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Please use this reference when citing this work:

Ross, E. & Oliver, C. (2003). The assessment of mood in adults who have severe or profound mental retardation. *Clinical Psychology Review,* **23**, 225-245.

The Assessment of Mood in Adults who have Severe or Profound Mental Retardation

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ABSTRACT

Empirical literature examining the emotional lives of adults with severe and profound mental retardation is limited. One area to have received attention is mood. It is proposed that the utility of assessment of mood extends beyond psychiatric diagnosis to issues such as the appraisal of quality of life for individuals with limited or no expressive language. Two themes related to the assessment of mood are evident in contemporary literature. First, attempts have been made to clarify the presentation of affective disorders, especially depression, and to improve the assessment of depressive symptomatology in adults with mental retardation. A review of current methods for assessing depression indicates significant problems with reliability and validity. There is a need to develop appropriate assessment methods for use in relation to adults with severe and profound mental retardation who are unable to self-report and behavioral methodology might be useful in this respect. Second, there is an emerging argument that the presentation of depression in adults with mental retardation, particularly in individuals with severe disabilities, includes challenging behaviors, referred to as "atypical symptoms". Methodological and conceptual issues related to this argument warrant closer examination. Finally, it is noted that research drawing on more rigorous methodology is required to interpret the emotional states of individuals with severe and profound mental retardation.

INTRODUCTION

Relatively little is known about the emotional lives of people who have mental retardation (Benson & Ivins, 1992), although the knowledge base is growing slowly (Lindsay, Michie, Baty, Smith & Miller, 1994). Examples of this emerging interest predominantly involve people with less severe mental retardation and include the areas of anger management (e.g. Benson, Rice & Miranti, 1986; Benson, 1994) and bereavement (e.g. Cathcart, 1995). Less interest has been paid to mood and emotions amongst people with severe and profound mental retardation (Favell, Realon & Sutton, 1996). Instead, applied psychological research with this group has focused on other areas. The most notable example is exploration of behavioral excesses and deficits, i.e. "challenging behavior" (especially aggressive or self-injurious behavior, see Journal of Applied Behavior Analysis, 1994, 27(2) Special Issue), although a limited number of other areas have been investigated, for example, skills teaching (Clements, 1987).

This review will focus on one aspect of the emotional lives of adults with severe and profound mental retardation: the assessment of mood. It will be proposed that there are important reasons for improving the assessment of mood in people whose ability to communicate verbally about their subjective experiences is, by definition, limited or non-existent. Initially, potential applications of mood assessment in adults with more severe mental retardation will be examined, primarily in relation to the appraisal of quality of life. A review will then be provided of the current state of research on affective disorders in adults with mental retardation. This will concentrate on the identification and assessment of depression (primarily unipolar depression), since most research relating to the expression of affect has been carried out in this area. This overview will highlight both the need for reliable and valid methods of assessing mood in adults with mental retardation, particularly people with more severe disabilities and some of the principal conceptual and methodological challenges pertaining to mood assessment in this group.

THE ASSESSMENT OF MOOD TO CONTRIBUTE TO THE APPRAISAL AND IMPROVEMENT OF QUALITY OF LIFE

Research into quality of life became the "pre-eminent issue of the 1990s" in the field of mental retardation (McVilly & Rawlinson, 1998). Parmenter (1992) highlights the limitation of early models of quality of life, which focused primarily on objective indicators, such as the physical

environment and activities for daily living. It is suggested that a balance is needed between objective and subjective factors (Parmenter, 1992). Subjective dimensions have been incorporated in later models. These have included a psychological/psychosocial category (Goode, 1988a, as cited in Parmenter, 1992), psychological wellbeing (Brown *et al*., 1989, as cited in Parmenter, 1992) and personal values and aspirations (Felce & Perry, 1995).

A prerequisite of subjective evaluation is the ability to assess an individual's feelings of happiness and satisfaction with aspects of his/her life. This becomes more problematic when appraising quality of life in people with more severe mental retardation who cannot directly self-report. There have been three main responses to this challenge. Firstly, the majority of research has involved people with mild and moderate mental retardation and has largely ignored people with severe disabilities (Campo, Sharpton, Thompson & Sexton, 1997). Alternatively, informants have appraised dimensions in the quality of life of people with mental retardation who cannot self-report (Campo *et al*., 1997; Felce & Perry, 1995). The validity of relying on informants to measure another person's quality of life has been questioned (McVilly & Rawlinson, 1998), since the concept of quality of life is, in essence, "deeply personal" (Parmenter, 1992). The final response is summarised by Felce & Perry (1995) who assert that for people with little or no language "…quality of life assessment in such situations must be restricted to objectively measurable phenomena, interpreted via norms and ranges relating to the general population" [e.g. measuring aspects of the physical environment].

Therefore, an ability to assess mood reliably and validly in people with severe and profound mental retardation might be beneficial, since mood could serve as a useful outcome measure of quality of life. An enhanced understanding of how an individual with very limited or no expressive language might convey a positive or negative affective state could reduce reliance on informants' estimations of subjective dimensions of quality of life. In this way, behavioral correlates of affect (i.e. objectively observable phenomena) might be able to offer insight into the subjective experiences of individuals with severe and profound mental retardation.

In this respect, it has been suggested that measuring happiness represents an untapped source of valuable information regarding clients' satisfaction with services (Favell *et al*., 1996; Green &

Reid, 1996). Both Favell *et al*. (1996) and Green & Reid (1996) contend that applied behavior analysis could respond to the "unmet challenge" of promoting quality of life for people with severe mental retardation. Green & Reid (1996) propose that it should be possible to operationally define behaviors that people generally agree to be indicative of happiness and then observe, quantify and examine the effect of interventions designed to increase happiness, thus providing a way of enhancing quality of life. It should be noted that Green & Reid acknowledge the difficulty of defining what "being happy" means. This problem is addressed by operationally defining behaviors "…… that represent what people agree to indicate 'happiness'" (e.g. smiling, laughing) and the same approach is used to define unhappiness. Thus, no attempt is made to provide an all-encompassing definition of these constructs.

