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Adapting psychological interventions for people with severe and profound intellectual disabilities: A behavioural activation exemplar

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Abstract

Background: People with severe to profound intellectual disabilities experience similar or higher levels of depression than those with more mild intellectual disabilities. Yet, there is an absence of evidence about how to adapt existing psychological therapies for this population.

Method: A behavioural activation intervention (BeatIt) for people with mild to moderate intellectual disabilities was adapted for people with severe to profound intellectual disabilities and depression. Key considerations include: (i) beginning with a more in-depth assessment process; (ii) including the person in session activities and developing a relationship with them; (iii) formulation and the use of film to document the link between activity and mood; and (iv) addressing barriers to change at an individual and inter-personal level and considering how the carer could support the person's engagement in activity.

Results: Successfully adapting BeatIt represents a first step towards gathering evidence about the effectiveness of behavioural activation for people with severe to profound intellectual disabilities.

KEYWORDS
adaptation, depression, manual, severe intellectual disability, psychological therapy

1 | INTRODUCTION

People with severe to profound intellectual disabilities are at high risk of mental ill health and the 2 year incidence of affective disorders for people with profound intellectual disabilities is reported to be 6.1% (Cooper et al., 2007). Life events and not living with family have been found to be related to mental health problems presented by people with severe to profound intellectual disabilities, with less opportunity for social contact, fewer choices, exposure to a variety of negative life events, and limited purposeful activity in their everyday lives (Cooper et al., 2007; Hulbert-Williams & Hastings, 2008; Jahoda et al., 2006; Johnson et al., 2012).

Depression is one of the most common mental health problems faced by people with intellectual disabilities and it has been found to be more enduring in people with intellectual disabilities compared with the general population (Collishaw et al., 2004). This may be due to depression in people with intellectual disabilities being more severe, and/or less well managed (Jahoda et al., 2018). Psychological therapies are first line interventions for people with depression in the general population in the United Kingdom (National Institute for

Health and Care Excellence: CG90, 2009) and internationally. However, there is almost a complete absence of evidence-based psychological therapies for people with severe to profound disabilities. A systematic review conducted by Vereenooghe et al. (2018) that evaluated existing evidence of psychological interventions for mental health in people with severe to profound intellectual disabilities identified only two studies with this population, both of which were single case experimental designs.

The first step towards addressing depression in people with more severe to profound disabilities is achieving a better understanding of their emotional lives and distress. There are complexities in the assessment and diagnosis of depression for people with severe to profound intellectual disabilities. Many individuals with more severe intellectual disabilities are unable to self-report on their internal states due to communication difficulties and are reliant on others in their lives to recognise the signs of depression. Diagnostic overshadowing can occur when a person's mental health difficulties are attributed to their intellectual disability (Dagnan, 2007). Depression can also present differently in people with severe to profound intellectual disabilities and diagnoses for this group emphasise observable changes in the affected person. In their review of the epidemiological evidence, Eaton et al. (2021) found that the commonly observed signs of depression for people with severe intellectual disabilities can include changes in sleep patterns, reduced appetite, crying, fatigue, and agitation. While Eaton et al. also found that aggression and self-injury were associated with a diagnosis of depression, they did not believe that these forms of challenging behaviour should be regarded as symptoms of depression or behavioural equivalents. Instead, they regarded them as signs of more general distress that could also be linked to pain or other mental health difficulties or aversive experiences. Hence, they proposed that challenging behaviour should prompt further investigation, to examine whether a diagnosis of depression would be warranted. Cooper et al. (2007) found that detailed assessments by trained mental health specialists using explicit diagnostic criteria, which take account of developmental and contextual factors, provide the most sensitive approach when diagnosing individuals with more severe and profound intellectual disabilities with a mental health problem like depression. This helps the mental health specialist to identify observed changes to key behaviours associated with depression, such as irritability, sleep disturbance or agitation. The beginning of any psychological therapeutic intervention for a mental health problem like depression in people with severe to profound intellectual disabilities needs to be a careful process of assessment and understanding.

