contained items that did not make clinical sense.

3.3.3. Internal consistency of factors

Cronbach’s alpha analysis was performed on the factors produced by both quartimax and oblimin rotation techniques to assess their internal consistency (Tables 25 & 26).

Table 25: Internal consistency of the 8 factor solution

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number of items</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>I - Organic / Psychotic / Autistic</td>
<td>12</td>
<td>0.90</td>
</tr>
<tr>
<td>II - Withdrawal</td>
<td>3</td>
<td>0.74</td>
</tr>
<tr>
<td>III - Sleep Disorder</td>
<td>4</td>
<td>0.63</td>
</tr>
<tr>
<td>IV - Anxiety</td>
<td>4</td>
<td>0.60</td>
</tr>
<tr>
<td>V - Depression</td>
<td>4</td>
<td>0.54</td>
</tr>
<tr>
<td>VI - Unspecified</td>
<td>3</td>
<td>0.45</td>
</tr>
<tr>
<td>VII - Psychosis</td>
<td>3</td>
<td>0.68</td>
</tr>
<tr>
<td>VIII - Invalid</td>
<td>1</td>
<td>n/a</td>
</tr>
</tbody>
</table>

Table 26: Internal consistency of 5 factor solution

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number of items</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>I - Organic / Psychotic / Autistic</td>
<td>12</td>
<td>0.90</td>
</tr>
<tr>
<td>II - Anxiety</td>
<td>5</td>
<td>0.57</td>
</tr>
<tr>
<td>III - Withdrawal</td>
<td>3</td>
<td>0.74</td>
</tr>
<tr>
<td>IV - Depression / Sleep Disorder</td>
<td>5</td>
<td>0.62</td>
</tr>
<tr>
<td>V - Non-specific</td>
<td>4</td>
<td>0.39</td>
</tr>
</tbody>
</table>

As can be seen, only five of the eight initial factors have acceptable internal consistency of 0.60 or above and only three of the five factor solution have good internal consistency.
3.3.4. **Internal consistency of scales**

Finally, Cronbach’s alpha analysis was completed on the totals for the three threshold scales and total score attained from the checklist (Table 27). The resulting data were compared with data provided by Moss et al. (1998) noted in brackets.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number of items</th>
<th>Cronbach’s Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective / Neurotic</td>
<td>21 (20)*</td>
<td>0.77 (0.84)</td>
</tr>
<tr>
<td>Organic</td>
<td>6 (6)</td>
<td>0.68 (0.63)</td>
</tr>
<tr>
<td>Psychotic</td>
<td>4 (4)</td>
<td>0.72 (0.51)</td>
</tr>
<tr>
<td><strong>Total items</strong></td>
<td><strong>27 (27)</strong></td>
<td><strong>0.86 (0.87)</strong></td>
</tr>
</tbody>
</table>

* It is unclear from the Moss et al. (1998) paper why one item was omitted or which item was omitted

The internal consistencies of all scales are acceptable and above the 0.60 level. Data compares favourably with that quoted by Moss et al.
VI. DISCUSSION

Study 2 had a number of aims and objectives. Initially, a replication and extension of Study 1 (year 2) was undertaken. That study had shown that the PAS-ADD checklist was difficult to complete for individuals with profound learning disabilities and for people with both expressive and receptive communication difficulties. Study 2, was therefore extended to investigate whether the checklist was more useful with those individuals with learning disabilities in the mild and moderate range.

The PAS-ADD checklist had undergone preliminary investigation regarding validity, reliability and factor analysis subsequent to Study 1 (Moss et al., 1998). Given the difficulties in applying the checklist identified in Study 1, and the criticism of the procedure, analysis and findings of Moss et al. (1998) (see pages 184 - 189), it was considered necessary to replicate and extend the Moss et al. study. Investigations were conducted into the test re-test reliability, inter-rater reliability, validity and factor structure of the checklist. The findings of this research are discussed below.

1. Study 2 (Part I): Replication and extension of Study 1 (Year 2)

1.1. Identified Cases

The PAS-ADD checklist identified 32 individuals as exhibiting indicators of psychiatric disorder. Twenty one were identified as experiencing single psychiatric disorders whilst 11 were considered to have multiple diagnoses. These figures related to 20%, 18.6%, 8.6% and 0% of those individuals with mild, moderate, severe and profound disabilities respectively. These figures, with the exception of the profound disability group, were in excess of those quoted by Borthwick-Duffy and Eyman (1994) who found rates of 16%, 9%, 5% and 3% respectively.