The following overview of the studies in this area will highlight both the value of a behavioral approach and some of the major challenges when assessing mood in people with severe mental retardation. Particular attention will be paid to studies by Green & Reid (1996), Green, Gardner & Reid (1997) and Green & Reid (1999). Studies by Favell *et al*. (1996), Green & Reid (1996), Green *et al*. (1997) and Ivancic, Barrett, Simonow & Kimberly (1997) have all shown that it is possible to operationalise and reliably observe behavioral indicators of affect. Indices of happiness (e.g. smiling, laughing) and unhappiness (e.g. frowning, crying) have been observed and recorded in relation to the presentation of the most and least preferred stimuli (previously identified by formal preference assessments (Green & Reid, 1996; Green *et al*., 1997). In both studies these indices were reliably observed in relation to people with profound multiple disabilities (Green & Reid, 1996, n=4; Green *et al*., 1997, n=3).

Validating indices of affective states has been more problematic. Evidence of social validity for proposed indices of happiness and unhappiness has been demonstrated by a strong association between observer ratings of happiness/unhappiness based on the defined indices and ratings of levels of happiness/unhappiness provided by experienced practitioners who watched video footage of the first phase of each experiment (Green & Reid, 1996; Green *et al*., 1997). Furthermore, participants' reactions to stimuli identified by structured preference assessments supported the hypothesis that indices of happiness would increase when presented with the most preferred stimuli and that indices of unhappiness would increase in relation to the least preferred

stimuli. However, it is important to highlight one possible limitation to the second approach. It is acknowledged that since positive and negative facial expressions are used as one of the criteria in the preference assessment, there is an element of circularity in the argument (Green & Reid, 1996). This clearly has the potential to affect the results, which were said to support the stated hypotheses. Nonetheless, it is equally important to consider Green & Reid's (1996) assertion that as the preference assessments were not based exclusively on facial expressions, there is a reduced likelihood that the results were "due solely to an overlap in definitions".

The behavioral approach has also demonstrated that it is possible to systematically increase indices of happiness and reduce indices of unhappiness in people with severe and profound mental retardation. Thus, the proposed behavioral correlates of mood states have contributed to the evaluation of interventions designed to improve quality of life. Green & Reid (1996) reported that indices of happiness could be increased by classroom staff for three individuals by implementing a "fun time programme" incorporating preferred stimuli previously identified in the preference assessments, as well as preferred stimuli informally identified by staff. Conversely, Green & Reid (1999) successfully employed an "unhappiness reduction programme" (consisting of stimuli based on structured preference assessments and staff opinions, presented in four steps: once before, twice during and once after aspects of an exercise routine) to reduce indices of unhappiness associated with movement exercises for three people with profound multiple disabilities. Behavioral correlates of affect have also been employed to evaluate which components of intervention programmes are the most effective, e.g. a component analysis indicated that activities based on a systematic preference assessment were preferable to activities based on staff opinion, since for 2/3 participants happiness levels during the opinion-based activities were similar to baseline levels (Green *et al*., 1997).

Further evidence of the usefulness of behavioral indicators of affect to evaluate interventions designed to improve quality of life is provided by Ivancic *et al* (1997), who aimed to replicate the Green & Reid (1996) study. Ivancic *et al*.'s (1997) "fun time programme" was based on staff identified preferred stimuli (instead of stimuli identified by formal preference assessments). An additional aim of the study was to draw distinctions between subgroups of individuals with profound multiple disabilities for whom "fun time" may be more or less appropriate (e.g. people

with very low responses/restricted movement). ABAB reversal designs using partial interval recording were employed with seven individuals with profound multiple disabilities. Four individuals were in a "movement group" and three in a "low movement group". As well as using the indices of happiness and unhappiness outlined by Green & Reid (1996), measurements were taken of closed eyes and open eyes. In the "movement group", Ivancic *et al.* (1997) were able to replicate an increase in indices of happiness for three participants. For the remaining participant in the "movement group", indices of happiness did not increase, but indices of unhappiness did decrease during the fun time programme.

Participants in the "low movement group" displayed no indices of happiness or unhappiness at any time. This still applied when a member of staff known to the clients implemented the fun time programme, instead of the undergraduate students originally used in the study. However, it was noted that closed eyes did not occur with familiar staff. Based on these findings, Ivancic *et al*. (1997) raise the possibility that less conventional indices (e.g. changes in eye opening) might apply to more profoundly disabled individuals, since limited movement appears to inhibit the outward expression of internal mood states.

Hence, the findings of these research studies suggest that it is possible to define, observe and increase indices of happiness for people with profound multiple disabilities, thus offering an added dimension to the assessment of the quality of life and service provision for people with severe and profound multiple disabilities. It is particularly useful that most of the studies reviewed above lend them selves to comparison because every study (except Favell et al., (1996) used identical definitions of happiness and unhappiness as those proposed by Green and Reid (1996). The studies by Green & Reid (i.e. Green & Reid, 1996; Reid *et al*., 1997; Green & Reid, 1999) are particularly well-designed, but would benefit from additional replication studies in other settings, given the small number of participants and the fact that the research has been carried out in only one environment, the classroom. Moreover, it has been suggested that there is potential for extending this area of research beyond 'consumer' satisfaction (Favell *et al*., 1996). For example, Favell *et al*. (1996) made a preliminary attempt to quantify the effects of social interaction on happiness for one individual by observing changes in a "happiness index" score before and after social interaction. It is important to note the selection bias, which is

acknowledged by Favell *et al* (1996): the person was selected because he was judged by carers to be particularly responsive to social interactions. Additionally, the psychometric properties of the "happiness index" have not been thoroughly investigated. Nevertheless, it points the way both to potential avenues of future research and to ways in which the application of the measurement of behavioral correlates of affect might be extended to other areas of quality of life. Favell *et al*. (1996) also usefully note that future attempts to measure affective states will need to incorporate the concept of intensity, not merely frequency of behavioral correlates of affect.

