


INVITED PAPER

Adapting cognitive behaviour therapy for people with intellectual disabilities: an overview for therapist working in mainstream or specialist services

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Abstract

This paper is an introduction to adaptations to make cognitive behaviour therapy (CBT) more accessible to people with intellectual disabilities. It is intended to inform therapists who may work with people with intellectual disabilities in mainstream services.

The paper describes adaptations that consider neuropsychological processes, such as memory, and executive functions, such as planning, problem solving and self-regulation, and identifies that these factors are not unique to people with intellectual disabilities. We describe adaptations based on a review of literature describing CBT for people with intellectual disabilities (Surley and Dagnan, 2019) and draw on clinical experience to give examples of adaptations where possible. The paper particularly emphasises the generalisability of adaptations used with people with intellectual disabilities to therapy with wider populations and suggests that CBT therapists working in mainstream services will have the skills to be able to adapt therapy for people with intellectual disabilities.

Key learning aims

- (1) To overview the evidence base supporting the use of CBT with people with intellectual disabilities.
- (2) To describe the epidemiology of intellectual disability and discuss its implications for the generalisability of adaptations discussed in this paper.
- (3) To describe a range of adaptations to make CBT more accessible people with intellectual disabilities.
- (4) To consider whether such adaptations are part of the skill set of CBT therapists mainly working with people without intellectual disabilities.

Keywords: adaptations; CBT; intellectual disability; introduction

Introduction

People with intellectual disabilities experience mental health difficulties at a level that is slightly greater than the general population (e.g. Cooper *et al.*, 2007). Cognitive behaviour therapy (CBT) is an effective treatment for a wide range of mental health difficulties (e.g. Hofmann *et al.*, 2012) and is identified as a first-line intervention for the treatment of mood disorders in typically developing populations (e.g. National Institute for Health and Care Excellence, 2011; National Institute for Health and Care Excellence, 2013). Studies that inform guidance for the wider population typically

do not include people with intellectual disabilities; however, there is little reason to suspect that the underlying processes that affect mental health in the general population are not the same for people with intellectual disabilities. For example, people with intellectual disabilities and mood disorders endorse similar dysfunctional thought patterns to those without intellectual disabilities (e.g. Esbensen and Benson, 2005; Glenn *et al.*, 2003). In addition, several studies have shown that many people with intellectual disabilities have the basic skills required to engage in CBT (e.g. Dagnan *et al.*, 2009) and can also be taught these skills (e.g. Bruce *et al.*, 2010).

There are papers describing CBT-focused interventions for people with intellectual disabilities with a range of presentations, including symptoms of psychosis (e.g. Barrowcliff, 2008), trauma (e.g. Stenfert Kroese *et al.*, 2016), and health related issues (e.g. McManus *et al.*, 2014). However, systematic reviews primarily support CBT as an effective intervention for anger and depression in people with intellectual disabilities (e.g. Graser *et al.*, 2022; National Institute for Health and Care Excellence, 2016; Vereenoghe and Langdon, 2013). There are fewer controlled studies evaluating CBT for anxiety in people with intellectual disabilities than there are for depression or anger, and a systematic review of CBT for anxiety in people with intellectual disabilities conducted by Dagnan *et al.* (2018a), found that much of the anxiety literature consisted of single case reports and case series. Dagnan *et al.* (2018a) conclude that the evidence is broadly supportive of the use of CBT for anxiety with people with intellectual disabilities, but that the area requires further research utilising more robust methodologies and larger sample sizes. Several papers have reported manualised interventions for depression and anxiety (e.g. Hassiotis *et al.*, 2013; Jahoda *et al.*, 2017; Lindsay *et al.*, 2015). It is important to note that these are all adaptations of existing interventions for people who do not have intellectual disabilities. For example, Jahoda *et al.*'s (2017) simplified behavioural activation for depression is a development of Lejuez's approach to behavioural activation (Lejuez *et al.*, 2001). Hassiotis *et al.* (2013) and Lindsay *et al.* (2015) base their approach to CBT for depression and anxiety clearly within mainstream transdiagnostic models (e.g. Clark, 2009).

