Chapter 1

Mental Health and Emotional Problems in People with Intellectual Disabilities

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Historically, there has been a general lack of regard for the mental health needs of people with intellectual disabilities (e.g., Stenfert Kroese, 1998). This is despite clear evidence that people in this population have higher levels of unmet needs and receive less effective treatment for their mental health and emotional problems, and despite the promotion of government policies and the introduction of antidiscrimination legislation designed to break down these barriers. For example, in England, the *National Service Framework for Mental Health* (Department of Health, 1999) applied to all working age adults and aimed at improving quality and tackling variations in access to care. Its successors, *New Horizons: A Shared Vision for Mental Health* (HM Government, 2009) and *No Health without Mental Health* (HM Government and Department of Health, 2011), prioritized better access to psychological therapies (especially cognitive therapy) for socially excluded groups and improved outcomes in mental health by promoting equality and reducing inequalities. The report on *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs* (Department of Health, 2007) recommended that "[mental health] services available to the whole community increase their ability to meet the needs of people with learning disabilities whose behaviour presents challenges and who have a diagnosed mental illness" (p. 17). In terms of primary legislation, people with intellectual disabilities who experience mental health problems should be able to access services and receive the same treatment as others with reasonable modifications being made in accordance with relevant legislation (e.g., the Disability Discrimination Act 1995, incorporated into the Equality Act 2010).

Despite this raft of policy and legislation, there are a number of reasons for the continuing inequality of access to mental health services and effective treatment for people with intellectual disabilities. These include (a) a lack of knowledge and awareness of mental health and emotional problems experienced by people with intellectual disabilities; (b) some reluctance on the part of therapists to provide these

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interventions to people in this population; (c) a lack of good quality evidence to guide practice with this client group; and (d) the difficulty of making an economic case in an increasingly challenging fiscal context. These and related issues are explored further in the following sections.

Identifying Mental Health and Emotional Disorders in People with Intellectual Disabilities

As a group, people with intellectual disabilities are more likely than people in the general population to experience living circumstances and life events associated with an increased risk of mental health problems, including birth trauma, stressful family circumstances, unemployment, debt, stigmatization, lack of self-determination, and lack of meaningful friendships and intimate relationships (Martorell *et al.*, 2009). People with intellectual disabilities report experiencing stigma and negative beliefs about themselves and their social attractiveness (MacMahon & Jahoda, 2008), and the stigma and discrimination so often associated with mental health problems add to these challenges (Thornicroft, 2006). In addition, people in this population are likely to have fewer psychological resources available to cope effectively with stressful events, as well as poorer cognitive abilities including memory, problem-solving, and planning skills (van den Hout *et al.*, 2000).

Prevalence

Despite these apparent disadvantages, it is not clear whether people with intellectual disabilities experience more mental health and emotional problems than those without disabilities. Studies of mental health problems among samples of people in this population report large variations in prevalence depending on the methodology used, such as the use of case note reviews versus clinical evaluation, the nature and type of diagnostic assessment used, the location of the study sample (e.g., inpatient vs. generic community services), and, importantly, the inclusion of challenging behavior as a mental health problem or not (see Kerker *et al.*, 2004 for a brief review).

Studies of populations of people with intellectual disabilities using *screening* instruments to identify potential cases report rates of mental health problems (excluding challenging behavior) of between 20 percent and 39 percent and studies involving clinical assessment of psychiatric diagnosis in people with intellectual disabilities have reported point prevalence rates of between 17 percent and 22 percent when behavior problems are excluded (see Table 1.1). These figures are quite similar to the rates between 16 percent and 25 percent for mental health problems found in the general population (e.g., McManus *et al.*, 2009; Singleton *et al.*, 2001). Although the overall rates of mental health problems (excluding behavior problems) among people with intellectual disabilities appear to be broadly consistent with those found in the general population, the profiles for types of disorders differ. In particular, the rates for psychosis and affective disorders are somewhat higher among people with intellectual disabilities, while those for personality, alcohol/substance use, and sleep disorders are considerably lower (Cooper *et al.*, 2007; Singleton *et al.*, 2001). Hatton and