However, it is possible to argue that there is a significant conceptual limitation regarding the application of these kinds of behavioral approaches to the concept of quality of life. Given that these studies examine transient states (e.g. a person's apparent affective response to a specific stimulus at a given point in time) the validity of drawing conclusions regarding quality of life could be questioned if it is argued that quality of life assessment requires consideration of mood over a prolonged period. Nonetheless, the methods proposed in these studies might be adapted to obtain information about a person's global mood state by re-examining responses to given stimuli over time in order to develop a profile of happiness. This might enhance the validity of assertions made regarding these methods and quality of life. Furthermore, it has been suggested that approaching the assessment of quality of life from a more global standpoint presents its own problems. Favell, Realon and Sutton (1996) cite an example in which they query the usefulness of attempting to answer a question about a person's overall enjoyment of their meals, when it may be more useful to establish how much pleasure an individual derives from a particular bite of food. Two final points merit consideration. First, Green & Reid (1996) who observe that caution is always required when making assumptions that certain behaviors relate to private events (e.g. happiness). Second, it could also be argued that there are problems with adopting such a technical approach, since behavioral concepts might not adequately capture the depth and richness of experiences such as happiness and unhappiness.

EVALUATING INTERVENTIONS DESIGNED TO REDUCE "CHALLENGING BEHAVIORS"

It has been emphasised that conclusions about the efficacy of behavioral interventions should "…take account of the range of outcomes of significance to all the major stakeholders in the intervention process" (Emerson, Cambridge & Harris, as cited in Emerson, 1995, pp 17). In

reality behavioral research and practice falls short of this aim, relying instead on observed changes in target behaviors to evaluate intervention programmes (Emerson, 1995). In contrast, generally attempts are not made to monitor behaviors that may reflect how the person with mental retardation feels about the intervention. This is a serious omission since the person with mental retardation (a "major stakeholder") is effectively excluded from the process of evaluating the intervetion. Therefore, by developing a better understanding of how behavior relates to mood in people with severe and profound mental retardation, this should make it possible to obtain vital information (e.g. does the person appear more or less distressed as a result of the intervention) about the person's experience of the intervention.

Only a few studies have explored this possibility. Oliver, Hall, Hales, Murphy & Watts (1998) operationally defined correlates of positive and negative affect, as one variable to assess the aversiveness of an intervention (flexion was introduced into a straight-arm splint to try to reduce self-injurious behavior in three individuals). The positive and negative correlates of affect employed were positive vocalisations (smiling, laughing) and negative vocalisations (crying, screaming or moaning). Positive and negative vocalisations have also been used to evaluate effective punishers for an intervention designed to reduce pica (Fisher *et al*., 1994).

A similar attempt was made by Lindauer, DeLeon & Fisher (1999) who employed indices of positive and negative affect (similar to those described by Green & Reid, 1996) to evaluate the effects of an enriched environment programme, designed to reduce self-injurious behavior. Results indicated a marked reduction in indices of negative affect and some increase in positive affect, as well as reduced levels of self-injurious behavior during the intervention. Kennedy (1994) also employed correlates of positive social affect as one measure of the efficacy of an intervention designed to reduce challenging behavior. While these studies are encouraging, it is important to note that no attempt was made in any of the studies to validate the proposed correlates of affect.

In addition to the use of mood assessment to appraise quality of life and evaluate interventions, there are a number of other potential applications in relation to people with severe and profound mental retardation. For example, an enhanced ability to assess mood could facilitate more

appropriate interactions between caregivers and clients, since caregivers currently rely on assumptions about likes, dislikes and feelings (Grove, Bunning, Porter & Olson, 1999). Similarly, very little is currently known about how indicators of pain and physical illness might be reliably and validly assessed in this client group (McGrath, Rosmus, Canfield, Campbell & Hennigar, 1998). Behavioral correlates of affect might provide valuable information in terms of general indicators of physical health. Finally, it has now been recognized that grief is experienced by people with mental retardation (e.g. Cathcart, 1995). Therefore, mood assessment could help monitor reactions to life-events, including bereavement, staff changes or changes in residence for people who are unable to talk about their thoughts and feelings.

THE APPRAISAL OF SIGNS AND SYMPTOMS OF AFFECTIVE DISORDERS

An improved ability to assess mood in people with severe and profound mental retardation would also facilitate the identification of affective disorders. Increased research investigating the direct expression of affective disorders, particularly depression, is indicative of recent interest in the co-occurrence of mental illness in people with mental retardation (Sturmey & Sevin, 1993). This has challenged the outdated view that people with a developmental disability were too "psychologically primitive" to develop mental health problems (Sovner & DesNoyers Hurley, 1983). It is recognized that this earlier misconception led to considerable "diagnostic overshadowing", whereby clinicians tended to attribute psychological and behavioral difficulties to a person's mental retardation, instead of considering the possibility that s/he may have a mental health problem (Luiselli, 1998).

There is now an alternative view that people with mental retardation are more susceptible to mental illness, including depression (e.g. Matson, Gardner, Coe & Sovner, 1991). However, these conclusions should be treated with caution, given enormous variations in prevalence estimates, as outlined below (Fraser & Nolan, 1994). The proposed underdiagnosis of depression is thought to be compounded by confusion surrounding depressive symptomatology in people with mental retardation and by difficulties assessing individuals with limited or no expressive language (Charlot, Doucette & Mezzacappa, 1993). Moreover, carers may not bring to the attention of clinicians the presence of possible affective symptoms (e.g. withdrawn behavior), because they often pose less management problems than "acting-out" symptoms (Wright, 1982).

