

Cognitive behaviour therapy and people with learning disabilities: implications for developing nursing practice

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People with learning disabilities are an ageing and increasing population and have been the subject of policy initiatives by the four countries of the UK, detailing the range of supports that need to be in place for this group. The evidence base of their mental health needs is growing and with it the need to ensure the full range of psychotherapies available to the general population are made available to people with learning disabilities. Cognitive Behaviour Therapy (CBT) is now a widely accepted and effective form of psychotherapy for many mental health problems and the evidence base is growing on the effectiveness with the learning disability population; however, the model needs to be applied differently for this group to take account of their cognitive impairment and support needs. Registered Nurses in Learning Disabilities are well placed to apply this approach within their clinical practice; however, there is an absence of leadership and direction in the development of CBT for this group of clinicians. There is a need to support education and practice development to contribute to addressing the emotional needs of people with learning disabilities. Action is required to support education to prepare Registered Nurses in Learning Disabilities to practice CBT and to contribute to the ongoing development of research in this area of clinical practice.

Keywords: cognitive behaviour therapy, education, learning disabilities, nurses, research

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Introduction

As a group, people with learning disabilities have high health needs, including mental health, yet they often go unmet and unrecognized. Cognitive Behaviour Therapy (CBT) is a recognized psychotherapy that can be used to treat a range of mental health disorders, with evidence developing on the application to people with learning disabilities. Registered Nurses in Learning Disabilities are beginning to respond and undertake training to become accredited Cognitive Behaviour Therapists and apply their skills in clinical practice.

The policy context

The last 5 years has seen the UK develop specific policies that focus on the needs of children and adults with learning disabilities, with the reviews being the first for some 30 years.

- Scotland – The same as you? (Scottish Executive 2000);
- England – Valuing people (Department of Health 2001a);
- Wales – Fulfilling the promises (Welsh Assembly 2002);

- Northern Ireland – Equal lives (Department of Health, Social Services & Public Safety 2004).

Collectively they set the policy direction and context of care across the UK and all seek to reflect the changing pattern of care of people with learning disabilities. While set within the specific policy context of each country, there are common elements and themes in all, such as the recognition of the right of people with learning disabilities to be viewed as equal citizens, with the opportunity to lead full and inclusive lives within the community. In the past the main focus of healthcare provision was in an institution setting, and over the last 10 years there has been a steady decline in this model and a move to community settings (Department of Health 2001b, Scottish Executive 2003).

From a health perspective, all the policy reviews recognize the high needs of this group and reinforce the need to promote and enable access to healthcare services available to the whole population wherever possible. For those with more complex needs, where assessment, diagnosis and treatment are more challenging, specialist services need to be in place, an element of which should be access to appropriate therapies. There are concerns that, without full recognition of the extent of the health needs of this group, they will continue to be marginalized, and that true social inclusion will not be achieved.

Terms of reference

Across the world a range of terms ranging from mental retardation, mental handicap, developmental disability and intellectual disability are used. While recognizing the differences that exist in definition, broadly they are conceptually the same. Psychiatry clinically uses the term 'mental retardation' ICD 10 (WHO 1992), DSM IV (APA 1994), having been operationally defined to include the psychometric definition of an IQ less than 70. The publication of DC-LD takes account of the differing mental health diagnostic criteria for people with learning disabilities and offers a classification system for mental disorder in this group with mild to moderate learning disabilities (Royal College of Psychiatrists 2001).

Within the UK, learning disability is the preferred term when referring to people with cognitive impairment that impacts on their capacity and ability to self-care and self-determine. It is defined as a significant, life-long condition with three main facets:

- reduced ability to understand new or complex information or to learn new skills;
- reduced ability to cope independently;
- a condition, which started before adulthood, usually before the age of 18 and with a lasting effect on the individual's development (Scottish Executive 2000).

A Differing pattern of health need

People with learning disabilities form some 2–3% of the population and as a group are increasing and ageing, a phenomenon that will continue in coming years (Patja 2000). The impact will be an increase in the number of people with learning disabilities, many with complex health needs, including a mental health dimension. As a result, they are high users of all aspects of the healthcare system, yet often get a raw deal. There is an increasing evidence base of the health needs of children, adults and older people with learning disabilities which points to their different pattern of health disease when compared with the general population (Beange *et al.* 1995, NHS Health Scotland 2004). They have high levels of physical and mental health needs that often go unrecognized and untreated (Cooper *et al.* 2004). Diagnostic overshadowing is prevalent and results in health needs being ignored (Jopp & Keys 2001).