Table 1.1 Selected Studies of the Prevalence of Mental Health Problems Experienced by Adults with Intellectual Disabilities Using (a) Screening Instruments and (b) Clinical Assessments

	N	*Prevalence (%)*
(a) Studies using screening instruments		
Taylor *et al.* (2004)	1155	20
Deb *et al.* (2001)	90	22
Roy *et al.* (1997)	127	33
Reiss (1990)	205	39
Iverson and Fox (1989)	165	36
(b) Studies involving clinical assessments[a]		
Cooper *et al.* (2007)	1023	18
Cooper and Bailey (2001)	207	22
Lund (1985)	302	17
Corbett (1979)	402	21

[a]Rates excluding behavior problems calculated using the data presented by Cooper *et al.* (2007) in Table 6, p. 33.

Taylor (2010) present a more detailed discussion of the prevalence of specific types of mental health and emotional disorders (anxiety, depression, psychosis, dementia, substance misuse, and anger) among people with intellectual disabilities.

Diagnostic overshadowing

Although case recognition is a crucial step in meeting the mental health needs of people with intellectual disabilities, many of these needs are not detected and so remain untreated. There can be several reasons for this.

Reiss *et al.* (1982) used the term "diagnostic overshadowing" to describe the phenomenon in which carers and professionals misattribute signs of mental health problems, such as social withdrawal as a result of feelings of depression, to an aspect of a person's intellectual disability, for example, poor social skills. Although it is likely that causes and maintaining factors overlap, the relationship between mental health problems and challenging behavior in people with intellectual disabilities remains unclear (Emerson *et al.*, 1999) and requires further elucidation. Taylor (2010) reported that correlations between scores on a challenging behavior schedule and the three subscales of the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) Checklist mental health screening tool (Moss *et al.*, 1998) were statistically significant (all $p < 0.001$), but relatively small in magnitude (0.32 affective disorder, 0.31 organic disorder, and 0.28 psychotic disorder) for 740 adults with intellectual disabilities. These data are consistent with the suggestion that while challenging behaviors and mental disorders experienced by people in this population are associated, they are distinct problems.

The issue of diagnostic overshadowing can be exacerbated by the values base and ethos of the training of many staff working in intellectual disability services. Staff in

these services tend to use a conceptual framework built around challenging behavior rather than one focused on mental health to understand problematic behavior. Consequently, they may be antithetic to viewing a person's behavior as indicative of a mental health problem rather than a form of challenging behavior (Costello, 2004). Furthermore, services for people with intellectual disabilities and those for people with mental health problems are often organizationally and functionally separate and have distinct cultures that can lead to gaps in the provision of diagnostic and treatment services (Hassiotis *et al.*, 2000).

Assessment of mental health problems

An additional obstacle to the identification of mental health and emotional problems experienced by people with intellectual disabilities is clinical assessment. The assessment measures available to detect mental health problems among people in this client group are not well developed and often lack reliability and validity. Although in its early stages, work is under way to develop measures for a range of purposes and conditions (e.g., screening and detailed diagnostic assessments for multiple mental health problems, anxiety, depression, psychosis, and trauma) using adapted and *de novo* measures that can be self or informant. The issues concerning the assessment of mental health problems in adults with intellectual disabilities and a description of a range of tools available to assess these problems are set out in more detail in Chapter 3 of this book.

Therapeutic Disdain

Therapist attitudes and beliefs

In the past, many therapists have been reluctant to offer individual psychotherapy, including cognitive–behavioral therapy (CBT), to clients with intellectual disabilities. Offering these treatment approaches requires the development of close working relationships with clients who may be thought to be unattractive because of their disabilities, which make the therapeutic endeavor more challenging and the achievement of quick treatment gains more difficult. Bender (1993) used the term "the unoffered chair" to describe this "therapeutic disdain" (p. 7). In addition, therapists may have assumed that people with intellectual disabilities do not have the cognitive abilities required to understand or benefit from psychological therapy. There is, however, no evidence in the intellectual disabilities field that deficits in particular cognitive abilities result in poorer outcomes, and studies involving children show that it is not necessary to have mature adult cognitive structures to benefit from CBT (Durlak *et al.*, 1991).