There is considerable debate regarding prevalence rates of mental illness amongst people with mental retardation. In the case of depression, for example, it has been argued that there are reasons why people with mental retardation might be more susceptible than people who do not have mental retardation. Certain syndromes might make people more susceptible to depression. For example, people with Down's Syndrome are vulnerable to hypothyroidism, which may be associated with the onset of depression (Davis, Judd & Herrman, 1997a). Other factors cited represent psychosocial factors commonly experienced by people with mental retardation; these include low levels of social support, poor social and communication skills (Davis *et al*., 1997a) and an increased risk of experiencing abuse (Turk & Brown, 1993). These have all been identified as risk factors for depression in people who do not have mental retardation.

Estimates of prevalence rates of mental health problems amongst people with mental retardation vary greatly and range from 10 – 60% (King, State, Shah, Davanzo & Dykens, 1997). Reasons for variations in prevalence rates are well documented:

1) Studies research different populations, although most populations have been institutionalised (Cooper & Collacott, 1996),

2) There is a variation in sampling approaches (e.g. random selection or clinically referred samples) (King *et al*., 1997),

3) Different diagnostic criteria are used (Cooper & Collacott, 1996),

4) There is a failure to be explicit about whether prevalence denotes lifetime risk of mental illness, or point prevalence (Lowry, 1998),

5) There are difficulties diagnosing people with limited or no expressive language (Davis *et al*., 1997b).

6) The diagnosis and identification of persons with mental retardation can present its own problems. It has been suggested that it can be difficult to decide whether or not persons with mild impairments meet the criteria for mental retardation. Moreover, many individuals with mild mental retardation may not be know to services. Hence, prevalence studies may not be addressing the same population samples (Holland, 1999).

7) Some studies include the category of behavior disorder, which considerably increases reported prevalence rates. Again this is not consistent. (Holland, 1999).

Thus, these variations prevent meaningful comparisons across studies.

The presentation of depression in people who have mental retardation

Research has concluded that people with mild or moderate mental retardation display the range of standard symptoms of depression, i.e. those in ICD-10 (World Health Organisation, 1992) or DSM-IV (American Psychiatric Association, 1994) (see the retrospective analysis of earlier studies by Pawlarcyzk & Beckwith (1987) and Sovner & Desnoyers-Hurleys (1983); group comparison studies, e.g. Meins (1995) and Marston, Perry & Roy (1997) and a review article by Sturmey (1995)). Hence, these standard diagnostic criteria are regarded as appropriate for use with people with mild or moderate mental retardation.

The application of standard diagnostic criteria becomes more problematic as the severity of mental retardation increases, since certain criteria are inaccessible in people with limited or no expressive language, e.g. "feelings of worthlessness" or "guilt" (Meins, 1995). Nevertheless, classic symptoms of depression have been described in people with severe mental retardation. These include informant reports of sleep (Charlot *et al*., 1993; Marston *et al*., 1997) and appetite changes (Charlot *et al*., 1993) and sad/depressed mood (Charlot *et al*., 1993; Marston *et al*., 1997).

However, certain difficulties with these studies are apparent. For example, checklists of standard diagnostic symptoms of unknown reliability have been used when interviewing informants of people with severe and profound mental retardation (Charlot *et al*., 1993; Marston *et al*., 1997). Similarly, assessment criteria tend to be poorly defined. For example, "depressed mood" has been assessed (Charlot *et al*., 1993; Meins, 1995; Marston *et al*., 1997), but the criteria used to assess this are not made explicit. Other methodological difficulties will be outlined in more detail below. Nonetheless, the appraisal of certain standard diagnostic criteria, e.g. sleep disturbance, present fewer difficulties because they are potentially observable behaviors and are not exclusively reliant on self-report. An excellent review of the challenges of applying DSM-

III-R diagnostic criteria to people with mental retardation is provided by Sturmey (1995).

Conclusions regarding "atypical symptoms" of depression

There is a growing body of literature suggesting that depression does not present a "classical picture" in adults with mental retardation, particularly in people with more severe disabilities. It is proposed that the presentation of depression includes both standard and "atypical" symptoms; the latter are sometimes referred to as "depressive equivalents" (Sovner, DesNoyers Hurley & LaBrie, 1982) or "behavioral depressive equivalents" (Marston *et al.*, 1997). These research projects will now be described before outlining significant methodological shortcomings common to most studies.

Meins' (1995) group comparison study investigating symptomatology in individuals experiencing major depression offers one of the most comprehensive descriptions of "atypical symptoms". These include irritability, self-injurious behavior, aggressive behavior (towards persons and/or objects) and screaming. The "atypical symptoms" were present in 55% of people with a mild mental retardation and in 83% of people with a severe disability. Also reported was an association between severity of mental retardation and (1) aggressive behavior towards objects, (2) aggressive behavior against persons and (3) temper tantrums. These behaviors (which were not operationally defined) were more frequent in people with severe mental retardation. This is put forward as evidence that in people with severe developmental disabilities depression can manifest itself via "atypical symptoms", particularly as a clear time link between the onset of the atypical and core DSM-III-R (American Psychiatric Association, 1987) symptoms was identified (Meins, 1995). Arguably these findings should be viewed much more cautiously than is suggested, given methodological problems outlined later.

Charlot *et al.*'s (1993) group comparison study examining the presentation of affective disorders is noteworthy, because the majority of participants (22/30, 73.3%) had either severe or profound mental retardation. The findings suggested a link between self-injury and/or aggression and affective disorders, including depression. The general findings support Meins'(1995) earlier conclusions that aggression was found more often in individuals with severe mental retardation and depression than in a comparison group. Similarly, Marston *et al.*'s study (1997) noted that as

the degree of disability increased, there was a trend towards standard diagnostic criteria of depression being seen less frequently and other behaviors being seen more often, notably self-injury, screaming and aggression.