Psychological interventions for depression could be developed from first principles or de novo for people with severe to profound intellectual disabilities. However, a second potentially fruitful approach may be to adapt existing interventions that have been robustly tested with those with mild to moderate intellectual disabilities. There are, however, factors that make adapting therapies for people with more severe intellectual disabilities challenging. This includes their significant cognitive and communicative difficulties, their reliance on others for support with everyday tasks, and the need to consider and adapt existing interventions to their particular life circumstances. There has been work to adapt existing psychological interventions for depression with people with mild to moderate intellectual disabilities. Osugo and Cooper's (2016) review found four studies in which researchers tested adapted versions of Cognitive Behavioural Therapy (CBT) in the management of depression in people with mild to moderate intellectual disabilities (Hartley et al., 2015; Hassiotis et al., 2013; McCabe et al., 2006; McGillivray & Kershaw, 2013). However, CBT is not an accessible intervention for those with more severe to profound intellectual disabilities, due to the associated cognitive and communicative demands. In fact, most psychological interventions are talking therapies and are likely to be inaccessible for people with severe and especially profound intellectual disabilities.

For depression, due to the focus on behaviour change, Behavioural Activation has the potential to be more accessible to those with more severe to profound intellectual disabilities. Behavioural activation is a psychological therapy that aims to increase overt behaviours that are likely to bring the individual into contact with positive environmental contingencies, with a corresponding improvement in mood, thoughts, and overall well-being (Lejuez et al., 2011). Behavioural Activation has been shown to be as effective as other psychological therapies such as CBT in the management of depression in the general population (Ekers et al., 2008).

Jahoda, Hastings, et al. (2017) conducted a randomised controlled trial with 161 adults with mild to moderate intellectual disabilities and depression, in which participants were randomised to receive an adapted Behavioural Activation intervention (BeatIt) or a guided self-help intervention. Significant improvements in self and proxy reports of the BeatIt participants' depressive symptoms were found during the intervention phase and were maintained at 12 months follow-up (Jahoda, Hastings, et al., 2017). There are different versions of Behavioural Activation, originating with more complex models (Martell et al., 2001). The version adapted by Jahoda, Hastings, et al. (2017) was Brief Behavioural Activation for Depression (Lejuez et al., 2011). This proposes a direct link between increasing meaningful or purposeful activity and improved mood and overall wellbeing. An avoidance or withdrawal from activity is proposed to underlie the development and maintenance of low mood and depression. The goal of therapy is to break this negative cycle by increasing the person's engagement in purposeful and meaningful activities, and promote a sense of achievement and control in their lives. The focus of the intervention is on behaviour, rather than cognition, and on engaging in activity within an environment with high levels of positive reinforcement (Lejuez et al., 2011). While this approach also addresses barriers to change, it is less cognitively demanding than the more complex Behavioural Activation interventions (Jahoda et al., 2015). It is also crucial to note that the focus is not on a functional analysis of the person's behaviour, as might be expected in a purely behavioural approach. The purpose is to address the person's depression and improve their emotional wellbeing.

In the current paper, we describe key conceptual and practical challenges that need to be addressed when working to adapt behavioural activation for people with severe to profound intellectual disabilities. People with severe to profound intellectual disabilities have

high support needs, requiring assistance with personal care and have limited or no expressive or receptive verbal communication, and significant impairments across adaptive functioning skills. The classification of a severe/profound intellectual disability can be confirmed using the Vineland Adaptive Behaviour Scale, with a composite score of 50 or below. This measure assesses four domains of adaptive functioning: communication, daily living skills, socialisation and motor skills (Sparrow, Cicchetti & Saulnier, 2016).

The aim of the current paper is to provide a detailed account of the adaptation of the behavioural activation intervention (BeatIt2) for people with severe to profound intellectual disabilities. A linked paper (Gillooly et al., in press) reports on the initial feasibility testing of the 0adapted BeatIt2 therapy. Given the absence of evidence based psychological interventions for this population (Vereenooghe et al., 2018), the adaptation of behavioural activation and its conceptual and practical underpinnings, is a key part of the process of developing and testing the feasibility of the intervention. Moreover, the analysis presented may also have wider implications for the adaptation of other psychological interventions for adults with severe to profound intellectual disabilities. Our main approach was to extend key considerations that informed the adaptation of behavioural intervention for people with mild to moderate intellectual disabilities (Jahoda, Hastings, et al., 2017). Hence, the rationale for these earlier adaptations provides an important backdrop to this work.

