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Promoting Healthy Lifestyles – Mental Health

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Introduction

It is widely acknowledged that people with learning disabilities are more vulnerable to mental health problems than people without learning disabilities (Deb et al., 2001; Moss, 1999; Moss et al., 1998). There are a number distinct, but overlapping reasons for this increased vulnerability. These include predisposing biological factors and limited psychological coping resources associated with different forms of learning disability. People in this population also have increased exposure to a range of psychosocial stressors such as stigmatisation, isolation, unemployment, poverty, and traumatising abuse.

Studies of mental health problems amongst people with learning disabilities report large variations in the prevalence of these problems depending on the study design and methodology. For example studies based on reviews of case notes as opposed to clinical evaluation of clients will yield very different rates. The reliability of the assessment instruments used, and the inclusion of challenging behaviour as a mental health problem (or not) will also affect the results obtained. Further, the sampling methods used and the location of the study sample will result in large differences in obtained prevalence. (See Deb et al. (2001) and Hatton (2002) for more detailed discussion of these issues.) Studies of general populations of people with learning disabilities, excluding behaviour disorder and using psychiatric evaluation to identify cases, tend to report prevalence rates between 25% and 40% (Hatton, 2002). It is likely, however, that in routine health and social care settings many individuals with learning disabilities have mental health problems that remain undetected and therefore untreated (Patel et al., 1993; Reiss et al., 1982). Possible reasons for this under-diagnosis include service gaps and resource problems, 'diagnostic overshadowing' (Reiss et al., 1982), and deficiencies in the assessment measures

available to identify these problems (Caine & Hatton, 1998). As cases that are not identified cannot be assessed and treated effectively, then case identification is a crucial step in meeting the mental health needs of people with learning disabilities (Moss, 1999).

Once mental health problems are recognised amongst people with learning disabilities, there are significant challenges in meeting their needs in terms of effective treatment and intervention. This is because, despite the increased vulnerability of this client group to these problems, clinicians and researchers have been slow to develop and implement effective treatments. It has been suggested that this gap between need and provision is due to: a lack of interest in the problems of people seen as different; people with learning disabilities being considered not clever enough to benefit from psychological therapies; and therapists' reluctance to offer therapy to people who are unattractive because of their disabilities (Bender, 1993; Stenfert Kroese, 1998).

In this chapter we aim to explore issues relating to causes and prevalence and of mental health problems amongst people with learning disabilities, as well as difficulties involved in the identification, assessment and treatment of these problems. This is done within a framework that sets out the prevailing models for understanding these phenomena, the evidence available to support different types of treatment approaches, and ethical and professional considerations in working in this area.

What is Mental Health?

Exercise 1. Quickly write down your own idea of what you mean by mental health and mental health problem. Ask other people to do the same exercise and compare your definitions.

- *Are your definitions consistent?*
- *How would they distinguish a mentally healthy person from a person with a mental health problem?*
- *How would your definition apply to people with learning disabilities?*
- *What problems are there with your definition?*
- *How easy or difficult was it to try and write a definition?*

Terms like mental health, mental illness, mental disorder and psychopathology are commonly used as if everyone has a common understanding of what they mean.

However, the fundamental question of what mental health is, and how it may be distinguished from mental illness, is still being hotly debated with no consensus in sight (Sims, 1988). This is not (only) a rarefied academic discussion; definitions of mental health and mental illness have real consequences for people with learning disabilities. Some influential ideas about health and mental health include:

1. The Bio-Medical Model

This model (see Bowling, 1997; Nettleton & Gustafsson, 2002) sees mental health as being the absence of disease, where disease is created by physical causal agents (genes, bio-chemicals, damage to the body) leading to changes in the structure and function of the brain. Changes in thoughts, emotions and behaviour are seen as being caused by these physical agents, and interventions (typically medication or surgery) are directed to these physical agents. One of the many problems with this model for people with learning disabilities is that a person's learning disability can itself be viewed as a "disease of the brain" (Sims, 1982). This view, and the therapeutic pessimism that goes with it, was partly responsible for the large-scale institutionalisation and social devaluation of people with learning disabilities in many countries from the 19th century onwards (Trent, 1994; Wright & Digby, 1996).

2. *Illness as Variation from the Norm*

On this view, experiences can be placed on a continuum, and people with an illness are defined as those at the extremes of this continuum (Kendell, 1975). The term psychopathology has been defined in this way, as “abnormal experience, cognition and behaviour” (Sims, 1982). The view of mental illness as variation from the norm raises several questions: Who decides what the relevant dimensions of mental health are and how they are measured? Can all experiences be placed on a continuum? (Richards, 1996). Of course, people with learning disabilities in most classification systems are already partly defined in these terms, as being at the wrong end of the continuum labelled intelligence (Luckasson et al., 2002), with profound negative consequences (Trent, 1994; Wright & Digby, 1996).

3. *Mental Illness as a Mismatch of Ideas to External Realities*

First proposed by John Locke in the 17th century, this view proposes that mental illness involves the application of reasoning powers to unhelpful or bizarre beliefs: Locke himself contrasted this with his view of a person without reasoning capacity, i.e. a person now labelled as having a learning disability (Goodey, 1996). This contrast assumes that people with learning disabilities will not have the capacity to develop mental health problems, resulting in distress amongst people with learning disabilities being ignored and left untreated by clinicians (Hatton et al., 1999).

4. *A Holistic View of Health*

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1946). This definition emphasises health as positive well-being within a broad social context, rather than health as being the absence of disease within an individual. This definition is helpful in two ways; it emphasises well-being as the crucial indicator of

health rather than physical signs of brain disease, and it emphasises the social context within which mental health is experienced. However, it can be seen as over-inclusive (can anyone be said to be in a state of mental health on this definition?) and somewhat woolly.

5. *Mental Health as Social Construction,*

This view suggests that mental health is whatever powerful people (such as psychiatrists) say it is. This position takes the view that there are no fixed experiences that can be called mental health problems; instead societies use terms such as mental health to license methods of dealing with people viewed as problematic for the smooth functioning of society (Parker et al., 1995; Sedgwick, 1982). Certainly, historical studies have shown that frameworks for describing mental illness and the populations of people identified as having mental illness have varied tremendously over time (Kutchins & Kirk, 1997; Porter, 1990; Scull, 1993). However, some authors have argued that some experiences labelled as mental health problems have occurred consistently throughout history (Berrios, 1996) and that some mental health problems have clear biological causes (Gelder et al., 2000). It is also worth noting that even if mental health problems are socially constructed, they are often still real to the people experiencing them and the society in which they live.

6. *Mental Disorder*

To avoid some of the murky waters associated with using labels such as mental health or mental illness, international psychiatric classification systems have instead adopted the term mental disorder (American Psychiatric Association, 1994; World Health Organization, 1993). Although recognised as a fuzzy term, mental disorder has been defined in the following way (American Psychiatric Association, 1994):

Each of the mental disorders is conceptualised as a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be merely an expectable and culturally sanctioned response to a particular event, for example, the death of a loved one. (p. xxi)

This definition includes aspects of many of the (sometimes conflicting) views outlined above. For example, clinical judgement and cultural norms are highlighted, to some extent recognising that mental disorders occur within a social context. However, the definition also locates mental disorders firmly within individuals, as well as assuming that there are patterns of experience that fall into coherent clinical syndromes much like physical disease categories. On closer inspection, the term mental disorder seems as problematic as the health-based terms it is intended to replace.

For the purposes of this chapter, the holistic view of mental health will be used as a basic framework, for the following reasons:

- i. It allows for multiple explanations of the causes of mental health problems, including biological, psychological and social explanations;
- ii. It emphasises well-being as the fundamental marker of mental health;
- iii. It emphasises the social context within which people live.