Across the life span there is recognition of the high mental health needs of children and young people with learning disabilities, with many experiencing significant problems in accessing a health service appropriate to their needs. As a result, many of their mental health needs go unrecognized and untreated (Foundation for People with Learning Disabilities 2002). The prevalence of mental health needs is greater within this population compared with the general population. Schizophrenia, depression, anxiety disorder, post-traumatic stress disorder, challenging behaviour, offending behaviour and sexual abuse are all found (Table 1).

Emerson (2003) conducted a study of prevalence rates in children and adolescents with learning disabilities and concluded that family characteristics, low social class, low income, stressful life-events, parental mental health, and use of punitive behavioural strategies lead to a higher incidence of anxiety disorders. The difficulties experienced within families with learning disabled children are bi-directional: is it the nature of the learning disability or the parent's difficulty to cope that leads to mental health problems? A recent systematic review identified the benefit of CBT in the treatment of children over the age of 6 years with anxiety disorders (Cartwright-Hatton *et al.* 2004).

Studies demonstrate a varying degree of incidence: Cooper & Bailey (2001) reported a range of 6–80% prevalence rate of psychiatric disorders. The growing interest in mental health issues has stimulated further research into possible causes that lead to the vulnerability factors effecting people with learning disabilities. Cooper & Bailey (2001) suggest that many interactional factors affect a person's personality. Parental difficulties of coming to terms with having a learning disability child may lead to rejection or overprotection. The lack of consistent parental figures, which may be a result of residential homes, institutions and

Table 1
Summary of the mental health pattern of people with learning disabilities

Autistic spectrum disorder	Public Health Institute of Scotland (2001)	Estimated to be 60 per 10 000 for children. No data available for prevalence within the adult population. Many have additional health needs including mental health, communication, epilepsy and behaviour problems.
Schizophrenia	Medical research council (2001) Lund (1985) Doody <i>et al.</i> (1998)	Higher prevalence rate at 3% compared with 1% in general adult population. May be associated with negative symptoms, memory problems, epilepsy and high support needs.
Depression	Richards <i>et al.</i> (2001)	Prevalence of 22% in people with learning disabilities compared with 5.5% by age 36 in general adult populations, excluding social class and physical illness.
Anxiety disorder	Patel <i>et al.</i> (1993) Moss <i>et al.</i> (2000)	Common mental illness in people with learning disabilities at all ages. Often unrecognized and may present as challenging or disturbed behaviour. Diagnosis may be problematic.
Self-injury	Collacott <i>et al.</i> (1998)	High rates of self-injury found at 17.4%, with 1.7% being of a severe and frequent nature, associated with autism, IQ, hearing and immobility.
Dementia	Cooper (1997) Patel <i>et al.</i> (1993), Holland (2000)	Higher rates than general population and occurring at an earlier age.
Sexual abuse	Sequeira <i>et al.</i> (2003) Hollins & Sinason (2000)	Sexual abuse associated with psychiatric and behavioural disorder in adults with learning disabilities. Limited access to psychotherapy

special schools, may lead to problems in developing close relationships, and therefore trust, which may subsequently lead to low self-esteem.

It has been suggested that the introduction of community care policy may have also created a higher susceptibility to mental health problems. Cooper & Bailey (2001) found that people with learning disabilities were socially disadvantaged, and perceived as easy targets, open to exploitation and abuse. Owing to their limited communication skills and dependant social networks, it was found that people with learning disabilities poorly accessed medical services, and therefore have difficulty receiving input from specialist psychiatric and psychological services. Arthur (2003) confirmed that mental health problems became more apparent as a result of community care but problems were treated through behavioural methods during the 1970s and 1980s, with little recognition given to working with emotions. The work highlighted that emotional well-being was secondary to promoting independent living skills and treatment of challenging behaviour. Arthur (2003) also found that the ideals of service planners in creating better physical environments were at the detriment of emotional well-being, leaving people feeling lonely, isolated, fearful and apathetic.