Initially, it is important to attend to the lack of case identification in the profound disability group. This group contained a minority of residents, six in total, and it is conceivable that they were not experiencing psychiatric disturbance. However, previous research by the author (Study 1) also failed to isolate cases from the 34 residents with profound disabilities at the same institution using the PAS-ADD checklist. While it is still possible that none of these individuals were experiencing
psychiatric disturbance, research indicates that one could expect to see psychiatric morbidity in at least 3% of this sub-group (i.e. 1 - 2 residents in the sample of 40 residents seen in Study 1 and Study 2 (part I)) (Borthwick-Duffy and Eyman, 1994). The failure to identify any such individuals in this study raises concerns regarding the suitability of the PAS-ADD checklist for people with this level of disability. It is considered likely that the lack of communication skills and cognitive ability in this group would lead to it being difficult for staff to comment accurately on their internal world thus leading to a lack of detail for case identification. The data on number of questions omitted reflects this view (discussed below). In Study 2 (part I), an average of 4.5 questions were omitted for the 6 residents with profound disabilities. Additionally, Study 1 found that more questions were omitted for individuals with profound disabilities. It is likely therefore, that the failure of the PAS-ADD checklist to identify mental health problems in people with profound disabilities reflects its insensitivity to symptom presentation in this subgroup as opposed to reflecting a lack of mental health problems.

The next question to be addressed is the increased prevalence seen in the population under investigation in comparison to that quoted by Borthwick-Duffy and Eyman (1994). A number of issues can be considered when reflecting on these results. First, it could be hypothesised that the population under consideration is significantly different to that presented by Borthwick-Duffy and Eyman thus resulting in the different prevalence rates observed. The Borthwick-Duffy and Eyman study, looked at a population of 78,603 individuals with a range of disabilities, receiving state services living in a range of settings from independent living to fully supported institutional care. The present study however, viewed only those individuals within one institution. It could be hypothesised that, given the political climate and the move towards community living, those individuals remaining in the institution would be those who were more difficult to place and therefore would be likely to present with the most complex needs resulting from the presence of psychiatric disturbance. This was not the case. The local situation resulted in few available community facilities for these individuals. Some of those assessed had been relocated to smaller homes, similar to those found in the community, but these were based within the
confines of the institution. Those living in these facilities were still considered residents of the institution despite their less complex needs. The process of relocating residents to smaller, community-based homes was just beginning and the residents assessed were therefore not those most difficult to place.

Second, it could be considered that the methodology and assessment tools employed related to the prevalence rates seen. Borthwick-Duffy and Eyman recorded details of dual diagnosis on individuals who had information on their files suggesting they had already received psychiatric diagnoses. They did not pay attention to issues of reliability or validity of diagnoses. As discussed in Study 1, Reiss (1990) identified that prevalence rates from client files increased following direct assessment, thus calling into question rates obtained from client files alone. It could be hypothesised therefore, that the increased rates obtained for those individuals within the mild to severe range of abilities more accurately reflected true rates of dual diagnosis.

1.2. Omitted Questions

As found in Study 1, the number of omitted questions increased as a function of specific client characteristics, in particular levels of disability and communication.

The number of omitted questions increased as the level of ability decreased to the extent that an average of 4.5 questions were omitted for the six individuals with profound disabilities (range 0 - 10). This will greatly affect the validity and reliability of the assessment for these individuals. Additionally, the number of omitted questions increased as a function of the client’s level of expressive communication with significantly fewer questions being omitted for those clients with good expressive communication than for any other group.

Additionally, more questions were omitted for clients with visual impairment. This could not be explained as an artefact of either the level of expressive communication or level of disability as the numbers of individuals with visual impairment were the same for all levels of communication and disabilities.
1.3. Informant Ratings

1.3.1. Utility

Results obtained on the relationship between client characteristics and measures of utility were less clear. Ratings of utility of the checklist were only significantly influenced by the degree of behavioural disturbance exhibited by the clients. However, closer examination of the data indicated that 20 (71.4%) of the 28 individuals exhibiting severe behavioural difficulties also experienced severe and profound learning disabilities. The relationship between ratings of utility and behavioural disturbance therefore may not solely reflect the role of behavioural disturbance, it may actually reflect a combined effect of severity of disability when accompanied by behavioural disturbance.

1.3.2. Ease of Use

As could be expected, the client’s level of expressive communication was significantly related to the informants ratings of how easy the checklist was to complete. No other client characteristics were related to these ratings.

Difficulties arose with analysis of both ratings of ease of use and utility due to the lack of independence in the data. It was necessary for care co-ordinators to complete questionnaires on a number of individuals in their care. Whilst questions regarding these issues were phrased in a way that required the informant to relate these ratings to the particular client under investigation, discussion with carers highlighted that most seemed to have very clear opinions of the utility and ease of use of the PAS-ADD checklist independent of the client under examination. This may have resulted in them giving global opinions of utility and ease of use. Given that some informants completed as many as 16 questionnaires, their opinions may have unduly influenced the results attained. As in Study 1, it is likely therefore, that the number of omitted questions and their relationship to client characteristics (discussed above) would be a more valid and reliable measure of checklist utility. It is more likely that the completion of the PAS-ADD checklist itself would have been directly related to the client and therefore less likely to be influenced by global views.

2.1. Inter-rater Reliability

Inter-rater reliability was conducted on 37 individuals. Raters with similar professional backgrounds and experience were used with the expectation that this would improve agreement between raters. The results did not uphold this view.