Applying a Mental Health Framework to People with Learning Disabilities

As other chapters in this book have demonstrated, the living circumstances of people with learning disabilities as a group can be quite different to the general

population, with welfare services often having a greatly increased role in the lives of people with learning disabilities. These differences can have a profound impact on the degree and nature of mental health problems experienced by people with learning disabilities, and also on the way that services understand and respond to mental health problems with people with learning disabilities.

Living Circumstances, Life Events and Other Risk Factors

Exercise 2. Quickly write down your ideas about what life circumstances are risk factors for mental health problems and which are protective factors.

- *Do you think people with learning disabilities are more or less likely to experience each of the life circumstances you have written down?*

As a group, people with learning disabilities are likely to experience several living circumstances and life events associated with an increased risk of mental health problems in the general population (Brown, 2000). These include birth trauma, stressful family circumstances, poverty, unemployment, stigmatisation, lack of self-determination, and a lack of meaningful friendships and intimate relationships (Emerson et al., 2001; Hastings et al., 2004; Hatton & Emerson, 2004). Brown (2000) suggests that the meaning of these life events can be crucial in triggering mental health problems; particularly important are feelings of humiliation (feeling put down or devalued), entrapment (feeling imprisoned in a punishing situation for some time), loss (death or separation from important other people) and danger (feeling the threat of a potential future loss). A strong argument can be made that people with learning disabilities are more likely than the general population to experience humiliation, entrapment, loss and danger in the course of their daily lives. Certainly, people with learning disabilities do report experiencing stigma, linked to feelings of being

different and negative beliefs about themselves and their social attractiveness (Dagnan & Waring, 2004).

People with learning disabilities may be at greater risk of developing mental health problems due to psychological factors such as a reduced capacity for coping productively with stressful circumstances, poorer memory and poorer problem-solving and planning skills (van den Hout et al., 2000).

Accessing Services

Exercise 3. Quickly write down your ideas about how most people with mental health problems get help.

- *How is the person's mental health problem recognised?*
- *How do people get access to services?*
- *Which services do they access and what help do they get?*
- *Is this likely to be the same for people with learning disabilities?*

Despite the rapid pace of hospital closure for people with learning disabilities throughout the UK in the past 30 years (Emerson et al., 2001), people with learning disabilities are still largely supported by specialist learning disability health and welfare services rather than accessing mainstream health services designed for the general population (Elliott et al., 2003). This can cause real problems for people with learning disabilities and mental health problems.

Services for people with learning disabilities and people with mental health problems are largely separate and have quite distinct service cultures, with relatively few specialist mental health services for people with learning disabilities (Bailey & Cooper, 1997; Bouras & Holt, 2000; Hassiotis et al., 2000). For example, support staff in social services may be quite hostile to seeing a person's behaviour as symptomatic of a mental health problem (Costello, 2004).

Support staff may also be using a conceptual framework of challenging behaviour rather than mental health to understand problematic behaviours. Challenging behaviour is commonly defined in the following way (Emerson, 2001):

...culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities. (p. 3).

Although the challenging behaviour definition does not include any references to well-being, and mental health problems do not necessarily involve the person or others being in serious jeopardy or denial of access to community facilities, there are clear overlaps in the definitions. There are also overlaps in assumptions about cause; whilst most challenging behaviours are assumed to be immediately functional responses to particular social environments (e.g. aggression may be more effective in gaining staff attention than polite requests for a conversation) it is likely that some challenging behaviours are maintained neurobiologically (Emerson, 2001). As yet, the relationship between mental health problems and challenging behaviours in people with learning disabilities is unclear (Emerson et al, 1999; Moss et al, 2000).

‘Diagnostic overshadowing’ (Reiss et al, 1982) may also occur, where carers and professionals misattribute signs of a mental health problem as being due to a person’s intellectual disabilities. For example, poor self-care symptomatic of depression may be attributed to a person being incapable of self-care due to his or her learning disabilities.

Typical referral pathways to mental health services, through a GP due to a person having problems fulfilling social roles (e.g. spouse, parent, employee) (Goldberg & Huxley, 1980), may also be less accessible to people with learning

disabilities. First, people with learning disabilities are less likely to be in social roles where problems would be apparent. Second, environments for people with learning disabilities may be so restricted that a mental health problem may not be activated or displayed (e.g. a specific phobia). Third, some mental health problems may not manifest themselves in behaviours that are seen as problematic by carers or professionals (e.g. depression manifesting in social withdrawal and loss of energy) (Edelstein & Glenwick, 1997, 2001). In contrast, people with learning disabilities may be referred to mental health services when their behaviour is construed as a problem by other people rather than being a problem for the person themselves (e.g. anger in response to restrictions on autonomy and choice).

Finally, training programmes helping care staff to work effectively with people with learning disabilities and mental health problems are relatively rare (Bouras & Holt, 1997; Quigley, 2001) and limited in their effectiveness (Costello, 2004).

Identifying Mental Health Problems

Exercise 4. Imagine you are trying to interview a person speaking a language different to yours about their mental health problems.

- *How would you tell them what you were doing?*
- *How would you communicate important ideas?*
- *How would you understand what the person was telling you?*

Most professionals working in services for people with learning disabilities are likely to be working with a person with learning disabilities and mental health problems (Quigley, 2001). It is vital that professionals are sensitive to the possibility of mental health problems in people with learning disabilities, including having the awareness and skills to identify potential mental health problems. It will not surprise

you to discover that identifying mental health problems in people with learning disabilities is far from straightforward, with a number of difficult questions arising.

Question 1. Do standard psychiatric diagnostic criteria apply to (some or all) people with learning disabilities? Problems with how to identify mental health problems have been around as long as there have been mental health professionals (Berrios, 1996), with some studies reporting that psychiatrists form a strong opinion about their diagnosis within the first three minutes of a clinical interview (Sandifer et al., 1970). Indeed, the unreliability of clinical judgement has been one of the driving forces behind the development of the two standard psychiatric classification systems currently dominant in the UK: the Diagnostic and Statistical Manual of Mental Disorders (4th edition), produced by the American Psychiatric Association (American Psychiatric Association, 1994), and the International Classification of Diseases Classification of Mental and Behavioural Disorders (10th edition), produced by the World Health Organization (World Health Organization, 1993). Both of these are designed to be comprehensive systems for reliably classifying experiences into a set of 'mental disorders' according to particular criteria, using accompanying standardised interview schedules (Cooper & Oates, 2000). Whilst these classification systems may have increased the reliability of psychiatric diagnoses for the general population (their validity is another matter; Kutchins & Kirk, 1997), it is unclear how applicable they are to people with learning disabilities (Sturmey, 1999).

First, it is possible that these ways of classifying mental health problems may not be applicable to the experiences of people with severe and complex learning disabilities, who frequently have little or no symbolic language skills (Moss, 1999; Sturmey, 1999). For example, can a person with no symbolic language experience

auditory hallucinations, or have the cognitive skills necessary to conceptualise and plan a suicide attempt?

Second, these classification systems are categorical; that is, they seek to establish whether a person is experiencing a mental health problem or not. To reach a threshold for a mental health problem, a person needs to experience a pattern of symptoms at a certain level of frequency and severity. Many people with learning disabilities may show clear signs of a particular mental health problem, but not show a sufficient range of signs to reach the threshold to trigger a diagnosis of a mental health problem (e.g. psychotic experiences and schizophrenia; Hatton et al., under review; Moss et al., 1996a). There are also broader questions about how useful categorical diagnostic systems are in guiding clinical work with people with mental health problems (Bentall, 2004). For example, is knowing that a person has a label of schizophrenia enough to guide a clinical intervention, or is it more important to discover which experiences are a problem for the person and how they might be managed?

Third, these classification systems contain some assumptions that might be difficult to apply to people with learning disabilities. For example, these systems often diagnose a mental health problem as a change from the usual. This can be a problem for a person with learning disabilities and unrecognised mental health problems, where their mental health problems may not have changed for months or years. These systems also assume a usual level of functioning that may be difficult to apply to people with learning disabilities; for example criteria for depression include a diminished ability to think or concentrate.