The research described above emphasises the adaptation of treatment models used with typically developing populations when treating people with intellectual disabilities, rather than the use of entirely novel interventions. This has important implications for the provision of psychological interventions for people with intellectual disabilities in mainstream services. It is not the case that these are interventions that must be delivered by specialist clinicians in specialist settings and with simple adaptation many people with intellectual disabilities can engage with and benefit from CBT interventions that have been developed for the general population.

Although the evidence on the application of therapies to people with intellectual disabilities is growing, there is less evidence concerning the availability, structures and processes of services that might provide therapy to people with intellectual disabilities, either within specialist or mainstream services. Whittle *et al.* (2018) report a scoping review of barriers and enablers for people with intellectual disabilities in using mental health services. Their study uses Gulliford *et al.*'s (2002) framework for understanding access; this has four dimensions; availability (the primary presence of services); utilization (the organisational, process and structural barriers to accessing services when available); relevance and effectiveness (the quality of service); and equity (the access to the service for different groups with the same needs). Whittle *et al.* (2018) conclude that whilst literature identifies barriers for people with intellectual disabilities in accessing mainstream mental health services, the research in this area has not been systematic and there is need for more research to understand what makes it easy for people with intellectual disabilities to access services.

This paper will review evidence and practice in therapy adaptations that will support people with intellectual disabilities to benefit from CBT within mainstream services. The paper highlights that the adaptations necessary to support people with intellectual disabilities do not require therapists to acquire new skills but depend on the use of existing meta-competencies in

adapting therapy to individual presentations. The paper will suggest that it is likely that the biggest barriers to people with intellectual disabilities in using mainstream therapy services are the structure of services rather than the skills of the therapists, but that more research is needed to fully understand these issues. The paper will further suggest that the adaptations that will support people with intellectual disabilities in accessing CBT in mainstream services will be relevant to a much larger group of people with lower abilities.

The definition and epidemiology of intellectual disability

To fully consider the adaptations that are likely to be helpful in mainstream services we should consider the nature of intellectual disability, its identification and epidemiology. Intellectual disability is defined by three characteristics:

- A significantly reduced ability to understand new or complex information and to learn new skills, usually measured with an intelligence scale and interpreted as a person having an intelligence quotient (IQ) score below 70, with:
- A reduced ability to cope independently, usually measured using a structured assessment of adaptive behaviour including home, community and social skills;
- Which started before adulthood, with a lasting effect on development (Department of Health, 2001).

People with intellectual disability are a heterogeneous group with a significant difference in abilities between those with the most severe and those with milder disabilities. People with mild intellectual disabilities are usually defined as people with IQ scores between 55 and 69 and it is this group of people who might routinely access talking therapies such as CBT. There are a small number of papers describing cognitively informed therapy with people with more severe disabilities (e.g. Williams and Jones, 1997), but the primary focus of this paper is those people with milder disabilities who could reasonably receive therapy from mainstream services.

National publications in 2016 suggest that there are 1,087,100 people with intellectual disabilities in England, which includes 930,400 adults (Public Health England, 2016; these data have not been updated since this report), which was 1.97% of the population at the time. However, although the prevalence of intellectual disability might be expected to be around 2% of the population (based on a normal distribution of IQ scores and the estimates above), Public Health England suggest that only 0.35% of the adult population receive long-term support from local authorities due to intellectual disability and only 0.5% of the population are flagged on GP systems as in the intellectual disability register (Public Health England 2022). The figures for long-term support and presence on the GP register probably represent the group of people with intellectual disabilities who are known to statutory services because they have greater levels of need and will include a large proportion of people with more severe disabilities. Thus, potentially 75% of people with, typically, milder intellectual disabilities are not immediately known to services (to put this into context, for a population of 100,000 around 500 people with intellectual disabilities will be known to services through GP registers whereas around 1500 people in 100,000 will not be known). Thus, 75% of the population of people with intellectual disabilities are likely to use health services without their intellectual disability being formally recognized.