2 | ADAPTATIONS TO BEHAVIOURAL ACTIVATION FOR PEOPLE WITH MILD TO MODERATE INTELLECTUAL DISABILITIES

BeatIt is a 12-session manualised behavioural activation intervention and the main elements of therapy involve goal setting, activity scheduling, and addressing individual, inter-personal and systemic barriers to change (Jahoda, Hastings, et al., 2017). There are three phases to the intervention. The assessment and socialisation phase (sessions 1–5) leads into the development of a formulation, the second phase (sessions 6–10) concerns work towards achieving the therapeutic goals, and the third phase (sessions 11 and 12) brings the therapy to a close with plans made for continued use of the learning from the therapy, and reflection on the lessons learned in the course of therapy. Adaptations to the BeatIt intervention were consistent with guidance provided for delivering psychological interventions to people with mild to moderate intellectual disabilities, including taking a structured approach and the use of accessible language with visual materials (Surley & Dagnan, 2019). The key features of the therapy that make it more accessible for people with mild to moderate intellectual disabilities are described below.

2.1 | Supporter involvement

As the main objective of Behavioural Activation is to increase people's purposeful activity, those taking part in therapy require the agency to take what they learn in therapy to make real life change. However, people with intellectual disabilities remain more reliant on practical and emotional support from others in their everyday lives (Jahoda et al., 2009). Hence, to increase the likelihood of change happening, the therapy is delivered to the person with intellectual disabilities alongside a significant other person in their lives (Scott et al., 2019). This could be a family member, paid carer, friend, or spouse/partner. A supporter session is held before the therapy proper starts, to provide the supporter with an understanding of the therapy and their role in the process.

2.2 | Accessible materials and activities

Careful piloting and development was carried out to ensure that the BeatIt session materials and activities are both accessible and engaging for people with mild to moderate intellectual disabilities. The tasks have been designed to minimise a didactic or direct questioning approach, with the dialogue stemming from the therapeutic tasks in which people are actively engaged. For example, in the first session participants are asked to select and organise pictures of activities that they do currently, activities that they had done in the past, and activities they would like to do in the future — and they place these into clearly labelled boxes supporting this sorting task. The selection of activities provides information in its own right as a part of the assessment phase, but also stimulates broader relevant discussion and a sense of collaborative endeavour (Knight et al., 2019).

2.3 | Personalisation

It is recognised that the therapist needs to maintain fidelity to the therapeutic model and manual while being afforded the flexibility to personalise the therapy to the individual's needs and circumstances (Kendall, 2021; Mignogna et al., 2018). Formulation is the key aspect of this approach. To ensure that the BeatIt intervention is meaningful and makes sense to the person and their supporter, the formulation is designed to be accessible and is shared and agreed with the person and their supporter before being finalised. This provides an individual focus and rationale for increasing activity and overcoming barriers to change.

2.4 | Individual barriers, facilitators, and context

When working to support someone to identify and schedule activities it is important to take account of individual and wider contextual factors (Smith et al., 2021). This includes participants' particular circumstances, their relationships and the opportunities that are available to them. Organisational factors, in terms of the nature of support and services people receive are crucial. For example, the amount, timing and flexibility of the support an individual receives might determine whether it is possible for them to engage in a particular activity like

swimming, gardening, or joining a community group. Access to transport and money are other tangible factors that often need to be considered. Difficulties with taking advantage of opportunities may also relate to the person's emotional wellbeing. Alongside low mood, a lack of confidence, anxiety or interpersonal difficulties may act as barriers to change. Therefore, another core component of the adapted BeatIt intervention is to identify and work to overcome key barriers to change, personalising this process to the person's strengths and available opportunities.

2.5 | A future focus

BeatIt is a time-limited intervention that was developed as a way of stimulating a process of change. The formulation booklet is updated at the end of the therapy, to provide a plan for continuing the work and building on any progress which has been made. The aim is for the person, with the assistance of their supporter, to sustain and build on the work completed in the therapy sessions.