A further reason for therapists and services routinely failing to offer psychological therapy to people with intellectual disabilities is the lack of research evidence to support its use with these clients. The lack of good quality research is in part due to difficulties in obtaining funding for research in this area from established grant-giving bodies. Another issue is research ethics committees' reticence about approving research studies involving participants with intellectual disabilities due to concerns

about their capacity to give valid consent to take part in clinical research. Although some people with intellectual disabilities may not be able to comprehend all of the information required to participate in research (Arscott *et al.*, 1998), there is evidence that research participants of average intellectual ability do not fully comprehend key aspects of treatment studies they have consented to take part in either (Featherstone & Donovan, 2002). Thus, we risk discriminatory practices in excluding people with intellectual disabilities from potentially beneficial or benign treatment outcome research based on erroneous assumptions about their capacity to consent compared with the general population.

Cognitive impairments

Over the last 30 years, psychological therapies, especially CBT, have become established in the treatment of common mental health problems and some severe mental health problems such as psychosis. More recently, this development has been underpinned by the inclusion of CBT for a range of mental health conditions in the National Institute for Health and Clinical Excellence (NICE) guidance. NICE is an independent organization in England that provides advice to the government on the evidence supporting interventions for the promotion of good health and the prevention and treatment of ill-health (www.nice.org.uk). Historically, it has been assumed that people with intellectual disabilities have cognitive impairments that hinder their ability to engage successfully in and benefit from CBT and other evidence-based psychotherapies.

Despite the concern that people with intellectual disabilities may have difficulties in coping with the complexity of interventions aimed at modifying cognitive distortions, experimental evidence shows that people with mild intellectual disabilities can recognize emotions (Joyce *et al.*, 2006; Oathamshaw & Haddock, 2006; Sams *et al.*, 2006); label emotions (Joyce *et al.*, 2006); discriminate thoughts, feelings, and behaviors (Sams *et al.*, 2006); and link events and emotions (Dagnan *et al.*, 2000; Joyce *et al.*, 2006; Oathamshaw & Haddock, 2006). However, there is some research showing that the majority of these participants with intellectual disabilities were unable to do an experimental task involving understanding of the mediating role of cognitions, particularly when the complexity of the task was increased (Dagnan *et al.*, 2000; Joyce *et al.*, 2006; Oathamshaw & Haddock, 2006). However, it is not clear whether this phenomenon is simply a function of the complexity of the experimental tasks presented to study participants or if it would be observed in routine treatment settings.

Changes in professional attitudes

There are encouraging signs that provision of evidence-based psychological therapies, and CBT in particular, to people with intellectual disabilities is increasing. Nagel and Leiper (1999) found that approximately one-third of British psychologists who responded to a survey on the use of psychotherapy with people with intellectual disabilities reported using these approaches frequently. An edited book on CBT for people with intellectual disabilities (Stenfert Kroese *et al.*, 1997) and a special issue of the *Journal of Applied Research in Intellectual Disabilities* devoted to CBT (Willner

& Hatton, 2006) point to increasing interest in the use of these therapeutic approaches with these clients. A special issue of *Behavioural and Cognitive Psychotherapy* – the official scientific journal of the *British Association for Behavioural and Cognitive Psychotherapies* (BABCP) – concerning contemporary developments in the theory and practice of CBT included a paper on applications for people with intellectual disabilities (Taylor *et al.*, 2008).

There is also emerging evidence that practitioners in the field are beginning to offer CBT interventions aimed at identifying and modifying cognitive distortions rather than relying on techniques that focus on ameliorating cognitive skills deficits. For example, Lindsay (1999) reported on successful outcomes of CBT interventions for people referred for a range of clinical problems including anxiety, depression, and anger that explicitly incorporated work on the content of cognitions underpinning and maintaining their emotional difficulties. Willner (2004) and Stenfert Kroese and Thomas (2006) used imagery rehearsal therapy, a technique that deals with dream imagery in the same way as cognitive distortions, to successfully treat a man and two women, respectively, who were experiencing postabuse traumatic nightmares. Haddock *et al.* (2004) reported a case series of five people with mild intellectual disabilities and psychosis who showed improvements following a cognitive–behavioral intervention adapted from an established therapy that included a cognitive restructuring component.