Within the ICD-10 system, there have already been modified diagnostic criteria produced for people with mild learning disabilities (World Health Organization,

1996) and people with moderate to severe learning disabilities (Royal College of Psychiatrists, 2001). However, both of these modifications have been the subject of some debate (Cooper, 2003; Einfeld & Tonge, 1999) and are based on informal expert consensus methods with limited validity (Black et al., 2001).

Question 2. Is it possible to accurately assess mental states in people with learning disabilities? What we call mental health problems are typically complex patterns of behaviours and experiences, expressed individually from person to person. Although the full range of mental health problems encompass very different behaviours and experiences, identifying a mental health problem almost always involves gaining some access to the mental state of the person (Sims, 1982). Many mental states, whether they involve perceptions (I can hear a voice), emotions (I feel really down) or beliefs (I believe there is a neo-conservative plot to take over the oilfields of the Middle East under the guise of removing weapons of mass destruction) can really only be accessed by the person describing what their mental state is; inferring a mental state from a person's behaviour can be highly questionable.

Research evidence suggests that most people with learning disabilities and good functional communication skills can give accurate descriptions of their own mental states, as long as interview schedules are sensitively adapted and potential response biases such as acquiescence (saying yes to a question), suggestibility (saying that the person thinks the interviewer wants to hear) and confabulation (making up a response to fill gaps in memory or uncertainty) are assessed (Dagnan & Lindsay, 2004; Finlay & Lyons, 2001; Moss, 1999). There are also many examples of self-report mental health measures that have been successfully developed or adapted for people with mild or moderate learning disabilities (see below).

However, there is little or no research evidence demonstrating that asking people with more severe and complex learning disabilities about their mental states produces reliable or valid responses (Moss, 1999; Ross & Oliver, 2003a).

Some of these problems in gaining descriptions of mental states seem to be a function of the person's skills; for example many people with learning disabilities have difficulties in recognising and describing emotions, often using restricted or idiosyncratic emotional vocabularies (Reed & Clements, 1989; Rojahn et al., 1995). It is also the case that many of the ideas involved when assessing mental states are abstract and complex (for example, distinguishing between a voice, a thought and a dream), and are likely to be imperfectly understood by large sections of the population, including people with learning disabilities.

Question 3. To what extent can we use information from other people to assess mental health problems in people with learning disabilities? Because of potential problems in gaining information from the person with learning disabilities directly, many measures to assess mental health problems in people with learning disabilities have been designed to be used with an informant (typically a paid carer or a family member) rather than with the person themselves (see below). There is some convergence between the self-reports of people with mild or moderate learning disabilities and informants using highly structured clinical interview schedules, with informants more likely to pick up behavioural signs and unlikely to reliably report mental state (Moss et al., 1996b). However, people with learning disabilities and carers are less likely to agree using less structured interviews concerning emotional distress (Bramston & Fogarty, 2000). Even high levels of agreement would not, however, demonstrate that informant reports of mental health problems were valid for people without formal communication skills.

Question 4. To what extent can we use observational information to assess mental health problems in people with learning disabilities? Many mental health problems are considered to have distinctive patterns of behaviour associated with them, although many of these behavioural patterns are less distinctive on close inspection (for example, criteria for major depressive disorder include significant weight loss or weight gain and insomnia or hypersomnia; American Psychiatric Association, 1994). Relying on behavioural observations is unlikely to yield sufficient information to reliably identify most mental health problems. For example, self-reports and behavioural observations often do not agree (Rojahn et al., 1995). Moreover, the frequent reporting of ‘atypical’ behavioural symptoms in people with severe and complex learning disabilities suggests that reliable behavioural markers of mental health problems are unlikely in this group (Ross & Oliver, 2003a).

Informed Consent and Capacity

Consent to treatment is an important ethical issue for clinical professionals (APA, 2002; Sturmey & Gaubatz, 2002). People with learning disabilities, particularly those living in institutional settings, have been subject to various forms of abuse, including dangerous interventions that have resulted in injury and harm. Although some people with learning disabilities can understand the elements necessary for participation in treatment, many cannot (Arscott, Dagnan, & Stenfert Krose, 1999). In any case, many people with learning disabilities living in institutional or hospital settings have been placed there because they are judged to be legally incompetent. In such cases it is unclear who can consent either to treatment or participation in treatment outcome research. However, this is probably not very different for people without learning disabilities (e.g. Featherstone & Donovan, 2002). Therefore, we need to avoid the situation where discriminatory decisions to exclude

people with learning disabilities from potentially beneficial treatments are made on the basis of erroneous assumptions about their capacity to give consent compared with members of the general population. A balance is required in order to protect potentially vulnerable individuals and to promote self-determination.

According to the Lord Chancellor's Department (1999) valid consent requires: (a) that clients are provided with sufficient accurate information concerning the treatment; (b) that they have capacity to make a decision about accepting treatment and to understand the consequences of the decision; and (c) that their decision to accept treatment is voluntary. Making information about treatment understandable and accessible to people with cognitive limitations is challenging for clinicians, but not insurmountable (Arscott et al., 1999). One helpful approach is to include a psycho-educational preparatory phase following which participants will be better informed and able to give or withhold valid consent (e.g. Taylor et al., 2002a). Further enquiry is needed concerning the evaluation of clients' capacity to give valid consent. Capacity involves the ability to comprehend information about the treatment, to be able to assimilate and recall the information, and to be able make a decision about accepting the treatment being offered (Wong, et al., 1999). However, the extent to which consent-giving by people with learning disabilities can ever be totally free, and so voluntary, given issues around acquiescence and suggestibility is questionable. This is a debate that needs to be brought into the open and not avoided or ignored. In that way clinicians, clients and their supporters can be clear about the ethical issues in this difficult area of work.

If consent cannot be given and the client would have benefited from a particular treatment, then another ethical dilemma is the denial of the benefits of particular treatment interventions to people for whom adequate consent cannot be obtained. In

England & Wales this issue is addressed in the Department of Health (2001) guidance document, *Seeking consent: working with people learning disabilities*. This guidance suggests that individuals who do not have the capacity to give consent can be given treatment if it is judged to be in the person's best interests. Treatments for mental health problems, including those for people with learning disabilities, have been subject to fashions and fads that sometimes are not harmless (Sturmeay, Taylor & Lindsay, 2004). Facilitated communication, for example, has been considered not just to be wasteful and ineffective (Mostert, 2001), it has resulted in the wrongful conviction of parents for the sexual abuse of their children and led to the separation of children from their families. We cannot assume that well intended treatments are always helpful, neutral or harmless. In the absence of good evidence to support particular interventions we should be cautious about offering them to people with learning disabilities who may have difficulty in resisting them.

How Many People with Learning Disabilities Experience Mental Health Problems?

Exercise 5. What proportion of people with learning disabilities and the general population do you think will experience the following mental health problems?

- *Depression*
- *Anxiety*
- *Psychosis/schizophrenia*
- *Substance misuse*
- *Dementia*

What were the reasons behind your guesses?

Given the problems in identifying mental health problems in people with learning disabilities discussed earlier, you won't be surprised to find that research on the rates

of mental health problems in this population is patchy and inconsistent, with prevalence rates of mental health problems varying between 10% and 80% (Borthwick-Duffy, 1994). Higher rates (40% upwards) are reported if challenging behaviour was included as a mental health problem (e.g. Gillberg et al, 1986), or if the population studied was referred for psychiatric evaluation (e.g. Bouras & Drummond, 1992). Low prevalence rates (15% downwards) are reported by studies using general case notes to identify mental health problems (e.g. Borthwick-Duffy & Eyman, 1990). Studies of general populations of people with learning disabilities using screening instruments or psychiatric evaluation to identify cases tend to report prevalence rates between these two extremes, usually between 20% and 40% (e.g. Iverson & Fox, 1989; Lund, 1985; Taylor et al., 2004a). This compares to a prevalence rate of approximately 25% for similar mental health problems in the general population (Goldberg & Huxley, 1980).