3 | CHANGES TO THE BEHAVIOURAL ACTIVATION MANUAL FOR PEOPLE WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITIES

The adaptation (BeatIt2) of the BeatIt manual was completed in the development phase of a modelling and initial feasibility study of behavioural activation for people with severe to profound intellectual disabilities and depression. The results of this initial feasibility study are provided in a linked paper (Gillooly et al., in press). In this section, we describe the development process before describing the key changes made to the manual.

3.1 | Adaptation process

In addition to ongoing work by the research team over a 6 month period, a series of four meetings were held to discuss adaptations to the BeatIt manual, involving therapists with experience of delivering the original BeatIt intervention and key members of the study team. Research partners and co-investigators, Promoting a More Inclusive Society (PAMIS; https://pamis.org.uk) played a key role in the process. PAMIS is an organisation run by and for families of people with more profound intellectual disabilities. They highlighted issues to be considered when tailoring the intervention to the needs of individuals with more severe and profound disabilities. However, it should be noted that those with severe to profound intellectual disabilities represent a heterogeneous group of people, ranging from those who will have both expressive and receptive verbal skills to individuals who have no spoken language (Cascella, 2004). PAMIS attended all the core research team meetings and were involved in all decisions concerning the adaptation of the BeatIt2 therapy manual. PAMIS also led on specific pieces of work including: (i) environmental considerations in helping people to engage in activity, such as appropriate postural support, and (ii) developing a list of local accessible activities for people with severe to profound intellectual disabilities.

During the final 3 months of the development phase, a clinical psychologist with experience of delivering psychological therapies to people with intellectual disabilities was employed to begin drafting the adapted manual, following the guidance from the research team (including all partners), who had expertise in manual development. In turn, the drafts were reviewed by the research team and all partners. This iterative process was used to produce the final adapted version of the manual. The manual was trialled in a feasibility study and further changes were made in light of the learning from working with the initial participants (Gillooly et al., in press).

The broad 12 session structure of the original BeatIt remained the same for BeatIt2 and is detailed in Table 1. Table 2 shows the main adaptations to the BeatIt2 manual for people with more severe to profound intellectual disabilities. Decision making for each of these changes is presented in greater detail below.

4 | NEW ELEMENTS ADDED TO THE BeatIt MANUAL, AND ADAPTATIONS MADE

4.1 | Supporter involvement

4.1.1 | Supporter session—Knowing the person and their life context

In addition to having more significant cognitive and communicative impairments than those with more mild to moderate intellectual disabilities, there are other notable differences that need to be borne in mind when considering an adaptation to BeatIt and other psychological therapies for people with severe to profound intellectual disabilities. For example, many individuals are likely to have additional sensory, mobility and physical health problems to contend with (Van Timmeren et al., 2017). Moreover, having greater support needs means that the nature and level of help people require to take part in activity will be different. For some individuals, with more complex needs, there may be a range of professionals involved in their care and support, including Occupational Therapists, Physiotherapists, Psychiatrists and other medical specialists. If a person is unable to express their own views or recall their own history, then it is difficult to obtain a good understanding of the person, including their current circumstances and past history. Hence, PAMIS emphasised the need for a more thorough process of data gathering at the initial supporter session, before the therapy starts.

The data-gathering process developed includes a sensory assessment, information about the person's communication, a detailed consideration of the person's routine, and an account of activities they find engaging or aversive. Aspects of people's health and physical needs are also taken into account. For example, postural care can be crucial in ensuring people with physical disabilities are seated or

TABLE 1 Outline of therapy sessions for BeatIt2.