The Evidence for Psychological Therapies for People with Intellectual Disabilities

The difficulties in developing an evidence base to support psychological (and other forms of) treatments for people with intellectual disabilities have been discussed previously (e.g., Oliver *et al.*, 2003; Sturmey *et al.*, 2004) and are covered in some depth in Chapter 17 of this book. In the following section, an overview of the evidence for psychological therapies for this client group is provided to frame the detailed discussion of the application of these approaches to particular types of disorders and client groups in succeeding chapters.

Reviews of reviews of the evidence

Gustafsson *et al.* (2009) surveyed systematic reviews that evaluated the effects of psychosocial interventions for adults with intellectual disabilities who experienced mental health problems. They found 55 reviews that concerned the effectiveness of psychotherapy (mainly behavioral and cognitive behavioral interventions) for adults with intellectual disabilities published between 1969 and 2005. Only two reviews met the survey inclusion criteria. The results of these reviews showed that interventions based on cognitive–behavioral approaches appear to reduce aggression at the end of treatment, although the reviews included studies judged to be of low quality.

In a narrative review of reviews that focused more specifically on psychotherapy for people with intellectual disabilities, Prout and Browning (2011a) described the conclusions of seven reviews published between 2000 and 2011. Prout and

Browning found that research on psychotherapy with this client group continues to lack a critical mass of studies with robust designs (particularly randomized controlled trials (RCTs)) required to establish the efficacy of these approaches. This lack of rigor notwithstanding, they concluded that psychotherapy is "at least moderately beneficial" for people with intellectual disabilities and a range of mental health problems (p. 57). They suggested that in addition to RCT studies, future research needs to consider the active ingredients of effective treatments, and the adaptations and process variables (e.g., therapeutic alliance) that contribute to successful outcomes.

Reviews and commentaries

There have been numerous narrative reviews and commentaries that have considered the effectiveness of psychotherapy for people with intellectual disabilities who have mental health and emotional problems. A summary of some of the key themes and conclusions from these reviews is given in the following discussion.

Prout and Nowak-Drabik (2003) reported on perhaps the most comprehensive review of psychotherapy for people with intellectual disabilities. Using a clear definition of psychotherapy, they considered 92 studies published over a 30-year period between 1968 and 1998. The pool of 92 studies was rated systematically by "experts" with regard to outcome and effectiveness. The studies in this pool involved behavioral (33 percent), cognitive–behavioral (13 percent), analytic/dynamic (15 percent), humanistic/person centered (2 percent), and "other" (37 percent) types of psychotherapy. Just 9 of the 92 study reports were found to meet the study criteria and provided sufficient information to be used in a meta-analysis of treatment effectiveness; this yielded a mean effect size of 1.01. Exploratory analyses suggested that published studies involving manual-guided individual treatment and behaviorally orientated therapies (excluding behavior modification) yielded higher outcome and effectiveness ratings. Prout and Nowak-Drabik (2003) concluded from their analysis that psychotherapy for people with intellectual disabilities produces moderate outcomes and benefits for clients. Although many of the studies included in the review lacked methodological rigor, the authors suggested that psychotherapeutic interventions should be more frequently considered in treatment plans for these clients.

Beail (2003) provided a commentary comparing "self-management" approaches, cognitive therapy, and psychodynamic psychotherapy outcome studies in the intellectual disabilities field. Numerous case studies, case series, and a small number of uncontrolled group studies concerning self-management approaches were identified, especially in the forensic intellectual disability field. Only a few attempts at controlled studies were cited – two studies in the area of problem-solving reported mixed results in terms of outcome, and three studies in the anger management field produced significant improvements.