Evidence on specific mental health problems experienced by people with learning disabilities is patchy:

Depression. Reported prevalence rates for depression vary widely (Stavrakaki, 1999), although studies focusing on depressive symptoms typically report very high rates from 44% (Marston et al, 1997) to 57% (Meins, 1993). People with mild/moderate learning disabilities display the range of depressive symptoms found in the general population, although the validity of the 'atypical' symptoms reported for people with severe/profound learning disabilities is questionable (Ross & Oliver, 2003a).

Anxiety. The little research evidence available suggests high levels of anxiety disorders in adults with learning disabilities (e.g. 27%; Stavrakaki & Mintsoulis,

1997), although the validity of diagnoses of anxiety is particularly questionable for people with severe/profound intellectual disabilities (Matson et al., 1997).

Psychosis. There is some evidence that rates of psychosis are substantially higher amongst people with learning disabilities (Doody et al., 1998; Lund, 1985; Turner, 1989), although estimated rates of psychosis vary from 2% to 6%. Once again, the absence of reliable self-report makes the diagnosis of psychosis in people with severe/profound intellectual disabilities difficult (Clarke, 1999).

Substance Misuse. General research suggests low levels of alcohol and drug use amongst adults with learning disabilities (e.g. Lund, 1985), although alcohol use may be higher in more independent living circumstances (Robertson et al, 2000).

Dementia. The prevalence of dementia is much higher amongst older adults with learning disabilities compared to the general population (21.6% vs. 5.7% aged 65+; Cooper, 1997). People with Down's syndrome are at particularly high risk of developing dementia, with an age of onset 30-40 years younger than the general population (Holland et al., 1998).

Anger and aggression. Studies conducted across three continents using broadly similar designs and methods have found the prevalence of aggression amongst people with learning disabilities to be between 10% and 16% in community populations, and 35% to 47% in institutional and specialist service settings (see Taylor, 2002; Taylor and Novaco, in press for reviews). Lindsay and Law (1999) found that the assessed rate of clinically significant anger problems amongst clients referred to a specialist community learning disability service in Scotland was 66%.

Recent epidemiological research suggests that the prevalence of anxiety and conduct disorders may be much higher amongst children and youths with learning

disabilities, although rates of depression are similar (Emerson, 2003; Linna et al, 2000; Tonge & Einfeld, 2000).

Assessing Mental Health Problems in People with Learning Disabilities

Most professionals are likely to be working with at least one person with learning disabilities and a mental health problem, even if that mental health problem is unrecognised by those around them (Quigley, 2001). The beginning of any effective intervention for a person's mental health problems must be accurate, timely and regular assessment:

- *Accurate* in terms of reliable and valid assessment tools to ensure that people's mental health problems are not being missed, but also that people are not being given unnecessary labels.
- *Timely* to ensure that people experience distressing and debilitating mental health problems for as short a period as possible.
- *Regular* to ensure that any mental health problems are recognised, but also to ensure that people do not acquire a permanent label of dual diagnosis when their mental health problem may have been resolved.

The development of reliable and valid mental health screening measures for people with learning disabilities is in its early stages, with a proliferation of measures and little evidence on the reliability or validity of any of them (Beail, 2004; Dagnan & Lindsay, 2004; Deb et al., 2001; Novaco & Taylor, 2004). Different measures vary according to:

- Whether are they measures developed for the general population and then used or adapted for people with learning disabilities, or whether they are specifically designed for people with learning disabilities.

- Whether they are designed as self-report measures to be completed by people with learning disabilities (almost always in an interview format), or whether they are designed to be completed by informants about the person with learning disabilities (in either a questionnaire or interview format).
- Whether they are designed primarily for people with mild/moderate learning disabilities, people with severe/profound learning disabilities, or the whole range of people with learning disabilities.
- Whether they are designed to act as a screen across a wide range of mental health problems, or whether they focus in more detail on a particular mental health problem.
- How much training and knowledge of mental health issues is needed to use the measure.
- The length of time they take the professional, person with learning disabilities and/or the informant to complete.

A wide range of mental health measures are presented in Tables 1 and 2, together with some information on their characteristics and purposes. When working in more depth with a person, it can also be useful to develop individual measures for the most important aspects of that person's experience (Dagnan & Lindsay, 2004; Finlay & Lyons, 2001; Stenfert Kroese et al., 1997; Taylor et al., 2004b).

Case Vignette 1

In addition to detecting and describing the mental health problems of clients, good clinical assessment is required to enable the clinician to carry out case formulations of complex problems and to make decisions about appropriate interventions and salient treatment targets. In this case study the use of different

assessment approaches to guide formulation and treatment planning is illustrated with a particularly complex mental health case.

At the time of the assessment Joan was a 45-year old women with mild learning disabilities (WAIS Full Scale IQ = 59). She was compulsorily detained under the Mental Health Act 1983 for treatment in an acute mental health ward of a specialist learning disability hospital service. Joan was the youngest of six siblings, and though she was a twin, her twin sibling died at birth. Her mother died of cancer when Joan was 4 years old. Joan attended special school due her learning difficulties, but on leaving school she got a job in factory that she enjoyed. She married her first husband in her early twenties and had a child soon after. Her husband was violent and sexually abused their daughter. They had two more children together, but after nine years of marriage Joan separated from her husband. She re-married, but this marriage lasted for only a few months. Thereafter Joan was supported by her family, and in particular her older brother.

Joan had a long history, starting at the age of 16, of contact with mental health and learning disability services due to difficulties with coping with life stressors, self-injury and suicide attempts. During the previous few years one of Joan's sisters died of cancer and her oldest sister emigrated. Her brother re-married and her father became frail. In this context of dwindling support, Joan's most recent contact with mental health services followed her overdosing on prescribed medication because she felt unable to cope with her children. She had a period of inpatient treatment, during which she reported experiencing sexual abuse from another patient. Her children were taken into care and Joan was eventually discharged home. Unfortunately, shortly after this Joan set fire to her house in a further attempt to kill her self because she felt

unable to cope once more. These events precipitated her admission to her current placement where she had been for 18 months.

In the past Joan had been treated with ECT and was currently prescribed antipsychotic medication which she disliked taking because of its side-effects. Joan presented a number of challenges to the team working with her including frequent agitation and aggression, and occasional violence. She also reported, almost continuously, a range of negative and distressing beliefs and fears such as “I’m dead”, “I’m brain-dead”, “I’m dying”, “I’m being poisoned”, “No one loves me”, “They (staff) hate me”, “They (staff) don’t believe me”. Joan was referred for an assessment and formulation of these problems to help with treatment planning. The assessment was carried out jointly by psychology and nursing colleagues over an eight-week period and included clinical assessment to gain information from Joan and staff working with her directly, formal assessment and a case-note review.

During the first few weeks regular sessions were held with Joan to build some rapport and trust in order to facilitate engagement in the assessment process. This involved listening to her concerns and fears uncritically, and without challenging any of the assumptions underlying them, and slowly introducing the rationale for formal assessment procedures to help her with her problems. The formal assessments conducted included the Mini-Mental State Examination (*MMSE*; Folstein et al., 1975). This indicated that, taking her learning disability into account, Joan was grossly cognitively impaired. She was significantly disorientated for time and place, her simple recall was poor, and her visuo-spatial planning and organisation was impaired. Joan’s performance on the Autobiographical Memory Inventory (*AMI*; Kopelman et al., 1990) showed that Joan had very significant problems with ordering and recalling details of significant events in her life, with memory for recent events

being even more compromised than for those from earlier in her life. For example, she could not recall or even estimate with any degree of accuracy her youngest child's date or year of birth. The Psychiatric Assessment Schedule – Adults with Developmental Disabilities (*PASS-ADD*; Moss et al., 1997) is the only standardised assessment of psychiatric disorder specifically for people with learning disabilities. It uses ICD-10 (WHO, 1993) standard psychiatric classification system for diagnosis. This assessment of present mental state, conducted with the patient and an informant, indicated that Joan was experiencing a 'severe depressive episode with mood congruent psychotic symptoms'. The assessment of Joan's situation also suggested that the staff team were inconsistent in their responses to and management of her problems and distress.