Inter-rater agreement was calculated on a number of scales. Initially, agreement on scores attained on threshold scales and the total score attained were analysed. Additionally, five *a priori* scales identified by Moss et al. (1998) were used. Results indicated correlations on threshold scales of 0.59, 0.15, 0.31 and 0.53 for the affective / neurotic scale, organic scale, psychotic scale and total scores respectively. Correlations for the *a priori* scales were similarly poor, 0.24, 0.31, 0.32, 0.27, 0.16 for the depression, anxiety, psychosis, dementia and autism scales respectively. These results were consistently below those found by Moss et al. (1998) with the only significant inter-rater agreement being found on the affective / neurotic scale and total scores. Even then, these correlations did not reach the required level of 0.6 generally considered indicative of good inter-rater reliability (Bakeman and Gottman, 1989).

Even when viewing inter-rater agreement on case identification, agreement was poor. Agreement on those individuals either above or below threshold scores on one or more scales was equivalent to that found by Moss et al. (75.7% in the present study against 78.8% observed in the original paper) but this still left disagreement on symptom presentation on nine of the individuals assessed (24.3%). Cohen's Kappa analysis, to correct for expected levels agreement, fell well below the level considered to indicate reasonable inter-rater reliability (Bakeman and Gottman, 1989).

The poor inter-rater reliability seen is surprising especially given the matching of informants for experience, level of qualification and knowledge of the resident. The results attained may have been influenced by the small sample size used. The difficulties identified with sample attrition left a data set of only 37 residents as opposed to 66 investigated by Moss et al. (1998). Despite this, the matching of informants should have enhanced findings. The low reliability found, suggests some
significant difficulties with the construction of the test. The lack of behavioural anchors may result in it being difficult to establish that both raters are viewing indicators of mental health problems as equally significant.

2.2. Test Re-Test Reliability

As no previous research had viewed the test re-test reliability of the PAS-ADD checklist, this part of the study was a major extension of the work of Moss and his colleagues. Again, as with the inter-rater reliability, reliability over time was measured on the three threshold scale scores, total scores and the five *a priori* scales. A time frame of three weeks was used to measure test re-test reliability as checklist scores are based on the assessment of experiences over a previous four week period.

The use of test re-test reliability with unstable conditions such as depression and anxiety is open to question. These conditions are prone to regular change and it is likely that poor test re-test reliability may not reflect poor psychometric properties of the assessment measure but may instead result from a change in mental health status. However, the PAS-ADD checklist relates to mood state over the previous 4 week period. The use of a test re-test period of three weeks resulted in an overlap thus increasing the likelihood of measuring a consistent set of symptoms. Additionally, this short time period could be expected to increase the test re-test reliability due to familiarity with the tool.

Reasonable test re-test reliability was attained. On threshold scales and total scores, rates ranged from 0.53 - 0.71, all in excess of 0.001 levels of probability. Levels on the ‘a priori’ scales identified by Moss et al. (1998) again reached significance levels in excess of 0.001, with the exception of the autism scale. Cohen’s Kappa analysis, to correct for expected levels agreement, again fell below the level considered to indicate reasonable test re-test reliability (Bakeman and Gottman, 1989).

When examining both the inter-rater and test re-test reliability of the PAS-ADD checklist, it is necessary to consider that reliability should exceed 0.9 to be used...
diagnostically. The kappa co-efficients seen in the present study suggest that there are significant limitations to the reliability of the checklist.

2.3. Validity

Criterion-related, concurrent validity of the PAS-ADD checklist was assessed against known psychiatric diagnosis. Thirty two residents with documented diagnoses were assessed using the checklist. Agreement between known diagnosis and threshold scores on the checklist were examined.

The validity of the PAS-ADD remained questionable following the current study with only 25% of those with known psychiatric diagnosis being identified by the assessment. However, this aspect of the present study was confounded by a number of significant methodological flaws which will be discussed in more detail below. These results should therefore should be viewed with caution.

Given the time constraints of the study, and the work pressure on psychiatric staff at the residential facility, it was not possible to gain up-to-date psychiatric assessments of the clients' levels of functioning. Information was not gained from carers regarding the recency of the psychiatric diagnosis or the date of the previous psychiatric input. Data were not provided regarding the severity of the psychiatric illness or its level of presentation at time of assessment. A number of these individuals therefore may not have been actively symptomatic at the time of assessment. Additionally, 31 of the 32 residents (96.9%) were in receipt of medication, 29 of whom (90.6%) were receiving psychotropic medication. It is likely that for many of these individuals, the provision of an appropriate medication regime resulted in them not actively displaying psychiatric symptoms at the time of assessment and thus not being identified from the PAS-ADD checklist. These flaws may reflect the poor validity seen.