Although the literature pertaining to cognitive–behavioral self-management approaches reviewed by Beail (2003) is quite limited, this contrasts with the evidence available for psychodynamic psychotherapy with this client group. Four pre-post treatment open trials of psychodynamic psychotherapy were included, which were successful in reducing behavioral and offending problems among people with intellectual disabilities. Very little evidence was available to support the use of cognitive

therapy as means of targeting distorted cognitions that underpin problem behavior, attitudes, and emotional distress in this population.

Beail (2003) concluded that the evidence base for cognitive behavioral psychotherapy had progressed a little in the previous five or six years, but more than that for psychodynamic psychotherapy. However, the paucity and quality of the outcome research in this area was such that claims for the effectiveness of these types of interventions could only be tentative. It was suggested that the potential of these emerging therapies warranted more thorough evaluation using more robust methodologies.

Sturmey (2004) selectively reviewed and critiqued cognitive therapy for people with intellectual disabilities with anger, depression, and sex-offending problems. He concluded that the evidence to support CBT approaches is weak when compared with the extensive evidence base for behavioral interventions based on an applied behavioral analysis paradigm. This view was reinforced in a later critique of cognitive therapy for people with intellectual disabilities (Sturmey, 2006). However, Prout and Browning (2011a) suggested that Sturmey's position is based on a "misunderstanding" (p. 56) of what defines psychotherapy and an attempt to separate out behavioral and cognitive elements of empirically supported multicomponent treatments in order to defend a particular conceptual view.

Willner (2005) critically reviewed psychotherapeutic interventions for people with intellectual disabilities. He found that CBT interventions utilizing cognitive skills training (e.g., self-management, self-monitoring, self-instructional training) show promise for a range of mental health and emotional control problems. Approaches focusing on cognitive distortions were considered to have only a very limited evidence base. Willner concluded that there is a "wealth of evidence" (p. 82) from methodologically weak studies that psychological therapies (chiefly CBT) can benefit people with intellectual disabilities with emotional problems for which there is no realistic alternative.

Dagnan (2007) considered "recent research" (unfortunately the time period is not specified) concerning individual interventions as part of a wider review of psychosocial interventions for people with intellectual disabilities and mental health problems. He concluded that although there is some limited evidence to support cognitive therapy for a range of problems (anxiety, depression, anger, obsessive–compulsive disorder, and trauma-related symptoms), there are significant gaps in the literature. There were, for example, few high-quality randomized trials, a lack of process research on the mechanisms for change for people with intellectual disabilities, and limited evidence for interventions for people with more severe and enduring mental health problems (e.g., psychosis).

Prout and Browning (2011b) looked at psychological treatment studies involving people with intellectual disabilities published between 2006 and 2011. They concluded that the published studies present generally positive results supporting the use of psychotherapy with this client group. Both individual and group approaches show benefits for clients, and anger reduction approaches are the most researched interventions in this population. Prout and Browning also reviewed doctoral dissertations completed between 1993 and 2009 to examine the *file draw* phenomenon that proposes a bias toward studies showing positive outcomes being presented in peer-reviewed journals. They concluded that these research dissertation study results

provide further support for the effectiveness of psychotherapeutic interventions for people with intellectual disabilities.

Making the "Economic Case" for Interventions

A final reason for the continuing inequity of access to appropriate interventions to meet mental health needs could be the difficulty in demonstrating that such actions are "economically attractive." Of course, the fundamental purpose of psychological and other therapies is not to save money or to achieve cost-effectiveness; it is to improve the health and well-being of individuals with (in this case) mental health needs, as well as the well-being of significant others, such as family members. However, as fiscal austerity comes to dominate decision making at every level within health and social care systems, it is inevitable that questions will be asked with increasing frequency (and indeed, increasing urgency) about the costs of interventions, any future savings they might generate, and the balance between amounts expended and outcomes achieved. Those questions are being asked by decision makers locally and nationally, frontline and strategic, as they each face unprecedented cuts to their budgets.