A formulation of Joan's problems was developed using a psychological model of mental illness whereby inter-related biological, environmental and social factors are mediated by psychological processes before being expressed as mental health problems. In Joan's case predisposing biological factors possibly included cognitive deficits and information processing difficulties associated with her learning disability. The environmental context included frequent experiences of abuse and loss of important family members, and more recently placement in an environment with carers who were confused about how to support her needs. Salient social factors included the repeated loss and break down of close supportive relationships leading to isolation, and currently antagonism and hostility with primary carers. It was proposed that these previous events, along with current stressors, impacted adversely on Joan's psychological functioning and were experienced by her as feelings of guilt, worthlessness and low self esteem, along with acute anxiety and fear that important others would reject and abandon her. At times of high stress and arousal these feelings

could be experienced intensely as depressive and negative automatic thoughts that she was useless, worthless, unloved and unlovable. As she may as well be dead, she felt dead (or 'brain dead') and her self-injury and suicide attempts were linked to this belief system. She dealt with her acute fear of abandonment and loss by alienating those around her so that they were unable to get close enough to harm or reject her. Carers' responses to Joan's aggression was interpreted by her as malevolent and expressed as paranoid ideation that others were trying to harm or kill her.

The treatment plan recommended for Joan based on this assessment and formulation included the following sequential but overlapping interventions:

1. Training and support for direct care staff working with Joan to help them better understand her problems and to help them develop more consistent approaches to the behavioural expression of these difficulties. It was hoped that this would help Joan to feel safer and more secure in her current placement.
2. Psychological intervention, utilising a modified cognitive-behavioural approach, to gently explore whether Joan could be encouraged to test some of her assumptions about herself and her environment and slowly begin to undermine the negative beliefs and schema that resulted in her feelings of depression, worthlessness and paranoia.
3. During Joan's short periods of relative remission, meaningful activities (and eventually occupation) could be encouraged and supported to counteract feelings of boredom and worthlessness, and to begin to build self-esteem and confidence.
4. Longer- term, depending on progress with the above measures, helping Joan to remember and order the important events in her life so that she

might deal with unresolved issues and place them in context could be considered using a life-story book type approach.

Promoting Good Mental Health in People with Learning Disabilities

Exercise 6. Imagine a person with a particular mental health problem.

- *What interventions might work for this person?*
- *How would you decide which intervention(s) to try?*
- *If this was a person with mild learning disabilities, would the range of possible interventions be different? Why?*
- *What adaptations, if any, would you have to make to an intervention to make it work for a person with mild learning disabilities? Why?*

Identifying and accurately assessing potential mental health problems in a person with learning disabilities is a necessary first step in trying to promote mental health. Once this has been achieved, what can be done to actively promote good mental health? As with mental health interventions for the general population, interventions with people with learning disabilities can be broadly put into three categories:

- i. *Biological interventions*, typically medication.
- ii. *Psychological interventions*, typically behavioural approaches, cognitive-behavioural therapy and psychodynamic psychotherapy.
- iii. *Social interventions*, which may involve changing the life circumstances of the person and working with families and staff systems.

Before discussing particular mental health interventions, it is important to note that evidence for the effectiveness of any mental health intervention for people with learning disabilities is sparse and very rarely at the level of well-designed randomised controlled trials. For any professional engaged in a mental health intervention with a

person with learning disabilities, there is needed both creativity in designing and conducting interventions, and rigour in assessing the effectiveness of the intervention for the individual.

Biological Interventions

Although there is a large evidence-base concerning the effectiveness of psychotropic medications (medication designed to alter some aspect of psychological functioning) in the general population, there is very little systematic evidence concerning their use with people with learning disabilities (Matson et al., 2000; Thompson et al., 2004). In the absence of systematic evidence, clinical recommendations suggest using similar medication strategies for people with and without learning disabilities, particularly in terms of prescribing specific medications for specific, diagnosed mental health problems (Berney, 2000; Rush & Frances, 2000). However, there is substantial evidence showing that particular psychotropic medications are often over-prescribed for people with learning disabilities, inappropriately prescribed for challenging behaviours rather than diagnosed mental health problems and prescribed in complex and dangerous combinations (Robertson et al., 2000).

Antipsychotic medication. Older, neuroleptic antipsychotics are frequently prescribed for people with learning disabilities (25%-57% of people living in NHS settings; 20%-50% of people living in community-based residential services; 10% of people living independently or with family members; Robertson et al., 2000). These antipsychotics are most often prescribed to reduce challenging behaviour, despite strong evidence that they have no specific impact on challenging behaviour beyond sedation and have long-term and irreversible side-effects (Robertson et al., 2000; Thompson et al., 2004). There is very little evidence concerning the use of newer,

atypical antipsychotics with people with learning disabilities; although some studies suggest they may reduce some aggression and self-injury, there are conflicting findings and associated side-effects such as sedation and weight gain (Thompson et al., 2004).

Antidepressant medication. Rates of antidepressant prescriptions with people with learning disabilities are much lower (14% in NHS settings; 6% in community-based residential services) and more closely associated with diagnoses of depression (Robertson et al., 2000). However, older antidepressants such as monoamine oxidase inhibitors and tricyclics are reported to be mixed in their effectiveness with dangerous side effects (Thompson et al., 2004). Newer SSSRIs have been reported to be effective in small studies of people with learning disabilities and depression (Thompson et al., 2004).

Antiepileptic medication. Rates of epilepsy are high amongst the population of people with learning disabilities, and anti-epileptics are frequently prescribed (46% in NHS settings; 36% in community-based residential services; Robertson et al., 2000). However, in the general population some antiepileptic drugs have also been shown to be effective in stabilising mood amongst people with bipolar disorder (manic depression), although there is only case study evidence concerning people with learning disabilities (Thompson et al., 2004).

Hypnotic and anxiolytic medication. A wide range of medications can be used to reduce symptoms of anxiety and panic, although their use is not widespread amongst people with learning disabilities (11% in NHS settings; 9% in community-based residential services; Robertson et al., 2000) and there is little evidence concerning their effectiveness with people with learning disabilities (Thompson et al., 2004).

Medication to change behaviour. Two types of medication have received attention for their potential to control specific challenging behaviours. The first are stimulants, increasingly prescribed to control hyperactivity in children; there is substantial evidence concerning both the effectiveness and the side effects of these medications for children with learning disabilities (Thompson et al., 2004). The second are opioid antagonists, which have been shown to be effectiveness in reducing certain types of self-injury show by people with learning disabilities (Thompson et al., 2004).

Clearly, many people with learning disabilities are regularly prescribed inappropriate and sometimes dangerous psychotropic medication with no clear rationale or evidence of effectiveness. If a person is prescribed any psychotropic medication, it is vital to ensure that:

- Any psychotropic medication prescription is accompanied by a clear rationale for its use.
- There are regular medication reviews by a person with the authority to alter medication prescriptions.
- There is ongoing regular assessment of a person's mental health status and behaviour, to be able to review the effectiveness of medication regimes.
- There is consideration of the latest available evidence concerning both the effectiveness and the side effects of psychotropic medications.
- Wherever possible, attempts are made to reduce both the dosages and the number of psychotropic medications prescribed; research evidence shows that the antipsychotics of 50% of people with learning disabilities can be reduced or withdrawn without any adverse impact on mental health or behaviour (Ahmed et al., 2000).