Lowry (see: Sovner & Lowry, 1990; Lowry & Sovner, 1992; Lowry, 1993; Lowry, 1994; Lowry, 1995; Lowry & Charlot, 1996; Lowry 1998) also maintains that there is a clear link between "maladaptive behaviors" and mood disorders including bipolar and unipolar depression; these conclusions are often based on single case studies, which include people with severe and profound mental retardation and use observational methods with clearly operationally defined behaviors (see Sovner & Lowry, 1990; Lowry & Sovner, 1992; Lowry & Charlot, 1996; Lowry, 1998). In one individual self-injury only occurred during episodes of depression, while in a second individual aggression was associated only with the manic features of the bipolar disorder (Lowry & Sovner, 1992). Thus, it is tentatively concluded that self-injury and aggression were "atypical symptoms" of an underlying mental illness. No information is provided regarding the criteria employed to diagnose these psychiatric disorders or regarding inter-observer reliability of the behaviors under investigation. On the basis of the single case studies, it is also not possible to ascertain whether the "atypical symptoms" would generalise to other people with mental retardation, although those identified by Lowry & Sovner (1992) do correspond with the findings of group comparison studies already mentioned (e.g. Meins, 1995).

Several studies have identified a link between irritability and depression (e.g. Meins 1995; Davis, Judd & Herrmann, 1997b and Charlot et al., 1993). Charlot et al. (1993) propose that the findings support this association because anhedonia (i.e. reduced levels of interest and pleasure) was present even if low mood was absent in people who were irritable.   Meins (1995) suggests that irritable mood should be used as a core diagnostic criterion for depression in people with mental retardation, as is the case with children. The general failure across studies to provide reliable and valid definitions of "irritability" is, however, a serious omission (Lowry, 1994). An additional problem relates to the use of "blind assessors". It is important that the researchers assessing irritability are blind to the diagnosis of depression, otherwise there is a risk of confirmatory bias. This methodological point is not clarified in the Charlot et al. (1993) and Davis et al. (1997b) studies and there appears to be no blind assessor in the Meins (1995) study.

Most studies that suggest a link between "atypical symptoms" and depression in people with mental retardation fail to offer any external validation for this view. Notable exceptions are Davis *et al*.'s (1997b) study, which demonstrated a reduction both in standard depressive symptomatology and other behaviors, e.g. aggression and regressed behavior, following a course of anti-depressants and "supportive psychotherapy" deined as opportunity for ventilation of feelings, education with regard to depression and focussed problem solving). A reduction in depressive symptomatology and maladaptive behavior following a course of Fluoxetine was also outlined by Sovner, Fox, Lowry & Lowry (1993).

Therefore, although a growing argument exists regarding "atypical symptoms" of depression in people with mental retardation, particularly in adults with more severe disabilities, the evidence is by no means conclusive. Charlot *et al*. (1993) report that a significant minority of the depressed group in their study did not engage in aggression, self-injury or property destruction. Meins (1995) also reports that the level of aggression against persons was not significantly different between the depressed and comparison groups. Finally, Marston *et al*. (1997) did not find irritability to be a significant symptom, even amongst participants with more severe mental retardation.

Finally, there are significant methodological shortcomings common to many of the studies which have identified "atypical symptoms" of depression:

1) The validity of studies is often weakened by the use of modified or substitutive diagnostic criteria to identify individuals with "depression" for group comparison studies, e.g. Charlot *et al*. (1993); Meins (1995) and Davis *et al*. (1997b). It has been reported that of all the studies reviewed in which DSM-III-R criteria were used, only one study used DSM-III-R unmodified (Sturmey, 1995). Equally, modified assessment tools have been used to identify individuals with depression (e.g. Meins, 1995).

2) There is a general reliance on a tautological rationale, whereby individuals with a prior diagnosis of depression are employed in studies which aim to explore how depression is

manifested in people with mental retardation (e.g. Charlot *et al*., 1993; Marston *et al*., 1997). Similarly, some studies which have documented links between irritability and depression (e.g. Lowry, 1995; Charlot *et al*., 1993; Meins, 1995) have used irritability as a diagnostic criteria to identify the depressed group, the behavior of which is then studied. Furthermore, "atypical symptoms" such as "maladaptive behaviors" are used as initial diagnostic criteria in studies which aim to clarify if certain maladaptive behaviors are actually symptoms of depression (e.g. Meins, 1995). Although some studies justify this approach by stating that maladaptive behaviors are only used as diagnostic criteria if there is a definite time link with the onset of other symptoms of depression, the circularity inherent in this methodology is still problematic.

3)   As yet, no studies have employed methodologies able to clarify the correlation and causation issue. However, statements have been made about causation, e.g. that "atypical symptoms" are caused by depression (Davis *et al*., 1997b). Rarely is it acknowledged that the relationship between depression and so-called "atypical symptoms" may actually be considerably more complex (exceptions to this include Lowry, 1994; Schloss, 1982). In this respect, Lowry (1994) has developed a model which attempts to explain how depressive symptomatology might interact with events in an individual's social environment to produce the kinds of behaviors described as "atypical symptoms of depression", such as self-injury, in people with mental retardation. The "bio-psycho-social" model (Lowry, 1994) suggests that when a person is experiencing a particular symptom of depression, certain events can become aversive. For example, loss of interest (a core symptom of depression) could result in self-injury or aggression, if someone were prompted to engage in an activity. It is proposed that this maladaptive behavior is then strengthened by the process of negative reinforcement once the demand is removed. As yet, there has been no empirical investigation of this model.

4)   A degree of caution seems advisable when interpreting findings highlighting a link between depression and certain "maladaptive behaviors", since there is some evidence that seretonin depletion may be associated with self-injurious behavior and aggression, without associated depressive symptomatology (Davanzo, Belin, Widawski & King, 1998). This applies to

studies which have used observed reductions in depressive symptomatology and concurrent self-injury following a course of anti-depressants as evidence that self-injurious behavior is a symptom of depression (e.g. Sovner *et al*., 1993). Consideration of a possible "common denominator" is needed, given the possible role of seretonin levels in depression and self-injury/aggression.