Therapy session	Content
Supporter session (person's support network including, where possible, family members and paid carers)	Meet with significant others to i) gain background information (communication, sensory needs, social network, and activities), and ii) provide them with an understanding of therapy and tasks they may need to support.
Session 1 (supporter and person) Exploring activities — Assessment and socialisation	Try out different activities with the person and their supporter, introduce activity and mood diaries, and prepare for the next session.
Session 2 (supporter and person) Task analysis — Assessment and socialisation	Complete planned activity, focus on task analysis. Review activity/mood diaries, plan homework task and activity for the next session.
Session 3 (supporter and person) Communication — Assessment and socialisation	Complete planned activity, focus on communication. Review activity/mood diaries, plan homework task and activity for next session.
Session 4 (supporter and person) Open session — Room to explore other potential barriers or facilitators to change	Complete planned joint activity. Review activity/mood diaries, plan homework task and activity for next session.
Session 5 (supporter and where possible person's wider support network) Formulation	Complete planned joint activity. Deliver formulation. Review activity/mood diaries, plan homework task and activity for next session.
Sessions 6–10 (supporter and person) Working towards change and overcoming barriers	Complete planned joint activity. Address barriers to change. Review activity/mood diaries, plan homework task and activity for next session.
Session 11 (supporter and person) Ending therapy — A review of progress	Complete planned joint activity. Address barriers to change. Review activity/mood diaries, plan homework task and activity for next session. Review progress over the course of the sessions and plan delivery of final booklet.
Session 12 (supporter and where possible person's wider support network) Ending therapy — updated formulation/plan for continuing work	Complete planned joint activity. Address barriers to change. Review activity/mood diaries, deliver final booklet.

TABLE 2 Adaptations to BeatIt for people with severe to profound intellectual disabilities.

Supporter involvement	
Supporter session—**knowing the person and life context**	An extensive information gathering exercise is completed with the person's family/support team in the supporter session before therapy starts.
Involvement of supporters and the person's wider support network	The person's wider support team and/or family are included in key sessions e.g. when the formulation and final booklets are delivered
Accessible materials and activities	
How to engage the person in activity	The initial assessment/socialisation sessions (1–4) focus on ways of helping the supporter to facilitate the person's engagement in activity.
Balance of therapy tasks completed with the person and their supporter	When the person does not have the ability to follow the reflective aspects of therapy, these are completed with the supporter alone.
Scheduling activity (homework tasks)	Greater focus on how activities are structured and delivered. Routine and managing transitions between activity are also taken into account.
Options and opportunities for activity	A list of potential domestic and sensory activities, and accessible activities in the wider community are included in the manual.
Personalisation	
Joint activity	A core element of each session for the therapist is a joint activity with the person and their supporter.
Formulation and final booklets: use of film	Film or pictures of the person engaging in activity are included in or accompany the booklets, to bring the documents to life when people cannot describe their own experience.
Individual barriers, facilitators, and context	
Barriers	Barriers to activity sometimes differ for people with more severe and profound disabilities — consequently different or additional examples and guidance have been added to the manual. For example, postural care.

positioned correctly to allow them to participate in activity. To ensure that this information-gathering process facilitates the behavioural activation therapy to follow, the supporter needs to have known the person with intellectual disability well and for some time. This is different from the adaptations for people with mild to moderate intellectual disability made for the original BeatIt intervention, since these individuals provide most of their own history.

4.1.2 | Involvement of supporters and the person's wider support network

Consistent with the original BeatIt, one main supporter is identified to accompany the person to each therapy session. However, given the larger numbers of family carers or paid workers providing support to those with severe to profound intellectual disabilities, it is important that the wider network of supporters understand the therapy structure, therapeutic goals, and the role they play in the therapy process. Thus, as many of those who know and support the person as possible need to be involved at crucial points in therapy. In particular, this larger group are invited to the initial supporter session (not just the main supporter), the formulation session, and when the final booklet is delivered by the therapist at the last session. There are also therapy tasks, such as the activity and mood diaries and scheduled homework activities, that may need to be communicated across the person's wider support team to ensure they happen. A better understanding of the assessment, formulation and intervention components of the intervention can promote a more cohesive and supportive circle of support, with positive implications for the success of the therapy. Unlike those with mild to moderate intellectual disabilities, few individuals with severe to profound intellectual disabilities will be able directly to keep their supporters up to date with what is happening in sessions. With this in mind, information booklets were developed for all carers and supporters to increase their understanding of these key issues and facilitate their involvement in the therapy.