Psychological Interventions

Research evidence concerning the efficacy of psychological interventions for people with learning disabilities and mental health problems is equally sparse, although some general reviews are beginning to appear (Beail, 2003; Hatton, 2002; Prout & Nowak-Drabik, 2003; Sturmey, 2004). Existing evidence consists of a small number of case studies using behavioural interventions with symptoms of mental health problems, a larger body of case series and occasional trials using cognitive-behaviour therapy for a range of mental health problems, and uncontrolled trials using psychodynamic psychotherapy with mental health problems. Whilst it is clear that people with learning disabilities can benefit from psychological interventions (Hatton, 2002; Prout & Nowak-Drabik, 2003), it is unclear how many people could benefit or what approaches work best for whom (Beail, 2003). Specific assessments of the skills required for particular therapeutic approaches rather than assessments of general ability are likely to be more clinically useful in guiding which intervention to use (Beail, 2004; Dagnan & Lindsay, 2004).

Psychological interventions have typically focused on five domains of mental health problem: depression; anxiety; psychosis; anger; and offending.

Depression. A small number of case studies and a case series of routine practice have investigated cognitive-behaviour therapy with people with mild/moderate learning disabilities and depression, and reported improvements in self-reported depressive symptoms and behaviour (Dagnan & Chadwick, 1997; Lindsay et al, 1993; Lindsay & Olley, 1998), with improvements maintained at two to six month follow-up (Lindsay, 1999).

Anxiety. Again, a small number of case studies and a case series have demonstrated the potential feasibility of cognitive and behaviour therapies in reducing

anxiety amongst people with learning disabilities. Behavioural interventions such as relaxation appear to be effective in reducing anxiety and improving cognitive performance amongst people with mild, moderate and severe intellectual disabilities (Lindsay & Baty, 1986; Lindsay et al, 1989; Morrison & Lindsay, 1997). Anxiety management training (e.g. Lindsay et al, 1989) and behavioural and cognitive-behavioural interventions for specific phobias (e.g. Dixon & Gunary, 1986; Lindsay et al, 1988) have been shown to be effective in isolated reports. Case studies and a case series of cognitive-behaviour therapy have shown reductions in self-reported anxiety and embarrassment (Lindsay et al, 1997), maintained at 6- month follow-up (Lindsay, 1999).

Psychosis. Little evidence is available concerning psychosocial interventions for people with learning disabilities and psychosis. Two case study reports of behavioural treatments with four people with mild to severe learning disabilities and psychosis have demonstrated reductions in the display of 'psychotic speech' (Mace et al, 1988; Stephens et al, 1981). A single case study and a case series of five people with mild learning disabilities and psychosis, using cognitive-behavioural and psychosocial approaches, resulted in improvements in psychotic and symptoms and other outcomes (Haddock et al., 2004; Leggett et al, 1997). Kirkland (2004) adapted an established cognitive-behavioural formulation model for use with three men with mild learning disabilities who experienced auditory hallucinations and/or paranoid delusions. An accessible diagrammatic approach to shared formulations helped these clients understand their symptoms better, test out their beliefs and resulted in some subjective relief from their distressing symptoms.

Anger. More intervention studies have been conducted concerning cognitive-behavioural interventions to reduce anger in people with learning disabilities, mainly

using adaptations of the Novaco (1975, 1993) approach to anger management. Taylor (2002) and Taylor and Novaco (in press) have reviewed numerous case and case-series studies, and a small number of uncontrolled group studies involving individual and group therapy formats that have yielded reductions in levels of anger and aggression that were maintained at follow-up. In addition there have now been three small outcome studies that have established the effectiveness of group cognitive-behavioural anger treatment over wait-list control conditions with clients with learning disabilities and anger and aggression problems living in community settings (Lindsay et al., 2004; Rose et al., 2000; Willner et al., 2002). The Lindsay et al. (2004) study is noteworthy in that it was conducted over a period of 10 years. Consistent with other studies, the treatment group improved significantly when compared to the wait-list control group and improvements were maintained for up to 15 months. In addition these authors compared the experimental and the control groups for the percentage of participants who were physically assaultive over an equivalent time period. They found that significantly fewer of the experimental group physically assaulted others (14% vs. 45% respectively) and concluded that this was a result of the anger management intervention.

Case series of cognitive-behavioural anger treatment has also been shown to be effective with female and male participants who were classified as forensic cases or who were convicted offenders (Allan et al., 2001; Lindsay et al., 2003). Taylor et al. (2002a, 2004a, in press, a) reported on a series of three concatenated controlled studies that involved male offenders with mild-borderline learning disabilities receiving intensive individual and formulation-guided cognitive-behavioural anger treatment in secure inpatient settings. The treatment groups improved significantly on self-reported measures of anger disposition, anger reactivity and anger control

compared to the control groups. Staff ratings of study participants' anger disposition converged with patient self-reports but did not reach statistical significance.

Improvements in observed behaviour are not inevitable, often due to a low base rate phenomenon, and the multi-faceted nature of these interventions makes it difficult to evaluate which elements of this treatment approach are most effective.

Offending. Lindsay, Taylor and Sturmey (2004) have comprehensively covered the field of offending by people with learning disabilities. Further, there have a number of reviews of psychological interventions with offenders with learning disabilities (e.g. Clare & Murphy, 1998; Lindsay, 2002; Lindsay & Taylor, in press; Taylor, 2002). These interventions are often delivered as condition of diversion from the prison system and may take place in community or secure settings under probation orders or mental health act sections respectively. Cognitive-behaviour therapy focusing on the attitudes of sex offenders with mild/moderate learning disabilities (see Lindsay, 2002, for a review), including offences against women and children, has been reported to be successful in changing attitudes in uncontrolled trials of six (Lindsay et al, 1998a) and 24 (Lindsay, 1999) sex offenders with learning disabilities (see also Lindsay et al, 1998c), although treatment has to be of sufficient duration to influence re-offending rates (Lindsay & Smith, 1998) A preliminary report of a group intervention for sex offenders with learning disabilities showed some success in reducing re-offending rates, and a case study of two stalkers with learning disabilities showed mixed success (Lindsay et al, 1998d).

A single case study has reported a successful cognitive-behavioural intervention for a man with mild learning disabilities convicted of firesetting (Clare et al, 1992) and a complex offending case (Clare & Murphy, 1998). In a pre-post group study design Taylor et al. (2002b) reported significant improvements on fire-specific

and associated clinical measures for 14 male and female convicted arsonists with mild-borderline learning disabilities who received a broadly cognitive-behavioural group intervention in a low secure hospital setting. Using the same treatment approach a case series of four male firesetters with mild learning disabilities were found to benefit clinically from this intervention (Taylor et al., 2004c), while five female firesetters with mild-borderline learning disability and chronic histories of frequent firesetting had not set any fires two years after completing this treatment (Taylor et al., in press, b)

Psychodynamic Psychotherapeutic Interventions

There have been several suggestions that psychodynamic psychotherapy can be useful for people with learning disabilities and mental health problems (Beail, 2003, 2004). Recent UK uncontrolled trials of routine clinical practice have demonstrated promising results for psychodynamic-interpersonal therapy with adults with mild/moderate learning disabilities, including adults referred for 'behaviour problems' (Beail, 1998; Frankish, 1989), adults with mental health problems (Beail & Warden, 1996; Beail, 2000) and adult offenders (Beail, 2001).

Case Vignette 2

As mentioned in the introduction to this chapter, one possible reason that people with learning disabilities have not historically been offered psychological therapies to help with their mental health problems is the belief that these approaches would not be effective as clients are not clever enough to understand or engage in talking therapies. This issue has been raised in connection with cognitive-behavioural therapy generally (e.g. Stenfert Kroese, 1998) and the cognitive component of cognitive-behavioural anger treatment for people with learning disabilities specifically

(Rose et al., 2000; Willner et al., 2002). So, can people with learning disabilities successfully engage in work on the content of thoughts/cognitions that play a role in maintaining mental health problems?