The use of cognitive behaviour therapy and people with learning disabilities

The Royal College of Psychiatrists (2005) describes CBT as a way of talking about:

1. How you think about yourself, the world and other people.
2. How what you do affects your thoughts and feelings.

Conceptually the main elements of the CBT model – thoughts, emotional responses, physical sensations and actions – form the basis of therapy. Therapy, therefore,

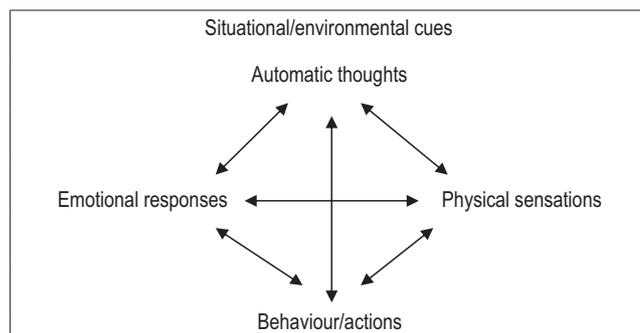


Figure 1
The basic CBT model – how it works

maybe indicated when beliefs and thoughts become dysfunctional or negative in nature, influencing behaviour and how circumstances are perceived (see Fig. 1). Treatment utilizing the CBT model enables the client to gain greater insight into their difficulties and supports a collaborative approach to therapy, where the focus is on 'the here and now' as opposed to childhood experiences. (For further information on CBT see the British Association of Behavioural and Cognitive Psychotherapies website at <http://www.babcp.com>.)

Williams & Garland (2002) report on the growing and evolving evidence base of CBT as an effective intervention within the general population for depression, panic disorder, generalized anxiety disorder and obsessive compulsive disorder. Additionally, guidelines on the management of depression in primary and secondary care recommend CBT for the treatment of depression and the combination of CBT and drug treatment for severe depression (NICE 2004).

Cognitive Behaviour Therapy is now attracting attention as a treatment option for people with learning disabilities following the publication of *Cognitive Behaviour Therapy for People with Learning Disabilities* by Kroese

et al. (1997). This is due in part to the recognition of the high mental health needs of this group and the need to respond appropriately. Up to this point, CBT had been suggested as a *potentially* useful approach with this population. Much of the current evidence is based on single case studies and small-scale projects, thereby making wider application and efficacy difficult to fully determine (Hollins & Sinason 2000). The situation is gradually changing as the research conducted evolves. To increase psychotherapy provision for this population there is recognition of the need to support education and development in this area of clinical practice (Hollins & Sinason 2000).

Following the first case-controlled study in this area, evidence that people with learning disabilities who are victims of sexual abuse experience increased rates of mental illness, behaviour problems and post-traumatic stress was established. The more severe the sexual abuse, the more severe symptoms experienced (Sequeira *et al.* 2003). A case-controlled study using a cognitive behaviour approach was found to be effective in the case of a man with learning disabilities suffering from nightmares and post-traumatic stress disorder (Wilner 2004). Wider consideration is now being given of the application of the therapy to people with learning disabilities who experience post-traumatic stress disorder (McCarthy 2001).

Lindsay & Hastings (2004) report a healthy increase in literature over the past 15 years relating to the effective use of CBT for people with learning disabilities with research focussing on developing assessment methods, controlled investigations and case studies. Although this is encouraging in developing knowledge and understanding in this field, Sturmey (2004) remains critical of the lack of strong evidence for CBT with this population. A review of the literature on anger, depression and offending behaviour found the treatment of anger showed the most promise. There was a dearth of research in relation to depression, despite possibly this being the most common mental health problem in this population. It was also reported that claims to using a CBT approach were mislabelled, when a predominantly behavioural approach was in fact being used in practice. The recommendations included the need for well-controlled, randomized trials focusing on specific areas of mental health.

While the evidence base of the use of CBT as a psychotherapy is increasing, an area that has attracted less attention is the evaluation of therapist education programmes, with those that have been undertaken limited to nursing samples (Ryan *et al.* 2005). The proliferation of clinical guidelines brings with them recommendations for training and, as a result, there is a need to ensure appropriately educated and skilled therapists are available prepared for clinical practice. There is also the issue of the continuing

practice development and supervision of those currently delivering CBT. Examples exist of attempts to equip practitioners with the range of helping skills to care for those with severe and enduring mental illness, including CBT. Evaluation, however, suggests that for some, the level of CBT training offered was too basic (Gauntlett 2005).

The application of cognitive behaviour therapy to people with learning disabilities

Cognitive Behaviour Therapy is most effective for people in the mild range of learning disability. This is mainly due to the ability to reflect on cognitions. Kroese (1997) highlighted that therapists must be aware of the following key factors when considering the suitability of people with learning disabilities:

- the level of comprehension;
- the level of expression;
- the ability to self-report;
- the self-regulation skills.