4.2 | Accessible materials and activities

4.2.1 | How to engage the person in activity

There are longstanding concerns that boredom and a lack of meaningful activity are typical experiences of people with more severe to profound intellectual disabilities living in residential services (Mansell et al., 2002). There may also be growing challenges with the financial resources available to support some activities (Forrester-Jones et al., 2021). However, it is not only institutional practices and financial pressures that act as barriers to activity. Some paid carers may lack the knowledge or skills to support these individuals to engage in activity. Therefore, the initial sessions (1–4) draw on Active Support, a structured intervention that trains staff supporting people with more severe to profound intellectual disabilities to take part in everyday activities (Flynn et al., 2018). The two session tasks taken from active support are working with the supporter to develop a task analysis plan to help scaffold the person's engagement in an activity, and working on good communication to encourage participation. These tasks build on the initial session exploring the person's preferred activities.

The joint activities carried out in these initial sessions also give the therapist an opportunity to observe the relationship between the person with intellectual disabilities and their supporter(s). The nature of this relationship is crucial because it is the supporter who will be taking forward the ideas and lessons during therapy and sustaining or building on change after therapy has finished. Moreover, the information from the initial (1–4) therapy sessions, along with insights from the activity and mood diaries and the attempts to schedule activities between sessions, allow the therapist to develop an understanding of the facilitators and barriers to change for the individual.

4.2.2 | Balance of therapy tasks completed with the person and their supporter

Emphasis is placed in BeatIt2 on ensuring the person with intellectual disabilities has an active part to play in the therapy sessions. There will be some individuals who are able to show or tell the therapist the parts of therapy that they enjoy or find engaging. Like any other therapeutic relationship, having someone new or different who is giving their undivided attention to you can also be a uniquely important part of the therapy process (Pert et al., 2013). However, it remains the case that most people with more severe and complex needs will not be able to understand or participate in many elements of the therapy, such as completing diaries, scheduling homework activity and discussing the formulation and final booklet. Yet these remain key ingredients of the therapy. Therefore, involving people with severe to profound intellectual disabilities in all the therapeutic tasks may not be possible, or desirable if they end up as bystanders being talked about by others. To avoid this happening, when individuals were unable to follow these parts of the sessions, some therapeutic tasks are completed with supporters alone.

4.2.3 | Scheduling activity—Homework tasks

Scheduling activity is a core element of behavioural activation interventions. When scheduling activities, more detailed planning is required when working with individuals who have more severe and profound intellectual disabilities. One reason for this is the nature of their support needs, which might include sensory or mobility problems. Fatigue or limited attention span may also mean that individuals can only engage in short bursts of activity and that session goals need to be carefully calibrated to be achievable. It is also noteworthy that activity scheduling can be about more than just the content of particular activities for individuals with more severe to profound intellectual disabilities. The structure, routine, planning and predictability of activities, and managing transitions across the person's day, might also play a crucial role in initiating or engaging some individuals in activity (cf. Bal et al., 2022).

4.2.4 | Options and opportunities for activity

Supporters need to be aware of opportunities for activity, if they are going to increase the engagement of people with more severe to profound intellectual disabilities. However, with the first pilot participants it became apparent that paid carers are often unsure about what steps

can be taken to help include people with more severe intellectual or profound disabilities participate in domestic activities. Community activities are also less accessible to these individuals for a variety of reasons, including access to appropriate toilets with changing facilities. As a consequence, PAMIS produced a list of potential activities that people with more severe to profound disabilities could take part in, at home and in their local area. This is included in the manual, and should be developed bespoke to the local area in any new clinical or research work.

4.3 | Personalisation

4.3.1 | Joint activity

Initial thinking about the adaptation of the BeatIt intervention for people with more severe to profound intellectual disabilities was concerned with *who* would be the focus of the intervention. In keeping with the original BeatIt manual, wherever possible the starting point was that the person with an intellectual disability should be supported to play an active part in therapy. The assumption was that the more severe the person's intellectual disability, the harder it might be for the therapist to engage the person in direct therapeutic work. Therefore, a key adaptation was to strengthen and extend the role of the supporter (see earlier), who would act as the main conduit to achieving therapeutic change with the target individual.