However, Moss et al. (1998) discuss their findings with reference to the severity of symptoms being displayed at the time of assessment and poor validity is observed at the mild end of psychiatric disturbance. Their assessments using the PAS-ADD
checklist correctly identified 92% of those individuals with severe symptoms of psychiatric illness but this rate reduced to 56% when assessing those with mild psychiatric disturbance. It is likely that those with mild presentation of psychiatric symptoms are those who are most likely to be overlooked by psychiatric services, while those with more extreme disturbance would be identified by carers without the necessity to complete a checklist measure. It appears that the PAS-ADD checklist does not help with case identification for those with milder forms of psychiatric presentation even in the Moss et al. study. Given the lack of information available on the severity of current symptom presentation, it was not possible to replicate this aspect of the study.

Another factor that may be relevant to validity was identified in informal discussion with care staff. Staff were concerned that the checklist appeared insensitive to long standing psychiatric illness which may not have been previously identified. They highlighted that many questions in the checklist were requesting information on behavioural change over the past four week period. They considered that those clients with more long standing difficulties (i.e. those already in receipt of diagnoses) may not have changed their behaviour over the recent past and may therefore still not be identified by the checklist. Finally, care staff considered that the lack of assessment of the presence of self-injurious behaviour and other challenging behaviours may result in the lack of identification of mental health problems. Moss (1995) questions the role of challenging behaviour in the presentation of psychiatric illness and suggests the need to focus primarily on Axis I disorders (DSM-IV) in the checklist but care staff believed that this may have led to some individuals being overlooked. It is possible that these factors resulted in some more long-standing cases not being identified by the PAS-ADD checklist.

Additionally, it would have been useful to look at both the sensitivity\(^1\) (true positive rate) and specificity\(^2\) (true negative rate) of the PAS-ADD checklist. The sensitivity

\[ \text{Sensitivity} = \frac{\text{True positive}}{\text{True positive} + \text{False negative}} \]

\[ \text{Specificity} = \frac{\text{True negative}}{\text{False positive} + \text{True negative}} \]
of the measure relates to the proportion of subjects who would be confirmed as having a psychiatric diagnosis that was correctly identified by the checklist, whilst the specificity would relate to those individuals without psychiatric disturbance who were correctly screened as not experiencing symptoms. Unfortunately, the sample considered in the validity study did not contain a comparison group of individuals known to be free from psychiatric illness resulting in it not being possible to calculate these scores. Given the results attained, it could be considered that the poor validity seen may reflect the poor sensitivity of the checklist.

2.4. Factor Structure of the PAS-ADD Checklist.

The factor structure of the PAS-ADD checklist was investigated using 360 residents, combining data from both Study 1 and Study 2. Following results reported by Moss et al. (1998), it was considered that an eight factor structure may be isolated from the checklist data, although flaws in their statistical analyses and conclusions left this factor structure open to question. Initial analysis upheld an eight factor structure. However, the use of more appropriate statistical analysis using Oblimin rotation with parallel extraction of factors indicated that a five factor structure was more appropriate for the checklist. Three of the factors isolated related well to clinically relevant clusters, i.e. anxiety, withdrawal and depression / sleep disorder. The final two factors made little clinical sense, however, with one factor containing indicators of a range of psychiatric disorders (organic, psychotic and autistic) whilst the fifth factor contained questions relating to appetite, concentration and odd gestures.

The methodology employed in the factor analysis of the checklist was good. A large number of clients participated in this component of the study, and the methodology employed was statistically rigorous, resulting in it being possible to draw firm conclusions. Unfortunately, the results attained are not consistent with those found by Moss et al. (1998) and do not relate well to the constructs under assessment. The utility of a checklist measure with a factor structure unrelated to the scales used for assessment is suspect.
2.5. Internal consistency.

The internal consistency of the five factors isolated in Study 2 (part II) were measured and provided reasonable results with Cronbach’s alpha ranging from 0.57 - 0.90. The exception was the ‘non-specific’ category with an alpha of 0.39, which was expected given the lack of obvious connection between the questions. When viewing the three threshold scales and total scores however, internal consistency improved to a range of between 0.68 - 0.86 roughly in agreement with that found by Moss et al. (1998).

3. Conclusions

In their discussion of the results attained in their study, Moss et al. (1998) suggest that “There were no apparent inadequacies or inconsistencies which would lead [the authors] ... to believe that the instrument needs radical alteration.” Unfortunately the results of the current study do not uphold such conclusions.

The results of the current study raise questions regarding the reliability and validity of the PAS-ADD checklist. Whilst test re-test reliability is good, the inter-rater reliability and validity are poor. The checklist does not appear to have a factor structure that relates well to the constructs under assessment.

Despite these findings, it is necessary to view some of the results attained with caution due to small sample sizes and the particular difficulties encountered when assessing the validity of the measure.

The difficulties with relying on a measure without good psychometric properties, even for general screening purposes, are significant. Reliance on such tools can result in either the non-identification of possible psychiatric disturbance, or the incorrect referral of individuals who are not experiencing psychiatric illness to services. The non-identification of those with psychiatric illness has far reaching consequences. This could result in these individuals not being referred to specialist services and therefore not receiving appropriate input. The possible relocation of these individuals to community settings may be brought into question. They are likely to display behaviours that challenge care staff and therefore may lead to failure of community
provision. The reliance of care staff on such a screening tool may leave them less likely to rely on their own experience and understanding of the presentation of dual diagnosis and therefore less likely to refer cases. Additionally, the reduced validity of the tool for those with mild psychiatric disturbance is concerning. Those individuals with severe mental health problems are likely to be identified by care staff. If the checklist cannot add to the identification of cases with mild disturbance, it may not be adding to the referral rates in a real sense.