Helpful adaptations to therapy are not predicted purely based on IQ score, and it makes little sense to suggest that an adaptation is required for someone with an IQ score below 70, but not for someone with an IQ score just above 70. Intellectual disability is seen as a socially constructed concept (Rapley, 2004) and the identification of an IQ score cut-off as 70 is somewhat arbitrary. If we consider that the adaptations that help people with intellectual disabilities

might also help those who have IQ scores between 70 and 80 then we would be making adaptations for 9% of the population (9,000 people in a 100,000 population) and if we raise this to an IQ score of 85 then we would be helping 16% of the population (16,000 people in a 100,000 population).

In general, people with intellectual disabilities have problems with engaging with and retaining large amounts of new information, with planning and with emotional and other self-regulation activities (e.g., Levén *et al.*, 2008; Dučić *et al.*, 2018). These problems are particularly present for people with intellectual disabilities however, there is evidence that some executive functions are associated with intelligence scores such that people with lower IQ scores that are outside of the intellectual disability range will also experience some degree of difficulty in these areas (Friedman *et al.*, 2006). The challenges in service provision for this wider population are significant but beyond the scope of this paper; however, data suggest that, in England, 42% of working-age adults are unable to understand and make use of everyday health information, rising to 61% when numeracy skills are also required for comprehension and 16% of the adult population are functionally illiterate (Public Health England, 2015). It is sufficient to say that we consider that many of the adaptations discussed here will help people with literacy and executive functioning difficulties regardless of the cause of their difficulties.

Adaptation of CBT for people with intellectual disabilities

There are several publications that describe adaptations to therapy for people with intellectual disabilities; these include book chapters (e.g. Dagnan *et al.*, 2007), books (e.g. Taylor *et al.*, 2013), reviews (e.g. Dagnan *et al.*, 2018a) and professional guidance (e.g. Dagnan, 2018). These publications often describe similar adaptations and add validity to the adaptations described in this paper. However, most of the available literature on adaptation is based on clinical experience and opinion, and there is little written that is based on empirical studies of effectiveness of adaptation. Most studies reporting outcomes for CBT with people with intellectual disability do not systematically report the adaptations they use (Surley and Dagnan, 2019). Surley and Dagnan (2019) reviewed 23 CBT interventions for a wide variety of clinical presentations reported in refereed journals from 2005 to 2017 using a framework which categorised adaptations developed by Hurley *et al.* (1998). Based on this framework, Surley and Dagnan (2019) found that *the use of activities* was reported in 21 (91%) of studies, that *simplification* of processes was reported in 16 (70%), the *involvement of carers* in 16 (70%), *adaptation to developmental level* was reported in 15 (65%), *adaptation of language* was reported in 11 (47%), *flexibility* was reported in 10 (43%) and *the use of directive methods* was reported in seven (30%); two categories on Hurley's typography (*consideration of transference/countertransference* and *consideration of disability/rehabilitation approaches*) were not observed in any studies. Surley and Dagnan (2019) conclude that there needs to be a more systematic approach to reporting adaptations in studies and that their data cannot be considered a comprehensive review of helpful adaptations; however, the adaptations described give a starting point for more detailed consideration of this area.

We now identify some of the literature and examples that support adaptations using the categories described by Hurley *et al.* (1998).

Simplification

The degree of difficulty that people will have in retention of new information will vary between individuals, and it may be challenging to identify the appropriate level of new information that each client can tolerate. The therapist will need to be sensitive to signs that the client is fatigued or not engaging in new ideas, and based on these observations sessions can be kept short or can be split into two with breaks. However, a general approach for people with intellectual disabilities

would be to introduce one new technique or significant learning element in each session, and to do that one element thoroughly rather than try to introduce numerous ideas into a session. Simplification can further be achieved through creation of shorter ‘chunks’ of information. By breaking down activities and information into shorter segments we can create repeated opportunities to check that the client is understanding and to celebrate progress and shared achievements.

In parallel with the presentation of one new technique or concept within each session is the need for repetition. The therapist should expect that retention of new techniques and information will be less efficient for people with intellectual disabilities and that generalisation of skills will also be less automatic. On this basis repetition both within and between sessions is likely to be required, with a possible criterion of between-session retention as a goal before moving to a different skill. For services that are structured around short durations and fixed numbers of sessions, this will often mean that a smaller number of techniques or skills need to be planned for each episode of therapy.