5) Conclusions regarding "atypical symptoms" in adults with severe and profound mental retardation are based on studies including small numbers of participants with this degree of disability. Numbers of people with severe and profound mental retardation in significant studies are: 3/48 (6.3%) (Sovner & DesNoyers Hurleys, 1983); 5/38 (13.2%) (Pawlarcyzk & Beckwith, 1987); 12/32 (37.5%) (Meins, 1995) and 8/36 (22.2%) (Marston *et al*., 1997). A notable exception is the Charlot *et al*. (1993) study, which included 22/30 (73.3%) people with severe disabilities. Furthermore, people with severe and profound mental retardation are frequently included in studies which do not explain how certain symptoms have been reliably and validly identified in people with limited or no expressive language (e.g. "guilt feelings" and "flight of ideas", Charlot *et al*., 1993).

6) The potential impact of the caring situation on the manifestation of symptoms of depression is disregarded. For example, Meins (1995) notes that hypersomnia is rare, but no consideration is given to the fact that many people with mental retardation, especially those with more severe disabilities, are put to bed and woken by carers, thus making it difficult to obtain a "true" picture of an individual's sleep pattern. Much the same can be said of appetite (appetite changes being another symptom of depression), since food intake is often directly or indirectly controlled by others.

In summary, research on prevalence rates and the presentation of depression could be improved by overcoming these methodological limitations and by finding more appropriate ways of assessing affect in adults who have limited or no expressive language.

Methods for assessing depression in adults with mental retardation
Before considering the particular difficulties inherent in the assessment of depression in adults

with mental retardation, it is important to note that the assessment process is not without its problems for people who do not have mental retardation. Snaith (1993) points out that one of the major problems relates to the confusion surrounding the clinical concept of depression itself, given that the same term employed by different professionals often signifies different concepts. Snaith (1993) contends that the meaning implied by the use of the term "depression" depends largely on the theoretical stance of the user. Thus, it is noted that "depression" used by a cognitive theorist might imply the presence of a collection of self-defeating beliefs, whereas "depression" for a biological psychiatrist probably implies a "state based on malfunction of neurotransmitter systems in the brain" (Snaith, 1993). Given these differences, it is inevitable that assessment techniques based on different theoretical standpoints measure different constellations of symptoms or underlying causes of depression. Indeed, Snaith (1993) cautions unwary researchers against the erroneous assumption that rating scales which claim to assess depression actually measure the same concept.

The assessment of depression in people with mental retardation is clearly more problematic. Firstly, it is inhibited by limitations to the current knowledge base regarding depressive symptomatology in this client group. Secondly, there are methodological problems, notably, how to develop reliable and valid methods of assessing depressive symptomatology in people with communication difficulties. For example, it clearly becomes more difficult to reliably and validly assess cognitions thought to mediate and maintain depression (e.g. Beck, 1976) as the severity of mental retardation increases.

Rating scales and interview measures

Rating scales used in the assessment of depression in adults with mental retardation are either screening tools for general psychopathology, which aim to highlight a need for further psychiatric assessment, or are tools designed to assess the severity of episodes of depression.

Rating scales for depression reliant on self-report are usually modifications of scales used in the general population (e.g. the Zung self-rating depression scale, Zung, 1965; the Beck Depression Inventory, Beck, Ward &mendelson, 1961); these have been used with people with mild and moderate mental retardation. The use of self-report rating scales in people with a developmental disability presents certain problems because of restricted language abilities and a tendency to

acquiescence (Reynolds & Baker, 1988). However, it seems reasonable to suppose that if scales are appropriately adapted for the needs of people with less severe mental retardation, this will provide a useful way of assessing symptoms of depression. This is supported by evidence that people with mild and moderate mental retardation have been found to reliably self report their symptoms (Kazdin, Matson, Senatore, 1983) and feelings and emotions (Lindsay *et al*., 1994). Studies comparing the reliability and validity of these rating scales for use with people with mild and moderate mental retardation have produced inconclusive results (e.g. Thompson-Prout & Schaefer, as cited in Cooper & Collacott, 1996; Kazdin *et al*., 1983). (For an excellent critique of these studies see Cooper & Collacott (1996)). One of the most pertinent criticisms is that modified rating scales have not yet undergone sufficient reliability and validity testing with people who have mental retardation.

Both the Reiss screen (Reiss, 1988) and the Psychopathology Inventory for Mentally Retarded Adults (PIMRA; Senatore, Matson & Kazdin, 1985) are informant rating scales to assess general psychopathology in people with mental retardation. Whereas the former is designed for use in relation to people across all levels of mental retardation, the latter is designed for people with mild and moderate mental retardation. Studies of the PIMRA (e.g. Sturmey & Ley, 1990) have questioned its psychometric properties. The Reiss Screen consists of an alphabetic listing of symptoms with brief definitions of each symptom. Items are combined into eight disorders/dimensions, including depression (behavioral signs) and depression (physical signs). These dimensions have been obtained from factor analysis of different versions of this screen and are based on DSM-III-R diagnostic classifications. It has been shown to have moderate to good reliability and validity (e.g. Sturmey & Bertman, 1994; Sturmey, Burcham & Perkings, 1995). Although studies have included people with severe and profound developmental disabilities, the Reiss Screen appears to pose some difficulties in this respect: it is unclear how certain items were ascertained, e.g. "suicidal tendencies". Another significant problem relates to the scoring system. It is recommended that a "no problem" rating is used if a behavior category does not apply to an individual (e.g. "lying" for someone who is nonverbal). On this basis, at least 8/38 items are inaccessible for individuals who are nonverbal and would be rated "no problem", i.e. zero. This suggests that there is a construct validity problem with certain items for individuals with severe and profound mental retardation. The validity of certain item definitions and

examples is also questionable, e.g. an example of "low energy" is given as "lacks initiative", while "suicidal tendencies" includes the example of "tries to get run over by cars". Arguably the latter example might represent an unintentional act by an individual with limited awareness of danger.