Additionally, the misidentification of cases will have significant impact on provision of services. This could result in referral to psychiatric services of well individuals, further overloading services and redirecting resources away from other individuals in need of assessment.

Finally, the reliance on screening tools based on standard diagnostic criteria continues to be brought into question. As discussed in previous work by the present author (see pages 113 - 119) prevalence rates of psychiatric illness are lowest in individuals with severe and profound disabilities, those same individuals who experience many risk factors for psychiatric disturbance. As discussed previously, it could be hypothesised that these low prevalence figures do not relate to a lack of psychiatric disturbance per se but instead reflect the insensitivity of standard diagnostic criteria to the presentation of psychiatric disturbance in these individuals. Even in general populations, diagnostic criteria fail to account for contextual information or the possible functional properties of unusual behaviours (Follette, 1996).

The presentation of mental health problems in people with severe and profound disabilities may be both qualitatively and quantitatively different to the general population and therefore continued reliance on diagnostic criteria may result in misdiagnosis (Sovner, 1986). Given the difficulties with diagnosis of individuals at the low end of the range of abilities, the reliance on standardised measures may always be insensitive to the needs of this subgroup of individuals. It may be more useful to take a more individualised approach to these individuals, looking at the presence of behavioural change and undertaking detailed functional analysis of their
behaviours in an attempt to gain a greater understanding of their inner world (Ruedrich and Menolascino, 1984)

4. Future Research

The development of tools specifically designed for the assessment of mental health problems in people with learning disabilities is in its infancy. The field of dual diagnosis is developing rapidly and the continued research interest in this field is certain. The PAS-ADD assessment tools developed by Moss and his colleagues is promising and the publication of such measures can only help to generate further interest in the field. However, as discussed in the introduction to this paper, the initial findings published by Moss et al. (1998) had a number of significant methodological problems that cast doubt on the validity, reliability and factor structure of the PAS-ADD checklist. The current study has failed to allay these concerns and therefore future research on the checklist is vital. It will be necessary to undertake reliability and validity assessments in studies with larger numbers of participants. Validity studies will have to be undertaken in conjunction with psychiatric services which are specialised in the diagnosis of psychiatric illness in people with learning disabilities to enable the provision of a “gold standard” against which the checklist can be validated. Research should also be undertaken to identify both the sensitivity and specificity of the checklist to establish its utility as a screening tool.

While the development of the PAS-ADD instruments is an appropriate step towards the assessment of mental health problems in people with learning disabilities, it is necessary to ensure the psychometric properties of such measures to ensure this population is being adequately served. It is particularly important for researchers to attend to those people at the severe end of the range of disabilities and ensure that the idiosyncratic nature of symptom presentation in these individuals is accounted for in the development of assessment measures.
REFERENCES


APPENDIX I
Ethics approval

EAST SURREY LOCAL RESEARCH ETHICS COMMITTEE

Santhams,
West Park Hospital,
Horton Lane,
Epsom, Surrey,
KT19 8PB.

SH/AJR
11 November, 1998

E. Crabtree,
3, Springfield Road,
Guildford, Surrey,
GU1 4DW.

Dear Ms. Crabtree,

RE: AN INVESTIGATION INTO THE UTILITY OF THE PAS-ADD MENTAL
HEALTH CHECKLIST AS A SCREENING TOOL FOR PEOPLE WITH
PROFOUND LEARNING & MULTIPLE DISABILITIES
REF: 82ECPA(103) - to be quoted on all future correspondence please

Thank you for your letter dated 25th September 1998 informing us that an extension of
the above project has been proposed.

After consulting with one of our Committee Members, it has been decided that you
may continue with your extension study, as with the original project, this also does not
require ethical approval.

Yours sincerely,

Selina Harris,
MANAGER - ESLREC
## Details of cases identified by the PAS-ADD checklist