This planned approach changed after the research team reflected on Adams and Jahoda's (2019) study of the views of mothers of people with more severe to profound intellectual disabilities about their experience of obtaining psychological help for their offspring's emotional problems. These mothers were highly critical of professionals' unwillingness to spend time getting to know or work directly with their offspring, believing this meant that professionals often lacked insight into subtle cues about their sons' or daughters' emotional wellbeing or lacked the necessary experience and skills to carry out direct therapeutic work with their offspring. Therefore, our attention shifted to the adaptations necessary to still include direct work with people with more severe to profound disabilities as a core part of the therapy.

To this end, it was decided that the person, supporter, and therapist would all take part in a joint activity at every session. This is consistent with the main focus of behavioural activation, to increase the person's engagement in purposeful activity (Lejuez et al., 2011). Trying out different activities provides evidence about what activities are meaningful or engaging for the person, and their likes and dislikes. Direct involvement by the therapist can also provide insight for them into the best ways to communicate with the person, foster their engagement in activity and sustain their interest. Taking this collaborative approach across sessions gives the therapist an opportunity to build an understanding of the person. This might include gaining insight into the person's ability to express their agency, including actions such as refusing to take someone's hand if they are not ready or interested in a particular activity. It might also be observing how the same person's body relaxes and their affect changes during activity, such as when their hands are placed in a basin of water to help with washing up dishes. McCormack (2020) has pointed to the need to take time to accumulate knowledge of people with more severe to profound disabilities, and the opportunity this also allows for the therapist to see beyond the person's difficulties and to build on their strengths.

Without having a strategy for working directly with the individual concerned, it would be impossible to develop a real connection or to show caring or respect. Moreover, this joint work may help to establish the therapist's credibility with the supporter and to develop a bond with them. Building a positive bond with the supporter is hypothesised to be crucial to the success of the intervention. If the supporter develops a connection with the therapist and feels understood, then they are more likely to be committed to the therapy (Stenfert Kroese et al., 2014). Listening to family members and paid carers in the supporter role is also important because they will have unique insights about the individuals they support, and because they may be finding it stressful to support someone who is in distress (Adams & Jahoda, 2019).

From a pragmatic point of view, there are other advantages of direct observation and engagement when working therapeutically with individuals who have more severe to profound intellectual disabilities. A difference can often be found between the rhetoric and reality when relying on third-person reports about someone's life. This can be particularly marked when there are difficulties with supporting people to take part in activity. For example, we observed a person who was reported to enjoy watching television programmes. However, they did not appear to be paying attention to what was happening on the screen. Instead, their engagement was with a supporter who was present with occasional responses to particular sounds or images on the screen.

4.3.2 | Formulation and final booklets—Use of film

Filming people with intellectual disabilities' involvement in the joint activities and scheduled homework tasks ensures that their voice can be heard and seen when they cannot describe their own experience. Using excerpts from these films can then be used to illustrate ways of supporting an individual to engage in activity and its impact on their mood. This use of film helps to bring the initial formulation and final booklets to life and shows what can be achieved. In turn, this supports the maintenance and generalisation of change, and illustrates the person's potential to other family members or paid carers. Permissions are required by guardians or next of kin, and it will not always be possible to obtain this consent. Where consent is obtained, the films can be embedded into an electronic version of the formulation booklet. Pictures can also be used. As with the regular booklets, when they are presented to the supporters and other key individuals involved in the person's life, they may think some of the film is unsuitable or suggest alternative footage. A consensus has to be reached about the final version.

4.4 | Individual barriers, facilitators, and context

4.4.1 | Barriers

One of the main tasks in the original BeatIt therapy is to identify and address key barriers to change, including emotional, practical, and organisational barriers. A number of potential examples of common barriers and ways of tackling them were included in the appendices of the original BeatIt manual. The challenge with people with severe to profound intellectual disabilities was that the barriers were likely to be different and different approaches would be required to tackle potential barriers. For example, given the greater reliance of people with more severe intellectual disabilities on family and paid carers, having sufficient or flexible enough support to engage in activity may be a greater challenge for these individuals. One person in the feasibility study was unable to go to activities unless a paid carer was working who could drive, since public transport was not accessible. There was often a lack of basic equipment in settings, like a stable chair or a table of the right height to allow someone with poor posture to engage in tabletop activities. Emotional difficulties that prevent people from engaging in activity included agitation and self-harm. In light of the findings from the feasibility study, careful consideration needs to be given to potential barriers faced by people with more severe to profound disabilities, to provide prompts and potential solutions as part of the BeatIt2 manual.