The PAS-ADD (The Psychiatric Assessment Schedule for Adults with a Developmental Disability; Moss *et al*., 1993) is also designed to assess general psychopathology in people with mental retardation and is available in three different forms. The full version of the PAS-ADD is a semi-structured clinical interview with a respondent and an informant. It is based on ICD-10 (World Health Organisation, 1992) and aims to "diagnose Axis 1 psychopathology in people with a learning disability (i.e. mental retardation)." The mini PAS-ADD, "an assessment schedule for the detection of mental health problems in adults with developmental disabilities (i.e. mental retardation)" is a rating scale, which consists of a detailed checklist and glossary of definitions. It is designed to provide professional care staff with a "framework to collect information about psychiatric symptoms" to make appropriate referrals. Referrals are generally recommended if scores relating to any of the seven areas of psychopathology (including depression) are above given thresholds. The PAS-ADD checklist requires no training or qualifications and is intended to enable care staff and families to screen for mental health problems or monitor symptoms and to then seek help if appropriate. The broad aim of the mini PAS-ADD and the checklist is to help staff and carers to recognize potential mental health problems and to make informed referral decisions.

Both the mini PAS-ADD and the PAS-ADD checklist make a valuable contribution to the area of assessment, since they are clear and practical to use and should facilitate more appropriate referrals. This is especially important when one considers past underdiagnosis and diagnostic overshadowing in this client group. The glossary of item definitions for the mini PAS-ADD is advantageous, although improvements could be made, for example the definitions for "appears depressed, sad or down" includes references to "low mood" without this being operationally defined. Moreover, the usefulness of the mini PAS-ADD for people with severe and profound mental retardation appears limited by items which would be difficult or impossible to rate because some level of verbal communication is required, e.g. "repeating words" or "loss of self-

confidence".

Some evidence of reliability and validity of the PAS-ADD interview is available. The Costello, Moss, Prosser & Hatton (1997) reliability study included forty individuals with sufficient language to be interviewed. The mean Kappa across all item codes of 0.65 was acceptable (range 0.35-0.94), although anxiety items were problematic. Evidence of good validity was provided by Moss *et al*. (1997) who compared PAS-ADD scores with scores on a referrer checklist (this sought clinical opinions of the referring psychiatrist).

The only measure specifically designed for evaluating emotional and behavioral disturbance in people with severe and profound mental retardation is the Diagnostic Assessment for the Severely Handicapped II (Matson, 1995), a revised edition of the DASH (Matson, Gardner, Coe & Sovner, 1991). This aims to assess the frequency, duration and severity of symptoms relating to thirteen diagnostic categories based on DSM-III-R and consists of an interview with an informant. The DASH-II highlights a number of conceptual difficulties. As noted above, it was designed to assess people with severe and profound developmental disabilities. However, a significant number of items on the DASH-II cannot be rated unless a person is able to communicate verbally. This is surprising, since most people with severe and profound mental retardation have, by definition, very limited or no expressive language. While this is made explicit in the instructions in relation to certain items (e.g. it is specified that "sees things that are imaginary" should be scored "not applicable" if the person is nonverbal), there are a number of other items for which this instruction is not provided, even though they seem equally inapplicable in people who are nonverbal. Examples include, "complains about mental disabilities" and "talks about the same subject or concern over and over".

It is also surprising that consideration has not been given to the impact of possible additional disabilities on symptom presentation, since it is not uncommon for people with severe mental retardation to have physical disabilities. A number of DASH-II items might not be applicable for people with additional physical disabilities, e.g. "runs away from supervision", "sleepwalks" and "starts a fire".

Additionally there are ambiguous or poorly defined items, which have the potential to compromise reliability and validity. For example, "is unable to remember things that s/he once knew" is open to many different interpretations, both in terms of different ways of assessing this and in terms of what kinds of memories might be considered. Other examples include, "is cranky or irritable" (which is highly subjective) and "is easily distracted" (which might be particularly hard to assess in individuals with a very limited concentration span).

Initial findings on the DASH suggested high inter-rater reliability (0.96, 0.95 and 0.91 for the dimensions of severity, duration and frequency respectively (Matson *et al*., 1991) but low internal consistency on the depression subscale (0.48, Matson *et al*., 1991). Internal consistency on the depression subscale of the DASH-II is slightly higher, 0.53, Paclawskyj, Matson, Bamburg & Baglio, 1997). Inter-rater reliability calculations (Matson, 1995) demonstrate means for percentage agreement calculations of 0.86, 0.85 and 0.95 for the frequency, duration and severity dimensions respectively. Percentage agreement (P) and Kappa (K) scores cited in the DASH-II manual for inter-rater reliability on the depression subscale are P=0.92, K=0.41 for frequency, P=0.92, K=0.32 for duration and P=0.96 and K=0.20 for severity. Mean percentage agreement calculations of 0.84, 0.84 and 0.91 were given for the frequency, duration and severity dimensions for test-retest reliability. Percentage agreement and Kappa scores for test-retest reliability on the depression subscale are P=0.88, K=0.52, P=0.88, K=0.49 and P=0.94, K=0.13 for frequency, duration and severity respectively. Hence, Kappa values for both inter-rater and test-retest reliability on the depression subscale are poor, since Kappa values need to be at least 0.60 to be viewed as indicating good agreement (Everitt, 1996).

Some evidence of validity of the DASH-II has been provided by Paclawskyj *et al*. (1997) who compared DASH-II scores and ABC (Aberrant Behavior Checklist, ABC, Aman & Singh, 1986) scores for 223 individuals, 90.5% of whom had severe and profound mental retardation. Overall, there was a high degree of convergent validity in terms of total scores. The depression subscale of the DASH-II was also shown to correlate with the lethargy, social withdrawal subscale on the ABC. A later validity study of the depression subscale by Matson *et al*. (1999) compared DASH-II scores to DSM-IV diagnoses provided by a psychiatrist blind to the DASH scores for 57 individuals with severe and profound mental retardation. The DASH-II was able to

distinguish between depressed and non-depressed individuals, although 4/15 individuals in the depressed group did not have elevated scores on the depression subscale of the DASH-II. Matson *et al*. (1999) offer possible explanations for these discrepancies. One individual was reported to suffer from bipolar disorder and was experiencing manic symptoms, as reflected in an elevated score on the mania subscale of the DASH. For the remaining individuals, Matson *et al*. (1999) suggest the diagnosis of "depression not otherwise specified in remission" might explain low depression subscale scores. While the first explanation appears informative, the second lacks clarity. It could reflect the difficulties inherent in using DSM criteria as a test of validity, given ambiguous diagnostic categories.