| Subject Number | Age | Sex | Level of Disability | Diagnosed Disability | Psychiatric Diagnosis | Expressive Communication | Receptive Communication | Medication | ID* | Age | Sex | Experience (Yrs) | Qualifications |
|----------------|-----|-----|---------------------|----------------------|-----------------------|--------------------------|--------------------------|------------|-----|-----|---------------|----------------|
| 318            | 46  | M   | Severe              | None                 | Limited Verbal Skills | Good Understanding      | Anti psychotie           | Anti convulsant | R  | 45 - 54 | M   | 23            | SEN            |
| 323            | 51  | F   | Mild                | None                 | Good Verbal Skills    | Good Understanding      | Anti psychotie           |             | M  | 45 - 54 | M   | 27            | RNMH           |
| 347            | 43  | F   | Severe              | None                 | Body Language         | Simple Commands         | Anti psychotie           |             | W  | 35 - 44 | F   | 21            | SEN            |
| 364            | 27  | F   | Moderate            | Autism               | Signs / Symbols       | Simple Commands         | Anti psychotie           |             | O'N| 25 - 34 | M   | 8             | RNMH           |
| 365            | 51  | M   | Severe              | Autism               | Body Language         | Simple Commands         | Anti psychotie           | Anti convulsant | C  | 25 - 34 | F   | 5             | RNMH           |
| 524            | 45  | F   | Mild                | None                 | Depression            | Good Verbal Skills      | Good Understanding       | Anti psychotie | F  | 25 - 34 | F   | 10            | RNMH           |
| 558            | 56  | F   | Moderate            | None                 | Good Verbal Skills    | Good Understanding      | None                     |             | N-2| 45 - 54 | F   | 20            | RNMH           |
| 571            | 64  | F   | Moderate            | None                 | Good Verbal Skills    | Good Understanding      | None                     |             | Ha | 35 - 44 | F   | 15            | RNMH, SEN      |
| 131            | 95  | F   | Moderate            | Psychosis            | Good Verbal Skills    | Good Understanding      | None                     |             | L  | 25 - 34 | F   | 17            | SEN            |
| 159            | 50  | M   | Moderate            | Psychosis            | Good Verbal Skills    | Good Understanding      | Anti psychotie           | Anti convulsant | K  | 45 - 54 | M   | 20            | RNMH           |
| 304            | 33  | F   | Severe              | None                 | Good Verbal Skills    | Good Understanding      | Anti psychotie           | Anti convulsant | Lo | 35 - 44 | F   | 20            | SEN            |

* Carer identification code

**Legend:**
- **Green** - Affective disorders scale
- **Purple** - Psychotic disorders scale
- **Red** - Both Affective & Psychotic disorders scales
- **Blue** - Both Organic & Psychotic disorders scales
- **Light Yellow** - Affective / Neurotic and Organic Scales
- **Pink** - All three PAS-ADD scales
| Subject Number | Age | Sex | Level of Disability | Diagnosed Disability | Psychiatric Diagnosis | Expressive Communication | Receptive Communication | Medication | ID* | Age | Sex | Experience (Yrs) | Qualifications |
|----------------|-----|-----|---------------------|----------------------|----------------------|-------------------------|-------------------------|------------|-----|-----|----------------|----------------|
| 377            | 39  | M   | Severe              | Autism               | None                 | Limited Verbal Skills   | Simple Commands         | Anti psychotic | C   | 25 - 34 | F   | 5              | RNMH           |
| 391            | 44  | F   | Moderate            | None                 | None                 | Good Verbal Skills      | Good Understanding      | Anti convulsant | F   | 25 - 34 | F   | 10             | RNMH           |
| 408            | 71  | M   | Moderate            | None                 | None                 | Good Verbal Skills      | Good Understanding      | Anti psychotic | Mi  | 35 - 44 | F   | 22             | RNMH           |
| 412            | 72  | M   | Moderate            | None                 | None                 | Good Verbal Skills      | Good Understanding      | Anti psychotic | Mi  | 35 - 44 | F   | 22             | RNMH           |
| 424            | 88  | M   | Moderate            | None                 | None                 | Limited Verbal Skills   | Simple Commands         | Other        | S   | 45 - 54 | M   | 27             | RNMH           |
| 440            | 47  | F   | Mild                | None                 | None                 | Depressive Disorder     | Good Verbal Skills      | Anti psychotic | L-P | 45 - 54 | M   | 10             | RNMH           |
| 441            | 55  | M   | Mild                | None                 | Missing data         | Signs / Symbols         | Simple Commands         | Anti psychotic | T   | 35 - 44 | M   | 10             | RNMH           |
| 460            | 43  | M   | Moderate            | None                 | None                 | Good Verbal Skills      | Good Understanding      | None         | Se  | 35 - 44 | F   | 18             | RNMH, SEN      |
| 470            | 26  | F   | Severe              | Autism               | None                 | Limited Verbal Skills   | Good Understanding      | Anti psychotic | P   | 35 - 44 | F   | 10 ½            | RNMH           |
| 550            | 47  | M   | Mild                | None                 | None                 | Body Language           | Body Language           | Anti psychotic | R   | 45 - 54 | M   | 23             | SEN            |
| 525            | 51  | M   | Moderate            | None                 | None                 | Body Language           | Body Language           | Anti convulsant | Th  | 45 - 54 | M   | 5              | None           |

Key for threshold values exceeded:
- Green: Affective disorders scale
- Blue: Psychotic disorders scale
- Pink: Both Affective & Psychotic disorders scales
- Light blue: Both Organic & Psychotic disorders scales
- Yellow: Affective / Neurotic and Organic Scales
- Red: All three PAS-ADD scales