5 | DISCUSSION

While several of the adaptations to behavioural activation described in this paper may be specific to behavioural activation, there are broader implications for the adaptation of psychological therapies for people with more severe to profound intellectual disabilities. Key wider considerations include: the role of the individual with intellectual disability in therapy, the involvement of significant others in the person's life, ensuring that change is generalised, and maintaining fidelity to the therapeutic approach.

Adapting a psychological therapy like BeatIt for people with more severe to profound intellectual disabilities is not merely a case of adapting the therapy to take account of their particular needs and circumstances. The process of adaptation and delivery of psychological therapies to this population also requires careful consideration of assumptions about what therapy is and how therapy works. This includes questioning the degree to which people who engage in psychological therapy must play an active and knowing part in the change process (Jahoda, Stenfert-Kroese, & Pert, 2017). Many individuals with more severe to profound intellectual disabilities will not be aware of the therapeutic content or process. In practice, psychological help may be best delivered via key supporter(s) in the person's life because they may be in the best position to interpret or make sense of the person's inner life and feelings and to help the person make changes. The personhood of individuals with more profound intellectual disabilities in particular is both recognised and enacted in relationships with others (McCormack, 2020). However, the supporter is usually seeking help on behalf of the person because they do not know how to help. Hence, working with the person alongside the supporter provides insights that can only be achieved through direct contact. Moreover, it allows the therapist to develop a meaningful direct therapeutic relationship with the person (Safran & Muran, 2006), and the person might see the therapist as part of a process of change, their presence indicating the new opportunities would be presented.

If the person with more severe intellectual disabilities expresses their agency in relationships with significant others in their lives, then those relationships are also likely to play an important part in therapeutic change. The adaptations to the BeatIt intervention drew on Active Support work to inform that element of the work (Flynn et al., 2018). Another consideration is that people with more severe intellectual disabilities are likely to have support from a number of individuals. Consequently, to generalise change, it may be necessary to include a variety of the person's carers in key sessions, to help them understand the therapy and implement changes. In a similar fashion, if people are unable to generalise their therapeutic learning from a clinical setting, then the therapeutic work needs to take place in everyday contexts where the changes will happen. This suggests that psychological therapy for people with more severe and profound intellectual disabilities, of this nature, should be on an outreach basis.

When adapting a psychological therapy for people with more severe to profound intellectual disabilities, another consideration is how to maintain fidelity to the therapeutic model. There can be compelling reasons to change course in therapy, when people present with a range of problems or if their emotional distress is expressed in a variety of ways (Eaton et al., 2021). Stepped care models of service delivery provide more intense and complex interventions for more complex emotional difficulties (Firth et al., 2015). However, for people who have lifelong complexities to contend with, it could be argued that adopting a focussed, time limited approach may bring much-needed clarity. This does not discount the importance of personalisation. Retaining a formulation as part of the BeatIt2 intervention is seen as vital in this respect. It helps to personalise the intervention and ensure there is a shared understanding of the process by the therapist and supporter. This includes formulating the role that the immediate and wider systems round the person have in facilitating or impeding engagement in reinforcing activities, essential when individuals with more severe intellectual disabilities remain so dependent on those systems. Formulation also provides a check on whether the therapist is working within a Behavioural Activation framework.

In the current paper, we have demonstrated how it might be possible to adapt psychological therapies for people with more severe intellectual disabilities. This has resulted in a manualised therapy that is designed to be both relevant to people with severe to profound intellectual disabilities and at the same time consistent with both the underlying model of behavioural activation and the broader principles of psychological therapies. Having a manualised approach opens up the opportunity to generate further evidence, including piloting and feasibility research to examine assumptions about the delivery of the

intervention and the underpinning logic. Ultimately, this process should lead onto larger scale efficacy and effectiveness evaluations.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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