Language

There are several papers that discuss the reading and spoken language skills of people with intellectual disabilities and offer adaptations to make therapy processes more accessible. These include the use of simplified language structures where the advice on spoken language is often very similar to the advice on adapting written communication. The core task is to keep sentences shorter (maximum 15 words), to address a single concept in each exchange, and try to use words of no more than three syllables (Jones *et al.*, 2006; Jones *et al.*, 2007; Lifshitz *et al.*, 2011). The use of verbal and visual metaphor also requires careful consideration with people with intellectual disabilities (Shnitzer-Meirovich *et al.*, 2017). Communication can be supported using visual aids and social stories, and text can be supported using drawings and other images (e.g. Jones *et al.*, 2007). When discussing concepts that may be new to the client or where the context they are discussed in is new, it is important to try to both ensure that there is a shared meaning and to be consistent in the use of terms and materials across and within sessions. Adjusting communication in this way can be challenging and requires active reflection and self-monitoring on the part of the therapist.

Activities

Interactions that might otherwise be verbal will be better delivered as structured tasks for people with intellectual disabilities. The online training for the BEATIT Behavioural Activation and the STEPUP guided self-help interventions (<https://www.e-lfh.org.uk/programmes/intellectual-disability-and-depression-talking-therapies/>) has several videos that illustrate key points in therapy and the activities that support these. For example, the BEATIT training has an activity that involves sorting pictures of activities into groups, first activities the person enjoys doing, secondly activities the person used to do but no longer does, and finally, activities the person would like to try. This type of exercise might be done with a person without intellectual disability as a purely verbal interaction; however, for people with intellectual disability, the shared activity of organising and sorting the pictures becomes significantly more engaging, is actively collaborative and can become a very central process of engaging the client and beginning to understand their priorities and values. It is also important that any homework tasks or skills to be used outside of therapy are practised; role play or watching videos where other people demonstrate a task or skill can support this process.

Developmental level

Hurley *et al.* (1998) identified that it is important to take the person's developmental level into account in adapting therapies. It has already been highlighted that there is an association between intellectual ability and some executive functions (Friedman *et al.*, 2006). It is clearly important to consider the person's abilities in problem solving, processing information into memory and other similar skills.

Other developmental areas that will be important to consider include the client's ability to understand the perspective of others (O'Brien *et al.*, 2013) which can be a core skill used in developing interventions in CBT. Other core social emotional skills, such as recognition of emotion, abilities to link emotions to events and cognitions and subsequent regulation of emotions are developmental skills and will vary within and between people with and without intellectual disabilities (Barthel *et al.*, 2018; Dagnan *et al.*, 2009; McClure *et al.*, 2009) but which will be a particular difficulty for many people with intellectual disabilities. Adaptations to therapy in response to this will include a greater focus on behavioural elements of intervention, and when cognitive approaches are used there may be an emphasis on cognitive rules and a focus on emotion regulation skills teaching (Dagnan *et al.*, 2018b)

Directive approaches

Therapy with people with intellectual disabilities will require a greater degree of 'scaffolding' from the therapist which will offer a clear structure for each session and therapy episode. Jahoda *et al.* (2009a) report detailed analysis of 'power' interactions in CBT with people with intellectual disabilities. This suggests that therapists may be more directive and ask more questions than might be usual in working with people without intellectual disabilities, but that collaborative and equal interactions can be achieved through the therapist focusing on the content that clients bring whilst therapists provide the structure of the therapeutic processes.

The use of collaborative agenda-setting and repeated structure within sessions will support people to feel confident and less anxious about engaging in an unfamiliar process such as therapy. Agenda-setting can be shared with the agenda being actively 'ticked off' as each step is achieved. The agenda can be held by the client and they can be collaboratively engaged in tracking the progress of each session. Sessions can be set up with a common structure throughout; for example, stages might be 'settling in', reviewing homework, activity and mood from the last few days, introducing or revisiting a new skill or task, practising tasks and skills, planning for their use/homework, review of learning from the session, and saying goodbye and setting arrangements for the next session (both collaborative agenda-setting and core session structure are illustrated in the video sections of both BEATIT and STEPUP online training; <https://www.e-lfh.org.uk/programmes/intellectual-disability-and-depression-talking-therapies/>).