James is a 22-year old man with mild learning disabilities (WAIS Full Scale IQ of 66) and borderline personality disorder. He has history of depression, self-injurious behaviour, sexually aggressive behaviour and physical violence. James attended special schools but was excluded on several occasions because of assaults on other students. As a 17-year old James was sexually abused by an older male friend of his family. His mental health and behavioural problems deteriorated after this time. The frequency of James' self-injury increased and he complained of mood swings and difficulty in controlling his temper. When he was 20 years old he was prescribed antidepressant medication for low mood, poor appetite, sleep problems and flashbacks to his own sexual abuse. Unfortunately, soon after James overdosed on his medication and was admitted to the acute mental health ward of a specialist learning disability hospital. After only a short-time in this environment James was displaying sexually predatory behaviour towards less able patients, refusing his medication, physically aggressive towards staff and required physical restraint. Consequently he was sectioned under the Mental Health Act 1983 and transferred to a low secure forensic ward in the hospital.

James continued to be disturbed and aggressive and he was assessed as a potential candidate for individual anger treatment. Self-rated anger assessments specially modified for clients with learning disabilities were used to assess the level of James' anger problems and to guide the treatment. The Novaco Anger Scale (*NAS*; Novaco, 1993) is a measure of anger disposition that assesses the cognitive, arousal and behavioural components of an individual's experience of anger. The Provocation

Inventory (*PI*; Novaco, 1993) is a measure of anger reactivity across a range of anger-provoking situations. James' scores on these assessments were significantly higher than the means for his reference group and his scores on the Cognitive sub-scale of the NAS and the Unfairness/Injustice sub-scale of the PI were particularly elevated.

The cognitive-behavioural anger treatment used with James was developed especially for clients with mild learning disabilities and severe or chronic anger control problems (Taylor & Novaco, in press). It incorporates cognitive re-structuring, arousal reduction and behavioural skills training components in equal measures. James completed all 18 sessions of anger treatment (6 sessions Preparatory Phase and 12 sessions Treatment Phase) within the planned time period and without incident. His approach towards the treatment was positive and generally enthusiastic. His response to the different components of the intervention was also positive. James learned how to control the physiological component of anger arousal through a combination of breathing control, progressive muscular relaxation, distracting imagery and self-instructions. He was able to show limited ability to deal successfully with angry situations using role-play, although his coping skills in terms of problem-solving lagged behind his understanding of these issues, and this was reflected in ongoing difficulties outside of the therapy sessions.

In terms of the cognitive component of the therapy James was able to learn to identify the automatic thoughts (usually negative and unhelpful) that accompanied angry incidents. As the treatment progressed he was able to spontaneously generate alternative and more adaptive cognitions in response to such incidents. In treatment James engaged in cognitive re-structuring with relative ease, and in so doing he demonstrated an ability to perspective-take by putting himself in another's position in relation to particular situations. Appendix 1 provides an example, from within a

treatment session, of how James was able to use an incident that occurred between sessions to generate alternative thoughts about a particular situation (being told that his behaviour programme was about to be changed). He could see that that thinking about this situation differently would lead him to feel less angry, be more in control and so react in a more adaptive and productive manner. The 'possible' or alternative *thoughts-emotional feelings-physical feelings-reaction* chain generated by James in response to the activating situation was the used in the session by James to practice coping more effectively with anger; first in imagination (using stress inoculation technique whilst relaxed) and then in practice (using role-play). James was then encouraged to practice thinking differently about situations between sessions using daily anger logs so that this skill is moved temporally closer to real situations.

It can be seen from this example that people with (mild) learning disabilities can make the link between cognitions/thoughts and feelings/reactions and unlink the automatic connection between events and feeling/reactions. Thus people with learning disabilities can engage in and benefit from the cognitive component of cognitive-behavioural therapy. James' pre-post treatment and follow-up scores on the self-rated anger assessments support this view. The cognitive sub-scale of the NAS came down following treatment and remained lower at 8-month follow-up. James' scores on the Unfairness/Injustice sub-scale of the PI followed a similar pattern. While James's behaviour on the ward continued to cause staff concern, their staff-rated anger scores converged with James' self-ratings and reflected his progress in the anger treatment.

Social Interventions

Given the life circumstances that put people with learning disabilities at potentially greater risk of developing mental health problems, it would be expected

that social interventions would be developed to reduce social and environmental risk factors and increase resilience (Jenkins, 2000). However, interventions at this level have very rarely been conducted with people with learning disabilities, beyond the involvement of broader interpersonal systems such as families or staff members around the person (e.g. Haddock et al., 2004; Rose et al., 2000; Taylor et al., 2002a). Interventions designed to improve people's living arrangements have rarely been designed with mental health as an outcome, and broader policy changes such as deinstitutionalisation have rarely been evaluated in terms of their impact on mental health (Emerson & Hatton, 1996). There is clearly a great potential for social interventions to improve the mental health of people with learning disabilities.

Conclusions

Resources

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(What about the National CBT in LD Network compendium of assessment materials that Emma and Kathryn are working on? Can it be included here?)

(What about the materials on mental health problems produced by ?Richard Whitehead et al. specifically for people with LD?)

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Table 1. *Assessment Measures: Multiple Mental Health Problems*

Measure	General population measure or specific for people with learning disabilities	Areas assessed	Completed with person with learning disabilities	Completed with informant	Details of measure
<i>A. Screening tools for multiple mental health problems</i>					
Reiss Screen for Maladaptive Behavior Reiss (1998a, b)	Specific	Total Aggressive behavior Psychosis Paranoia Depression (behavioural signs) Depression (physical signs) Dependent personality disorder Avoidant behavior Autism	No	Yes	36 items Adequate reliability Adequate sensitivity Questionable specificity (Sturme & Bertman, 1994)
Diagnostic Assessment for the Severely Handicapped (DASH) Matson et al. (1991)	Specific	Total Anxiety Depression Mania Autism Schizophrenia Stereotypies/tics Self-injury Elimination disorders Eating disorders Sleep disorders Psychosexual disorders Organic syndromes Impulse control/miscellaneous	No	Yes	Designed for people with severe learning disabilities 83 items Adequate reliability Unknown sensitivity or specificity

Psychopathology Instrument for Mentally Retarded Adults (PIMRA) Matson et al. (1984) Senatore et al. (1985)	Specific	Total Schizophrenic disorder Affective disorder Psychosexual disorder Adjustment disorder Anxiety disorder Somatoform disorder Personality disorders	Yes	Yes	56 items Adequate reliability Questionable sensitivity and specificity (Sturmev et al., 1991)
PAS-ADD Checklist Moss et al. (1996c)	Specific	Total Affective/neurotic disorder Organic condition Psychotic disorder	No	Yes	29 items Adequate reliability Reasonable sensitivity Questionable specificity (Moss et al., 1998; Taylor et al., 2004a)
Mini PAS-ADD Prosser et al. (1996)	Specific	Total Anxiety & phobia Depression Expansive mood Obsessions & compulsions Psychoses Dementia Autistic features	No	Yes	86 items Good reliability Good sensitivity Some specificity (Deb et al., 2001; Prosser et al., 1998)
Symptom Checklist 90 (revised) (SCL-90-R) Derogatis (1983) Kellett et al. (1999)	General (adapted)	Global severity index Positive symptom distress index Positive symptom total Somatization Obsessive-compulsive Interpersonal sensitivity Depression Anxiety Hostility Phobic anxiety Paranoid ideation Psychoticism	Yes	No	Adapted by using an assisted completion format 90 items Good reliability Adequate sensitivity & specificity (Kellett et al., 1999)