It is important, therefore, that clients are fully assessed prior to entering into therapy and typical assessments that are useful include the Wechsler Adult Intelligence Scale – Third edition (Wechsler 1997) or the British Picture Vocabulary Scale II (Dunn *et al.* 1997) that can be administered by a Clinical Psychologist or Speech and Language therapist respectively. The assessment process continues thereafter focusing on the patients understanding of the therapy process.

Dagnan *et al.* (2000) found, in a study of 40 people with mild learning disabilities, that most had difficulty in mediating the links between situations, beliefs, and emotions. There is evidence to support the effectiveness of linking a situation to an emotion. It is crucial, therefore, that the therapist assesses these areas before commencing CBT. Reed & Clements (1989) devised a useful assessment of understanding emotional states which comprised of six simple scenarios in which a situation is presented and the client is asked to choose an appropriate emotional response, for example, ‘You get up in the morning and it’s your birthday. How do you feel? Happy or Sad’.

Where clients have difficulty in using the basic CBT model, this may be due to their developmental and cognitive delay. Graham (1998) suggests addressing cognitive deficiencies where the therapist takes on a more psycho-educational approach before proceeding to address cognitive distortions that are specific to CBT. The dilemma for any therapist when treating people with learning disabilities is to establish whether they are addressing cognitive deficiencies or cognitive distortions, therefore it is imperative that they conduct a rigorous assessment process with continual review.

The clinical application – a case study

The concepts that outlined the positive and challenging aspects of applying CBT with someone with a learning disability can be illustrated by a clinical case study from practice.

Kylie, female, 37-year-old, with a mild learning disability who lived independently in her own flat, was referred to CBT by a community nurse, with concerns about Kylie's self-esteem and lack of assertiveness. Kylie had a history of forming unsuitable relationships with men, finding it difficult to assert herself when relationships became turbulent and abusive. Her relationship became difficult when her boyfriend, a drug user, moved in with her. He increasingly took her money, which increased to stealing and selling some of her possessions to support his drug habit. Subsequently, her mood deteriorated and her contact with friends and family reduced. She generally neglected her appearance finding it difficult to make decisions to help resolve her problems.

On assessment it was established that Kylie was able to understand and participate in CBT. Exploring her problems established that she was a person who wanted to be liked, with a need to help people, which in turn made her feel good about herself. Kylie could clearly see the thoughts 'I feel sorry for people', 'I'm afraid of disappointing people' as being problematic, resulting in her being used, leaving her feeling angry with others and herself. Her lack of assertiveness and poor problem solving led to her feeling depressed, as she had difficulty finding a solution to her situation. To support the assessment it was necessary to make modifications to the CBT model through identifying her current issues in the sessions by using free hand drawings of each CBT concepts, for example, thought bubbles, emotional faces, and internal body map for physical symptoms.

A difficulty in making decisions became evident during therapy sessions, as she would check to see if she was giving the 'right' answer. Therapeutically the focus was to help explore the impact of different decisions by focusing on the situation, thoughts, and the emotional and behavioural consequences, supplemented and supported with pictorial representations. This approach was developed further and a novel visual representation of potentially difficult situations was referred to it as the 'good road' and the 'bad road' plan. In essence this demonstrated two particular types of thoughts and actions, either dysfunctional or functional, which resulted in emotional responses and consequences (Fig. 2).

A plan was developed as part of the therapy comprising a list of plausible reasons that could be use when feeling pressured on the telephone by her ex-boyfriend to let him visit. These were rated for effectiveness during role-plays,

Table 2

Excuses to use if feeling pressured on the 'phone'

-
- My dad is coming over
 - I'm going to my mum's and I don't know when I'll be back
 - The police are coming up, I've had problems with children ringing the buzzer
 - My community support worker is coming round
 - My community support worker is here
-

and a final list was kept next to her telephone (Table 2) to reinforce their use. The plan allowed a number of strategies to be available, thereby addressing the potential emotional and behavioural consequences. It was also useful in highlighting her suitability for responding to other peoples' problems and needs more appropriately and assertively.

Despite numerous role-plays within her sessions, Kylie had difficulty transferring the skills into a 'live' situation. It was helpful to support therapy maintenance when Kylie began receiving 4 extra hours of support from a care provider, and it was possible to link the worker in the latter sessions to explain the plan and how best to support Kylie on a day-to-day basis. This was seen as necessary as Kylie had difficulty in applying her plan in real situations, for example when her ex-boyfriend telephoned.

Discussion

For CBT to be more widely available for people with learning disabilities it is necessary for developments to occur on several fronts.