Flexibility

The therapist working with people with intellectual disabilities needs to be flexible in their approach. This can be at the level of the specific therapeutic interaction where recognition that the process is not working may require alternative approaches to be tested within session. It may also require flexibility at the level of therapeutic approaches; for example, if it becomes evident that cognitively mediated approaches are proving difficult, then therapists might shift to more behavioural approaches (such as exposure or behavioural activation) or to more skills-based approaches (e.g. Bouvet and Coulet, 2016).

Context/involvement of supporters

There is substantial evidence which suggests that people with intellectual disabilities are disempowered and lack agency in their lives (Jahoda *et al.*, 2009b), and which would suggest that, without support, implementing new skills and making changes to their lives will be hard for people with intellectual disabilities. Surley and Dagnan (2019) identified that 16 out of 23 (70%) of CBT papers reviewed for people with intellectual disabilities involved adaptations that included supporters in some way. There are several detailed accounts of interventions that clearly include supporters (e.g. Jahoda *et al.*, 2017) and subsequent analyses of the supporters' experience of direct involvement in therapy (Scott *et al.*, 2019).

There are complexities in including supporters in therapy. The advantages of supporters being present include their ability to support homework, skills practice, and maintenance of changes after therapy has concluded. They can also be supportive in helping people attend therapy and in enabling communication with the therapist in the early stages of therapy. However, there is a need to be clear with the supporter about their role in the therapy session and to be able to challenge if the supporter steps out of the agreed roles. There is a greater risk of the areas being worked on being influenced by carer concerns and not fully representing the concerns of the client, and the unobserved influence on activities and skills practice outside of therapy will have similar challenges. There are often practical challenges in continuity of carer, particularly in paid-for services where client appointments and shift patterns may not allow the same supporter to be consistently present throughout therapy. Some interventions (e.g. Jahoda *et al.*, 2017) have separate and clear guides for supporters on what to expect in therapy and what their role is, although these are specific to the intervention described by Jahoda and colleagues (available at: <https://www.e-lfh.org.uk/programmes/intellectual-disability-and-depression-talking-therapies>); they form the basis for similar communications that can be prepared for other CBT interventions.

Therapy relationship

There is surprisingly little written about the therapy relationship for people with intellectual disabilities, particularly in the context of CBT. The challenges of the therapy relationship can be seen as related to the devalued and stigmatised experiences of people with intellectual disabilities. Cameron *et al.* (2020) report an exploratory study of the perspective of clients with intellectual disabilities and therapists of the components of therapeutic relationship based upon Bordin's (1979) model of therapy relationship, which suggests that the therapeutic alliance is made up of shared goals, agreed roles in activities and a 'bond'. Cameron and colleagues find a generally good overlap between therapist and client understanding of goals, roles in activities and bond, although some dyads had quite different views of these components of alliance and the language used to describe these elements within dyads was often very different.

The therapeutic relationship is affected by several factors including expectations and achievement in therapy (Waddington, 2002). Shared goals setting, negotiating roles in activities, engaging in simple activities to illustrate key learning points, 'chunking' how information is presented into smaller sections and using structured agendas supported by the client all give opportunities for celebrating shared achievements and emphasising positive expectations and shared processes of therapy with a person with an intellectual disability.

Addressing disability

Several papers describe the impacts of stigma and negative self-evaluations that can arise because of the devalued status of people with intellectual disabilities (e.g. Dagnan and Sandhu, 1999). It is likely that people with an identified intellectual disability will recognise that the world sees them as

different but will respond to stigma in different ways (Jahoda *et al.*, 1988). It is likely that this will impact on people's views of themselves and their interaction with the world. Some people may be very wary and distrustful of others, particularly professionals, and some may be very acquiescent and passive. There is little clear guidance on how to incorporate these factors into CBT therapy although several books and papers are helpful in discussing how people with intellectual disabilities manage these issues in daily life (e.g. Crocker and Major, 1989; Scior and Werner, 2016) and in placing this context into wider considerations for therapy (e.g. Jahoda *et al.*, 2009b).