<p>Brief Symptom Inventory Derogatis (1993) Kellelt et al. (2003, 2004)</p>	<p>General (adapted)</p>	<p>Global severity index Positive symptom distress index Positive symptom total Somatization Obsessive-compulsive Interpersonal sensitivity Depression Anxiety Hostility Phobic anxiety Paranoid ideation Psychoticism</p>	<p>Yes</p>	<p>No</p>	<p>Adapted by using an assisted completion format 53 items Good reliability Adequate sensitivity & specificity (Kellelt et al., 2003, 2004)</p>
<p><i>B. Detailed diagnostic assessments for multiple mental health problems</i></p>					
<p>Psychiatric Assessment Schedule – Adults with Developmental Disability (PAS-ADD) Moss et al. (1997)</p>	<p>General (adapted)</p>	<p>To ICD-10 criteria: Schizophrenia Depression Phobic anxiety disorders Other anxiety disorders Autism screen</p>	<p>Yes</p>	<p>Yes</p>	<p>Comprehensive adaptation of Schedules of Clinical Assessment in Neuropsychiatry (World Health Organization, 1992) Extensive re-wording and re-design for use with both person with learning disabilities and an informant Uses ICD-10 standard psychiatric classification system for diagnosis (World Health Organization, 1993) Semi-structured interview; core 145 questions Adequate reliability and validity (Costello et al., 1997; Deb et al., 2001; Moss et al., 1996a, b, 1997)</p>

Table 2. *Assessment Measures: Specific Mental Health Problems*

Measure	General population measure or specific for people with learning disabilities	Areas assessed	Completed with person with learning disabilities	Completed with informant	Details of measure
Zung Depression Scale Zung (1965) Dagnan & Sandhu (1999); Kazdin et al. (1983); Lindsay et al. (1994); Prout & Schaefer (1985)	General (adapted)	Depression	Yes	No	20 items Original measure used (Prout & Schaefer, 1985) Adapted with wording changes and fewer response options (Dagnan & Sandhu, 1999; Kazdin et al., 1983; Lindsay et al., 1994) Good reliability and validity
Beck Depression Inventory Beck et al. (1961)	General (adapted)	Depression	Yes	No	21 items Original measure used (Prout & Schaefer, 1985) Adapted with wording changes and fewer response options (Helsel & Matson, 1988; Kazdin et al., 1983; Nezu et al., 1995) Good reliability and validity
Glasgow Depression Scale Cuthill et al. (2003)	Specific	Depression	Yes	Yes – carer supplement	20 items Carer supplement 16 items Good reliability Good sensitivity and specificity (Cuthill et al., 2003)
Mental Retardation Depression Scale Meins (1995, 1996)	Specific	Depression	No	Yes	9 items Adequate reliability and validity (Meins, 1995, 1996)

Zung Self-Rating Anxiety Scale Zung (1971) Lindsay & Michie (1988; Lindsay et al., 1994)	General (adapted)	Anxiety	Yes	No	20 items Adapted with wording changes and fewer response options (Lindsay & Michie, 1988; Lindsay et al., 1994) Adequate reliability and validity
Beck Anxiety Inventory Beck & Steer (1990) Lindsay & Lees (2003)	General (adapted)	Anxiety	Yes	No	21 items Adapted (Lindsay & Lees, 2003) Unknown reliability and validity
Glasgow Anxiety Scale Mindham & Espie (2003)	Specific	Anxiety	Yes	No	27 items Good reliability Good sensitivity and specificity (Mindham & Espie, 2003)
Mood Interest & Pleasure Questionnaire Ross & Oliver (2002, 2003b)	Specific	Mood: Interest & pleasure	No	Yes	Designed for people with severe learning disabilities 25 items Good reliability, adequate validity (Ross & Oliver, 2002, 2003b)
Positive & Negative Syndrome Scale (PANSS) Kay et al. (1999) Hatton et al. (under review)	General	Psychotic experiences: Positive symptoms Negative symptoms General symptoms	Yes	No	28 items Good reliability Good validity on positive symptoms and general symptoms, inadequate validity on negative symptoms (Hatton et al., under review)
Psychotic Rating Scales (PSYRATS) Haddock et al. (1999); Hatton et al. (under review)	General	Psychotic experiences: Auditory hallucinations Delusions	Yes	No	17 items Good reliability Good validity on auditory hallucinations, unknown validity on delusions (Hatton et al., under review)

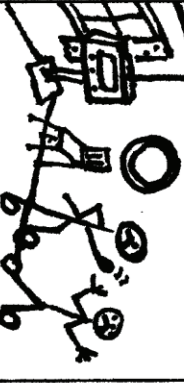


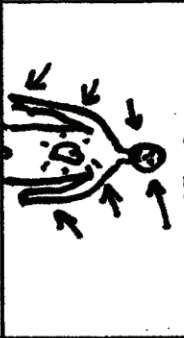
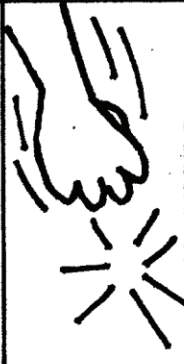
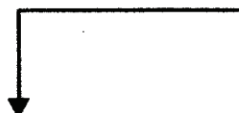
Novaco Anger Scale (NAS) Novaco (2003); Novaco & Taylor (2004)	General (adapted)	Anger: Disposition and experience in the cognitive, arousal and behavioural domains	Yes	No	48 items Original measure (Novaco, 2003) Adapted for people with mild-borderline learning disabilities and to be administered as a structured interview (Novaco & Taylor, 2004). Good reliability and validity.
Provocation Inventory (PI) Novaco (2003); Novaco & Taylor (2004)	General (adapted)	Anger: Reactivity across a range of potentially provoking situations	Yes	No	25 items Original measure (Novaco, 2003) Adapted for people with mild-borderline learning disabilities and to be administered as a structured interview (Novaco & Taylor, 2004). Good reliability and validity.
Ward Anger rating Scale (WARS) Novaco (1994); Novaco & Taylor (2004)	General	Anger: A two-part scale regarding (a) verbal and physical behaviours associated with anger and aggression; and (b) anger attributes displayed during the previous 7 days	No	Yes	25 items Original measure (Novaco, 1994). Part B has good reliability and validity with men with LD (Novaco & Taylor, 2004)
Imaginal Provocation Test (IPT) Taylor et al. (2004b)	General (adapted)	Anger: An idiographic measure of anger reactivity in terms of emotional and behavioural responses and attempts to regulate these.	Yes	No	10 items (administered in two parallel forms) Original measure (Novaco, 1975) Adapted for use with people with LD. Good reliability and validity and sensitive to change following intervention (Taylor et al., 2004b)

THINKING DIFFERENTLY ABOUT ANGER SITUATIONS

Handout/Exercise Sheet 10.1

Name: James

Date: 9/1/02

	<p>Situation Where? What? Who?</p> 	<p>Thoughts About the Situation</p> 	<p>Emotional Feelings 0-10</p> 	<p>Physical Feelings 0-10</p> 	<p>Reaction What did you Do/behave?</p> 
<p>A C T U A L</p>	<p>I was in my room getting ready to go out. A member of staff came in and told me they were changing my behaviour programme</p>	<p>Why are they changing my programme? They are trying to make it harder for me; to get me into trouble. It's not right. They don't care!</p>	<p>Very angry 8/10</p>	<p>Really tensed-up. Tight chest and sore head</p>	<p>I shouted at the staff and swore at him. Called him names.</p>
<p>P O S S I B L E</p>		<ul style="list-style-type: none"> • They are changing my programme to try to help me. • He is telling me this cos he thinks I'll be pleased 	<p>Not very angry - maybe a bit worried 2/10</p>	<p>More relaxed - less tense 2/10</p>	<p>I would talk to them nice and calm to find out why they want to change my programme</p>