* Carer identification code
### CARE CO-ORDINATOR CHARACTERISTICS

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<th>Experience (Yrs)</th>
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<td>M</td>
<td>45-54</td>
<td>M</td>
<td>27</td>
<td>RNRMH</td>
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</tbody>
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### CLIENT CHARACTERISTICS

| Subject Number | Age | Sex | Level of Disability | Diagnosed Disability | Psychiatric Diagnosis | Expressive Communication | Receptive Communication | Medication | ID* | Age | Sex | Experience (Yrs) | Qualifications |
|----------------|-----|-----|---------------------|-----------------------|----------------------|--------------------------|-------------------------|------------|-----|-----|------------------|----------------|
| 547            | 46  | F   | Moderate            | None                  | None                 | Good Verbal Skills       | Good Understanding      | Anti psychotic | R-f | 25 - 34 | F   | 4             | RNRMH |
| 401            | 67  | F   | Mild                | None                  | None                 | Good Verbal Skills       | Good Understanding      | Anti psychotic | N-2 | 45 - 54 | F   | 20           | RNRMH |
| 463            | 60  | M   | Severe              | None                  | None                 | Limited Verbal Skills    | Simple Commands         | Missing data   | H   | 45 - 54 | M   | 28           | SEN  |
| 474            | 44  | M   | Moderate            | Autism                | None                 | Limited Verbal Skills    | Simple Commands         | Anti psychotic | V   | 45 - 54 | M   | 30           | RNRMH |
| 342            | 77  | F   | Moderate            | None                  | None                 | Good Verbal Skills       | Good Understanding      | Anti psychotic | Fri | 35 - 44 | F   | 15           | RNRMH |
| 406            | 93  | F   | Mild                | None                  | None                 | Good Verbal Skills       | Good Understanding      | Other         | Fri | 35 - 44 | F   | 15           | RNRMH |
| 536            | 72  | F   | Moderate            | None                  | Alzheimer's          | Good Verbal Skills       | Good Understanding      | Anti psychotic | P   | 35 - 44 | F   | 10½         | RNRMH |
| 564            | 77  | M   | Moderate            | None                  | None                 | Good Verbal Skills       | Good Understanding      | None          | Mi  | 35 - 44 | F   | 22           | RNRMH |
| 573            | 38  | M   | Mild                | None                  | Depressive Disorder  | Good Verbal Skills       | Good Understanding      | Anti psychotic | M   | 45-54  | M   | 27           | RNRMH |

* Carer identification code

- Green: Affective disorders scale
- Pink: Psychotic disorders scale
- Red: Both Affective & Psychotic disorders scales
- Orange: Both Organic & Psychotic disorders scales
- Yellow: Affective / Neurotic and Organic Scales
- Pink: All three PAS-ADD scales
### APPENDIX III
Statistical analysis of client characteristics in relation to omitted questions.

#### Hearing Impairment

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<tr>
<td>Impaired</td>
<td>15</td>
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Mann Whitney U, $z = -1.02$ (p = 0.3061)

#### Behavioural Problems

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<tr>
<td>Mild / Moderate Problems</td>
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<td>Severe Problems</td>
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$\chi^2 = 1.623$ (df = 2) (p = 0.266)
APPENDIX IV

Statistical analysis of client characteristics on perceptions of utility.

<table>
<thead>
<tr>
<th>Level of Disability</th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
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<tr>
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<tr>
<td>Severe</td>
<td>91</td>
<td>102.32</td>
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\[ \chi^2 = 1.779 \text{ (df} = 2 \text{) (p} = 0.387 \]

Hearing Impairment

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</thead>
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<td>205</td>
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<tr>
<td>Impaired</td>
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</tr>
<tr>
<td>Deaf</td>
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</tbody>
</table>

\[ \chi^2 = 0.586 \text{ (df} = 2 \text{) (p} = 0.731 \]

<table>
<thead>
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<th>Mean Rank</th>
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<tbody>
<tr>
<td>No Impairment</td>
<td>205</td>
</tr>
<tr>
<td>Some Impairment</td>
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</table>

Mann Whitney U, \( z = -0.675 \) (p = 0.499)

Vision

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<tr>
<td>Impaired</td>
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</tr>
<tr>
<td>Blind</td>
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\[ \chi^2 = 3.16 \text{ (df} = 2 \text{) (p} = 0.185 \]
<table>
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Mann Whitney U, z = -1.211 (p = 0.226)

**Mobility**

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<td>Occasional help</td>
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<td>Regular help</td>
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\[ \chi^2 = 4.36 \text{ (df = 3)} \text{ (p = 0.199)} \]

**Expressive Communication**

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<td>Signs / Symbols</td>
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<tr>
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\[ \chi^2 = 6.66 \text{ (df = 4)} \text{ (p = 0.130)} \]
### Receptive Communication

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<th>Category</th>
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<tr>
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<td>Body Language</td>
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<td>Signs / Symbols</td>
<td>5</td>
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<td>Simple Commands</td>
<td>108</td>
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<tr>
<td>No Understanding</td>
<td>98</td>
<td>105.91</td>
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\[ \chi^2 = 4.456 \text{ (df = 4) (p = 0.3133)} \]

<table>
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<td>111.36</td>
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<td>18</td>
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Mann Whitney U, \(Z = -0.919\) (\(p = 0.358\))
APPENDIX V

Statistical analysis of client characteristics on perceptions ease of use.