Discussion

The adaptations described here are generally not different from those that would be required for other specific groups (for example, those who are older, those with other significant disabilities, autistic people) and most are within the range of adaptations that therapists will be used to making for the variation found in the general population. The adaptations suggested here are of degree rather than adaptations of fundamental approach. How people learn, how therapists support people to acquire insights and learn skills are generally the same, although processes might be slower and require careful reflection by the therapist. However, we suggest that working with people with intellectual disabilities will generally be an extension of existing skills for therapists rather than a process that requires therapists to acquire completely new and different skills.

The structures of therapy used with people with intellectual disabilities are fully recognisable to therapists from the mainstream. This is not surprising as most therapies that are used with people with intellectual disabilities are adaptations of therapies from mainstream. The adaptations that are generally reported are not so radical that the resulting interventions are not recognisable as such by therapists who do not routinely work with people with intellectual disabilities. We suggest that the core CBT competency framework (Roth and Pilling, 2008) identifies that the ability to adapt therapy to specific needs of the client is a clear meta-competency. Several studies have further identified that CBT therapists have a high degree of flexibility and have been observed to adapt their approaches. For example, Mignogna *et al.* (2018) discuss flexibility in manualised interventions and identify that adaptations depended on therapist ability to be flexible in content and approaches that promote therapy engagement, were based on 'ensuring the therapy addresses client's broader life/clinical concerns', and required flexibility in the use of the time and structure of sessions. There is also guidance for therapists on adapting therapy to meet cultural needs, which is required within BABCP ethical guidelines (Stone *et al.*, 2018).

Training courses in general offer experience in working with people in protected groups (e.g. module 3, Values, diversity and context; UCL, 2015) and reflective, supervisory processes have been shown to support the development of meta-competencies (Thwaites *et al.*, 2015). There is, however, a need to further understand how therapists use the flexibilities that their training and experience enable in routine practice with people with and without intellectual disabilities. Training therapists in mainstream services to work with people with intellectual disabilities has been reported. Dagnan *et al.* (2018b) describe an approach which focuses on therapist confidence to emphasise that they typically already have the skills to work with this client group. There is, however, a significant need to understand how effectively therapists can use the flexibilities developed in their training and practise with people with intellectual disabilities. If we can demonstrate that it is possible to train therapists who have both accreditation level competencies in CBT and experience of working across a range of needs that routinely present in mainstream services, to equally work with people with intellectual disabilities, this will be a substantial contribution to understanding how to make cognitive behaviour therapy as widely available as possible to this client group.

Although not the focus of this paper, there is a significant challenge for many services in managing the service structures that support the processes of enabling the client to see the

individual therapist. Service structures vary considerably. There is no coherent evidence regarding the processes adopted by services to support referral, triage, prioritisation and allocation to therapist.

Conclusions

Whilst the evidence base to support specific adaptations to CBT for people with intellectual disability is weak, there is considerable consensus in the types of adaptation that may be useful in published reviews, case studies and trials describing interventions. Adaptations consider neuropsychological processes such as memory and executive functions such as planning, problem solving and self-regulation and factors associated with the devalued context of the lives of people with intellectual disabilities. This paper has emphasised that these factors are not unique to people with formal diagnoses of intellectual disability and we emphasise the generalisability of adaptations described here to therapy with wider populations and suggest that CBT therapists working in mainstream services will have the skills to be able to adapt therapy for people with intellectual disabilities.

Key practice points

- (1) The evidence base for CBT with people with intellectual disabilities is small compared with that for the general population; however, the data that are available support the use of CBT for depression and anxiety.
- (2) CBT for people with intellectual disabilities is largely adaptation of models and approaches developed for the general population.
- (3) The adaptations that will help people with intellectual disabilities will help people who potentially have an intellectual disability but who have not yet been identified as such, people with lower abilities that border onto the intellectual disability range of skills and people with significant literacy needs.
- (4) The general areas of adaptation made for people with intellectual disability are easily understood within the range of adaptations that therapists make with other specialist groups and for the ordinary variation of ability that therapists see on a day-to-day basis.
- (5) Reflection, training and supervision will support therapists to become confident in using their skills with people with intellectual disabilities.

Further reading

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