The evidence base of the high mental health needs of people with learning disabilities continues to develop, and along with it the evidence of the application of cognitive behaviour therapy for this group. While there is recognition from a policy perspective of the need to develop psychotherapy interventions and services that focus on people with learning disabilities, the overall application and practice is an area that requires a focus and development. There are particular challenges in achieving this. In the absence of a well-defined research evidence base of the clinical benefits, the development and availability of the therapy for this group may remain limited, despite the potential for wider application. This is particularly relevant given the concerns expressed about the use of psychotropic medication within the learning disability population (Ahmed *et al.* 2000). Their use may in part point to the limited availability of appropriate alternatives, thereby placing clinicians in the position of wishing to help and respond as best they can.

There is increasing evidence that for some people with learning disabilities CBT offers an appropriate treatment option. To support the successful application of the CBT for people with learning disabilities, it is necessary to undertake modification and adaptation of the model within clinical

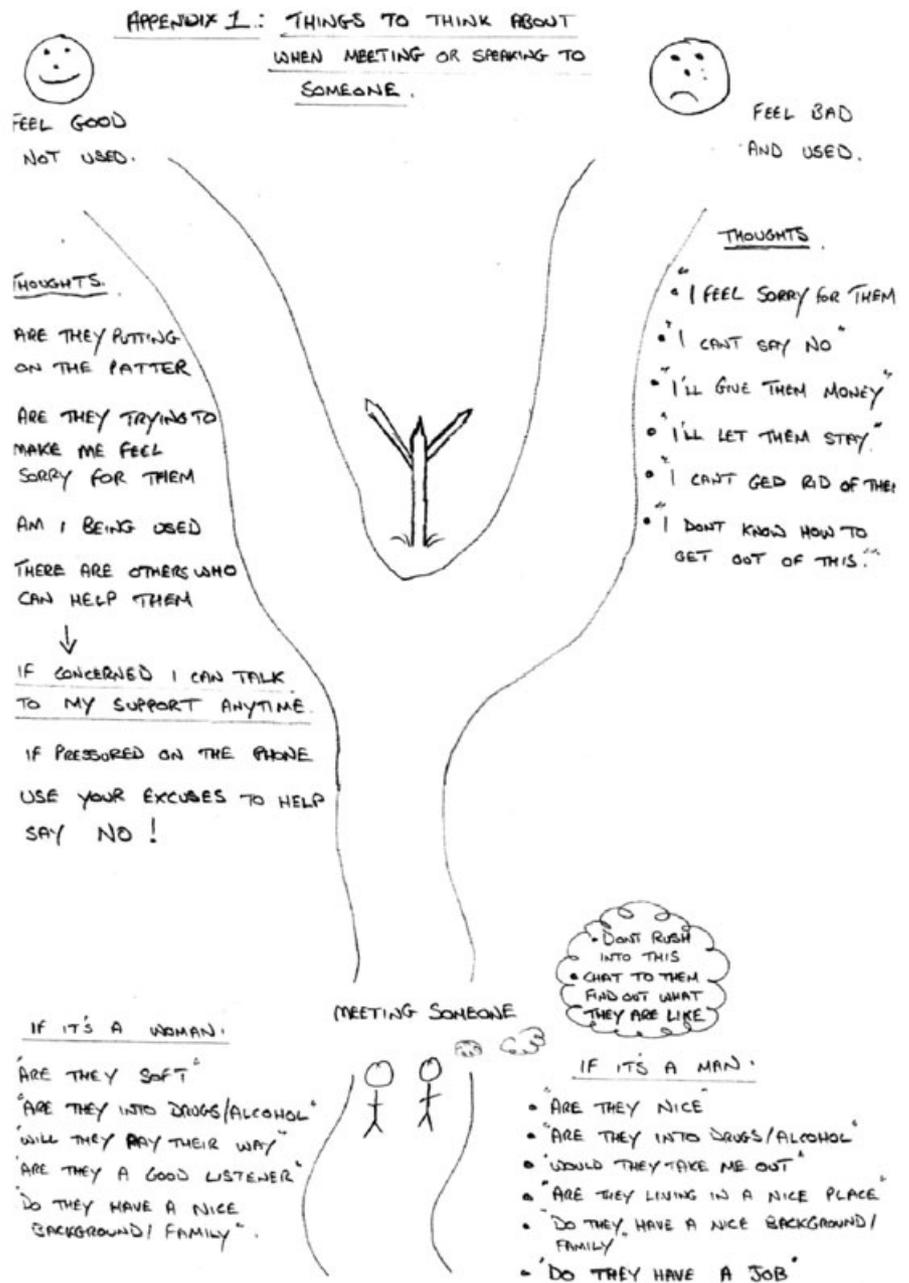


Figure 2
The Road Plan – things to think about when meeting someone

practice to take account of the cognitive and developmental deficits of the individual and the impact on the ability to engage therapeutically. Modification needs to include the additional assessment issues that help to determine suitability for commencing therapy; the use of symbols, pictures, drawing and role-play to develop understanding of personal situations and support the development of treatment plans. Therapists must also determine the ability of the individual to transfer skills from the therapy room to real-life situations, as dependant on the level of learning disability the individual may need additional support. It is therefore necessary to adopt a more systemic approach to therapy by involving others, such as community nurses, support staff,

carers and parents to reinforce and support the implementation of plans as part of the therapeutic process. The role therefore of the therapist diversifies from the traditional approach, as they also become a trainer, co-ordinator, and consultant to ensure therapeutic gains are maintained.

It is now recognized that the mental health profile of people with learning disabilities differs from that of the general population (NHS Health Scotland 2004). From there, there is the scope to undertake research in the area of CBT applied to the treatment of people with learning disabilities, which is important given the differing health needs of this group and as a result the clinical application and support necessary for effective treatment. Conse-

Table 3Tiered model of CBT education, adapted from *Promoting Health, Supporting Inclusion Tiered Model of Care* (Scottish Executive 2002)

Tier 0	All students undertaking nurse registration programme with education on the mental health needs of people with learning disabilities and broad understanding of the psychotherapies that may be used, including CBT
Tier 1	Registered Nurse of Learning Disabilities undertaking National Qualification Frameworks at Level 8 or 9 continuing professional development modules in the theory and application of CBT as a treatment option for people with learning disabilities