Local commissioners within health, housing, social care, and other systems, for example, must work within annual budgets to purchase services and treatments that best meet the needs of their populations. Although they will be acutely aware of the wider impacts of decisions they take, that is beyond their own budget boundaries, pressures on them to manage their resources make it inevitable that they focus primarily on their own concerns and balances. Thus, a group of people such as those with intellectual disabilities and mental health needs, whose needs might spread beyond the health system into social care, welfare benefits, specialist housing, and beyond, may lose out because of this tendency to withdraw back into "silos" at the time of acute fiscal austerity. Even strategic decision makers at the highest level of government, for example, within the Treasury, will be particularly focused on public sector expenditure and associated borrowing, and so may be less concerned about the spillover consequences of decisions for private individuals, particularly for families. Decisions taken by a local or central decision maker to place more reliance on unpaid family carers will appear relatively "costless" because the impact will be felt by the family, perhaps by the employers of family members and so on.

The difficulty that the field of intellectual disabilities and mental health faces is that the interventions that are available and for which there is an evidence base that they work (in terms of improving health and well-being) cannot point to cost savings for public budgets. There might in due course be a reduction in the need for expensive interventions, but to date, there has been little investigation of this area. Another consequence of the current fiscal austerity, over and above the focus on own budgets, is short-termism, with budget holders desperate to achieve savings from their investments within the current or maybe the following financial year, but not to be so heavily influenced by savings that might follow over a number of years.

The territory has also changed in the last few years. At a time when budgets were growing, albeit relatively slowly in many cases, it was often sufficient to point to the outcome advantages of interventions that actually increased expenditure rather than

reduced it, on the grounds that the better outcomes were worth the additional expenditure necessary to achieve them. In a context where there is no margin for "additional expenditure," this algorithm of cost-effectiveness gains but without cost savings often looks somewhat out of place.

Conclusions

People with intellectual disabilities are potentially more vulnerable than others to the risk of experiencing mental health problems. Despite this increased susceptibility, their assessment and treatment needs have often not been recognized, and they have experienced significant obstacles in accessing appropriate services. Although the picture is gradually improving, and despite the various policy developments and government guidelines concerning inclusion of those with disabilities, some basic issues concerning access to and delivery of mental health services for people with intellectual disabilities have yet to be resolved (Michael, 2008). For example, the Department of Health *Improving Access to Psychological Therapies* (IAPT) program is focused on the implementation of NICE guidelines for common mental health problems in England (www.iapt.nhs.uk). The *Learning Disabilities Positive Practice Guide* (Department of Health, 2009) indicates that IAPT services need to be flexible in providing effective psychological therapies for people with intellectual disabilities. This could include offering treatment information in easy-to-understand formats, using easy-read or therapist-administered self-report assessments, and utilizing NICE-approved psychological interventions modified to meet the needs of people with intellectual disabilities. However, despite this guidance, and the hundreds of millions of pounds invested in this program, it is not known, and no data are being systematically collected to indicate whether or not people with intellectual disabilities are accessing or benefitting from these highly resourced new psychological therapy services.

In the past, psychological therapists have avoided engaging with clients with intellectual disabilities in order to provide effective interventions aimed at reducing symptoms and alleviating subjective distress associated with their conditions. Based on the emerging evidence concerning the effectiveness of psychological interventions for the emotional problems experienced by this client group, this historical "therapeutic disdain" can surely no longer be justified. From work described in the professional and academic literature, the picture is gradually changing from one of professional indifference to one of increasing interest in and concern for the needs of clients with intellectual disabilities who experience mental health difficulties.

The research literature supporting the use of psychological therapies with clients with intellectual disabilities is developing, albeit at a slow rate. Reviewers and commentators consistently call for significant gaps in the evidence base to be filled, including

- more rigorous outcome studies, including RCTs, to establish the efficacy of clearly defined psychotherapeutic interventions for specific types of problems with distinct patient populations;

- process research into the active ingredients of psychological therapies and mechanisms of change for people with intellectual disabilities experiencing mental health problems;
- follow-up research examining sustainability of treatment effects over time and the generalizability of gains from treatment settings into routine care conditions;
- an understanding of the economic consequences of delivering these treatments.

Developments in service provision, professional practice, and research and evaluation concerning psychological therapies for adults with intellectual disabilities who experience an array of mental health and emotional problems in a variety of contexts are described by experts from a range of perspectives in the remainder of this book.

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