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<tr>
<th>Level of Disability</th>
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<td>Severe</td>
<td>92</td>
<td>106.99</td>
</tr>
</tbody>
</table>

$\chi^2 = 1.820$ (df = 2) (p = 0.372)

<table>
<thead>
<tr>
<th>Hearing Impairment</th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Impairment</td>
<td>206</td>
<td>110.55</td>
</tr>
<tr>
<td>Impaired</td>
<td>11</td>
<td>121.05</td>
</tr>
<tr>
<td>Deaf</td>
<td>4</td>
<td>106.75</td>
</tr>
</tbody>
</table>

$\chi^2 = 0.230$ (df = 2) (p = 0.850)

<table>
<thead>
<tr>
<th>Vision</th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Impairment</td>
<td>197</td>
<td>113.19</td>
</tr>
<tr>
<td>Impaired</td>
<td>22</td>
<td>124.73</td>
</tr>
<tr>
<td>Blind</td>
<td>6</td>
<td>63.75</td>
</tr>
</tbody>
</table>

$\chi^2 = 4.15$ (df = 2) (p = 0.105)
<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Impairment</td>
<td>197</td>
<td>113.19</td>
</tr>
<tr>
<td>Some Impairment</td>
<td>28</td>
<td>111.66</td>
</tr>
</tbody>
</table>

Mann Whitney U, z = -0.121 (p = 0.904)

### Mobility

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walks unaided</td>
<td>151</td>
<td>112.23</td>
</tr>
<tr>
<td>Occasional help</td>
<td>35</td>
<td>113.51</td>
</tr>
<tr>
<td>Regular help</td>
<td>23</td>
<td>138.04</td>
</tr>
<tr>
<td>No help</td>
<td>16</td>
<td>83.19</td>
</tr>
</tbody>
</table>

$\chi^2 = 6.784$ (df = 3) (p = 0.110)

### Receptive Communication

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Understanding</td>
<td>2</td>
<td>152.00</td>
</tr>
<tr>
<td>Body Language</td>
<td>11</td>
<td>139.05</td>
</tr>
<tr>
<td>Signs / Symbols</td>
<td>5</td>
<td>95.30</td>
</tr>
<tr>
<td>Simple Commands</td>
<td>109</td>
<td>115.76</td>
</tr>
<tr>
<td>No Understanding</td>
<td>98</td>
<td>107.11</td>
</tr>
</tbody>
</table>

$\chi^2 = 3.846$ (df = 4) (p = 0.382)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Receptive Communication</td>
<td>207</td>
<td>111.67</td>
</tr>
<tr>
<td>Some Receptive Communication</td>
<td>18</td>
<td>128.33</td>
</tr>
</tbody>
</table>

Mann Whitney U, Z = -1.086 (p = 0.278)
<table>
<thead>
<tr>
<th>Behavioural Problems</th>
<th>N</th>
<th>Mean Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>No problems</td>
<td>53</td>
<td>99.99</td>
</tr>
<tr>
<td>Mild / moderate problems</td>
<td>143</td>
<td>113.21</td>
</tr>
<tr>
<td>Severe problems</td>
<td>28</td>
<td>132.54</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 4.668 \text{ (df = 2)} \quad (p = 0.08) \]
**APPENDIX VI**

Eigen values generated from parallel extraction

<table>
<thead>
<tr>
<th></th>
<th>Values from Random Matrix</th>
<th>Values from Factor Matrix</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1.605</td>
<td>6.228*</td>
</tr>
<tr>
<td>2</td>
<td>1.443</td>
<td>3.303*</td>
</tr>
<tr>
<td>3</td>
<td>1.405</td>
<td>1.622*</td>
</tr>
<tr>
<td>4</td>
<td>1.298</td>
<td>1.594*</td>
</tr>
<tr>
<td>5</td>
<td>1.274</td>
<td>1.286*</td>
</tr>
<tr>
<td>6</td>
<td>1.259</td>
<td>1.139</td>
</tr>
<tr>
<td>7</td>
<td>1.211</td>
<td>1.114</td>
</tr>
<tr>
<td>8</td>
<td>1.191</td>
<td>1.013</td>
</tr>
<tr>
<td>9</td>
<td>1.144</td>
<td>0.950</td>
</tr>
<tr>
<td>10</td>
<td>1.097</td>
<td>0.937</td>
</tr>
<tr>
<td>11</td>
<td>1.061</td>
<td>0.822</td>
</tr>
<tr>
<td>12</td>
<td>1.037</td>
<td>0.770</td>
</tr>
<tr>
<td>13</td>
<td>1.007</td>
<td>0.756</td>
</tr>
</tbody>
</table>

* = Factors extracted