Tier 2	Registered Nurse in Learning Disabilities with a first degree undertaking continuing professional development Master's module in the broad theory and practice of CBT prior to undertaking a programme of CBT training as an independent practitioner
Tier 3	Registered Learning Disability Nurse registered with BABCP and qualified to independently practice CBT either as a specialist practitioner or integrated within a nursing role
Tier 4	Registered Learning Disability Nurse holding a Masters degree in CBT, registered with BABCP and independently practicing CBT with additional contributions to education and research and the development in CBT locally and nationally for people with learning disabilities

quently, further work requires to be undertaken on the efficacy of CBT for this population, with the identification of effective adaptation models and treatment outcomes.

To support the concept of education of nurses in CBT practice from undergraduate pre-registration to postgraduate level, a Tiered model of education, developed from the Tiered model of care detailed in *Promoting Health, Supporting Inclusion* (Scottish Executive 2002), has been developed. The use of a Tiered model of cognitive behaviour education is helpful from a number of perspectives and provides a conceptualisation of the tiers of education and development opportunities required, commencing with undergraduate nurse education programmes, moving on to developing and increasing the awareness of the theories of cognitive behaviour therapy and the application within clinical practice (Table 3).

A significant number of cognitive behaviour therapists are registered nurses, predominantly from the mental health field. For Registered Nurses in Learning Disabilities educated to first-degree level, CBT presents an opportunity for post-registration development, thereby increasing the number of trained therapists with an interest and focus on providing the therapy for people with learning disabilities.

Following on from this are opportunities for Registered Nurses in Learning Disabilities wishing to develop their clinical practice, who educated to first-degree level, have the opportunity to undertake postgraduate CBT training which may be applied within clinical practice from a number of perspectives. There is scope for Registered Nurses in Learning Disabilities to develop nurse specialist roles providing cognitive behaviour therapy for people with learning disability as one dimension of their existing clinical role. This service might be offered as an integral part of psychotherapy services available within learning disability mental health services or alternatively for the practitioner to integrate within psychotherapy services delivered as part of mainstream mental health services. The model developed will depend on local availability and demand. Full accreditation as a qualified therapist in CBT prepares clinicians at postgraduate education level.

Conclusion

The learning disability population is an increasing population with many living into older age. The high mental health needs of this group are now well established, yet opportunities to access clinicians, who are skilled, interested and motivated to offer CBT for this group of patients, remains limited.

There is a need to recognize and take account of the modifications necessary to implement the CBT model with this group. CBT needs to be promoted as a career development for Registered Nurses in Learning Disabilities and others as well as undertake research in this area of practice to contribute to the developing evidence base. These are issues and shortfalls that need to be addressed in order to ensure appropriate access to psychotherapy, thereby contributing to the wider social inclusion of this group.

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