Meins (1996) piloted the only informant rating scale, designed to "assess" depression in people with mental retardation across all levels of disability, the Mental Retardation Depression Scale (MRDS). Meins (1996) found that the MRDS was able to separate adults with mental retardation and major depression from those with other depressive disorders and from those without depressive disorders. However, the assertion that this scale can be applied across all levels of disability should be viewed with caution for two reasons. First, only 14/51 (27.5%) of the participants had severe or profound mental retardation and second it is unclear how items such as "inner tension", "inability to feel" or "muscular tension" were ascertained in people with more severe disabilities. Moreover, "hostility" has been included as an item, even though it has not been shown identified conclusively in the literature as an "atypical symptom" of depression in this client group.

In conclusion, there are two main criticisms relevant to the rating scales for use with people with mental retardation:

1) Some scales, which are said to be applicable across all levels of disability, do not explain adequately how certain items can be assessed validly in people with very limited or no expressive language (e.g. "suicidal tendencies", Reiss Screeen; "complains about mental disabilities", DASH-II) and

2) Items included on rating scales and in interviews are often ambiguous and poorly defined (e.g. "Dependent: an excessive reliance on others. Examples: seeks help to an excessive

degree, excessive advice seeking, excessive need for companionship; Reiss Screen). This is also highly subjective and risks compromising reliabiltiy.

Observational techniques

Recent suggestions have been put forward regarding the application of observational techniques to assess mood disorder (Sovner & Lowry, 1990; Lowry & Sovner, 1992; Lowry, 1993; Lowry, 1994; Lowry & Charlot, 1996; Lowry, 1997; Lowry, 1998). This method is advantageous for people with severe mental retardation, since it does not rely on self-report. Sovner & Lowry (1990) propose that the majority of standard affective signs and symptoms in DSM-IV can be operationally defined and systematically observed, thus behavioral equivalents of "depressed mood" might include "sad or flat facial expressions", "rarely smiles or laughs", "cries out of the blue and/or often whines or complains" (Lowry, 1998). Lowry & Charlot (1996) contend that the only standard criteria, which cannot be defined in terms of observable behaviors, are feelings of guilt/worthlessness and recurrent thoughts of suicide.

This approach is promising, since it has the unique advantage of offering a methodology which, objectively tracks the daily fluctuations in discrete symptoms of a mood disorder (Lowry, 1998). However, it has only been applied to individual case studies (e.g. Lowry & Sovner, 1992; Sovner *et al*., 1993): the reliability and validity of this method and the "behavioral equivalents" (e.g. Lowry, 1998) need to be studied systematically with larger numbers of participants.

The assessment of mood in adults who have severe or profound mental retardation. Future directions.

Given the problems with existing assessment methods outlined in the preceding discussion, alternative ways are needed in order to assess mood in adults with severe or profound mental retardation. One possible improvement would be to develop an informant based rating scale, based on clearly defined behaviors that correlate with an individual's affective state. A preliminary study of a scale based on this principle (The Mood, Interest and Pleasure Questionnaire, MIPQ; Ross and Oliver, in press) has produced encouraging results. Initial findings indicate robust inter-rater and test retest reliability and internal consistency. There is also evidence for good concurrent validity. The use of scales such as the MIPQ and the use of

observational techniques (Lowry, 1998) highlight alternative ways of addressing the issue of mood assessment in adults who have severe or profound mental retardation.

In a clinical setting these methods could be further enhanced by considering the context for the individual's mood and behavior. When assessing mental health in persons with mental retardation, it has been noted that it is important to take into account the person and context by obtaining information from several sources (people and across settings) and by attending to changes in behavior and mood (Caine and Hatton, 1998). These considerations are, arguably, of equal importance when attempting to assess mood in adults with severe or profound mental retardation.

CONCLUSION

This review has demonstrated the importance of developing reliable and valid methods of assessing mood in people with severe and profound mental retardation, who cannot communicate directly about their thoughts and feelings. It has been proposed that there are a variety of applications of mood assessment. As indicated, most of the available research has been within the field of psychiatric diagnosis. While improving the diagnosis of affective disorders is clearly essential, psychologists could make a valuable contribution to the research literature by widening the scope of mood assessment. As highlighted, this could be applied in various contexts, for example, in order to appraise aspects of quality of life or to evaluate interventions.

Examination of the literature on affective disorders in people with mental retardation has illustrated several important points. Given the methodological limitations of studies investigating symptomatology, particularly in people with severe and profound developmental disabilities, the need for caution has been emphasised when interpreting findings regarding the "atypical symptoms" of depression. It has also been emphasised that there is a greater need to consider a wider context when attempting to understand "symptoms": Lowry's (e.g. 1994) biopsychosocial model might prove useful in this respect. The discussion has also highlighted the scarcity of assessment tools available for people with severe and profound mental retardation. While some useful initial attempts to meet this need have been made (e.g. DASH-II) measures of

this kind have been shown to present particular problems. There is a need to develop methods of assessing affect in adults with severe and profound mental retardation which are reliable, valid and do not rely on self-report. Observation of operationally defined behavioral correlates of affect (e.g. Green & Reid, 1996; Lowry, 1998) might offer a useful way forward.

Overall, it is apparent that much more research is required to address the emotional needs of people with severe and profound mental retardation. A better understanding of the process of assessing mood would be a valuable starting point. Beyond the theoretical applications already outlined, it is surely essential to find better ways of assessing mood states, such as happiness, for their own sake. By doing so, this should help all staff in contact with people with severe and profound mental retardation to be better able to answer fundamental questions relating to how individuals are feeling, given their limited ability to communicate this directly.

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